Ordinary and extraordinary acts of integration: People's perceptions of integrated health care within their everyday lives

by Karen Dierdre Patterson

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under the supervision of Professor Joanne Travaglia,
Adjunct Associate Professor Benjamin Harris-Roxas, and
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Certificate of Original Authorship

I, Karen Dierdre Patterson, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Public Health, Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Knowledge Sharing Related to Research

Peer Reviewed Publication

Patterson, K.D. (2017). Why understanding what matters to the patient matters. *Journal of Integrated Care 25*(1),17-25. https://doi.org/10.1108/JICA-08-2016-0027

Invited Speaker

Braithwaite, J., Patterson, K., Hallam, L., Wells, L., Newton, L., Marles, L., & Dawda, P. (2022, July 25). *Are consumers the chief improvement change agents? A Debate* [Conference Session] International Forum on Quality and Safety in Healthcare, Sydney, Australia. https://internationalforum.bmj.com/sydney/2022/04/11/c1-are-consumers-the-chief-improvement-change-agents-a-debate/

Peer Reviewed Conference Abstracts, Presentations and Posters

Patterson, K., Cockburn, J. Lloyd, Y., Wells, L., Harvey, A., & Parham, J. (2019 October 9-11) Unearthing new and sustainable energy for change through building collaborative relationships among consumers, carers, health services and communities in rural and remote Australia. [Conference Session] ACHSM Asia- Pacific Health Leadership Congress, Gold Coast, Queensland.

Patterson, K., Jackson, D., & Travaglia, J. (2019, April 01-03). *Help me understand what is important to you, co-designing outcome measures that matter to people: A systematic review of the literature*. [Poster Presentation] 19th International Conference on Integrated Care, San Sebastian. DOI: 10.5334/ijic.s3532

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Three-Minute Thesis (3MT) presentations, UTS Research Students Forums, March 2015

Five-minute poster presentations, UTS Research Students Forums Dec 2017

*Note between 2020 -2022 the COVID-19 global pandemic limited opportunities to present at conferences. During this time I took leave of absence from candidature, supporting NSW Health response through my fulltime employment with the

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Abstract

The World Health Organization published the *Framework on Integrated People-Centred Health Services* in 2016. An ideal of this framework is that everyone adopts participatory roles, with people's perspectives equally influencing health decisions, as well as shaping health policy and services.

The thesis drew from my curiosity about the reported absence, or silence, of the individual's perspective within related policy, practices, or research. Informed by the literature, I engaged in qualitative, interpretative health research. I adopted a phenomenological stance influenced by social constructivism, pragmatism, and feminism perspectives. Case study research was selected to explore the complex, social interactions in the messy, dynamic context of health services. A strength of this research is the personal exploration of my role as the socially situated, reflexive, researcher.

The thesis preserves the voice and experiences of the study participants. I engaged deeply with a purposive sample of 11 participants to provide insights into their reality and subjective meanings related to their recent interactions with the same geographically located integrated health service. My analytic method included synthesis through progressive focusing guided by the three heuristics of understanding, interpreting, and theorizing. I engaged with abductive thinking processes to create metaphors as a form of provocative speculation, and produced an interpretative statement of claim.

This research found that the participants were both influenced by, as well as influencing, their experience. The participants shared how they critically assessed the strengths and limitations of their own and the health service's effectiveness. They had ideas and were motivated to contribute to, lead, and test changes. They expressed an understanding of their own circumstances, the wider financial and political landscape, and were willing to be activists within their community in raising awareness of the service, in sharing their knowledge and experiences with others, and to lobby and influence health service decisions.

I propose that the embodied knowledge, practical experiences, and motivation to innovate and experiment with integration as a process, where integration happens in the moment, is situated within the individual's everyday life. Taking this perspective, rather than focusing integration efforts on re-organising internal structures, which Ackoff (2004) described as trying hard to do the wrong thing righter, I propose that community living individuals are

well placed to lead from the outside, to collaborate with existing knowledge and power holders, and coproduce change. This would be the right thing to do, even if it is not always done well.

Prologue

I am the storyteller of this thesis.

Embedded within these pages, the study participants' and my story entangle.

As the reader of this thesis, you become part of the story and the story telling.

Chapter 1: Introduction

1.1 INTRODUCTION

"Integrated" and "integration" have become globally accepted terms within policy, strategy, and operational planning related to health services (World Health Organization [WHO], 2008). Furthermore, health services integration has been framed as being both a paradigm shift and a compelling strategy for achieving global health goals, such as addressing fragmentation and inequities, ensuring better use of finite resources at lower overall cost, and contributing to improvements in staff satisfaction and engagement (WHO, 2015).

In Latin "integrat" means to "make whole", building on this root, the English word integrate means "combining with another to form a whole or bringing (people or needs) into equal participation" (Oxford University Press, n.d.). In response to the many ways in which governments and health services apply the term integrated to health services, the World Health Organization (WHO) clarified that they saw integration as a process, a continuum rather than an entity, or something you have or do not have (WHO, 2008).

The proposed advantages for the individual who experiences integrated healthcare include a greater sense of enablement, in that individuals can "live an independent and fulfilling life" (The Health Foundation, 2016, p. 6) through being in a better position to meet their immediate day-to-day health care needs and, potentially, their future health needs (Consumers Health Forum of Australia, 2018; Royal Australasian College of Physicians, 2018; WHO, 2015).

1.1.1 Framework on Integrated People-Centred Health Services

In 2016, when the sixty-ninth World Health Assembly (WHO, 2016a; WHO, 2016b) adopted the endorsed vision for the *Framework on Integrated People-Centred Health Services*, they described the requisite reorientation as being "fundamentally transformative" (p.10) and cautioned that "there are no universally utilised indicators to measure progress" available (p.12). They placed emphasis on the need for local and global leadership in investing in research and development to establish appropriate indicators and metrics, and to share these insights and learnings with others (WHO, 2016a; WHO, 2016b).

> All people have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are

> comprehensive, safe, effective, timely, efficient and acceptable; and all carers are motivated, skilled and operate in a supportive environment (WHO, 2016a, p.4)

In placing people at the centre of health care, the experience of integrated care is proposed by WHO (2007) as being inclusive of the everyday citizen living their lives within their socio-community environs rather than beginning with or confined by being a patient receiving hospital-based health care. Framing integration as a coordinated continuum of care implies a connected pathway across the socio and biomedical systems capable of following an individual on their health journey, wherever their life course takes them. Instead of this pathway being a prescribed destination, the primary tenant is responsiveness (WHO, 2007). Integration is offered as an opportunity to re-balance or "harmonize" the individual's health needs and goals with those of their neighbours and others beyond their line of sight (WHO, 2007, p. vii).

Taking into account the WHO's (2015) perspective that no two health systems across the globe are the same, it could be assumed that integrated people-centred health services will manifest uniquely within different health systems in both form and focus. Furthermore, defining health as being part of every person's life course, which includes their everyday health related activities as well as seeking out health services from others, means that their personal health systems will express unique features and could extend across different socio-political-medical systems and more. This school of thought supports the person's experience and understandings as being integral to understanding what is important, what is progress, and ways for monitoring their health in the context of their life course (Consumers Health Forum of Australia, 2013; National Voices, 2015; Redding, 2013; WHO, 2016a).

1.1.2 Co-production of Health

The development of the integrated people-centred health service framework was underpinned by the belief that when the individual adopted a participatory role in their health experiences, they would be in a better position to make decisions and take actions proportionate to their immediate health needs and their anticipated future health needs (WHO, 2015). However, the WHO (2016a) report that there is limited evidence to support that health services or providers shared this belief or are experienced in engaging with participatory practices such as coproduction.

With an appreciation gained from examining case studies of integration within NHS England health services, Fulop et al. (2005) advocated for the importance of establishing relationships, based on shared values and beliefs, which they called "normative integration" (p.4). This approach draws on population health and community participation methodologies, where the focus is on facilitating harmony through relationships and reciprocity rather than structures and functions (Evans, 2014). Recognising the novelty of co-production for health services, the WHO (2016a) explicitly defined co-production of health as a relationship that is central to the effectiveness of the integrated people-centred health services framework.

> Co-production of health: care that is delivered in an equal and reciprocal relationship between professionals, people using care services, their families and the communities to which they belong. It implies a long-term relationship between people, providers and health systems where information, decision-making and service delivery become shared (WHO, 2016, p. 4).

1.2 INITIAL IMPRESSIONS

My first impression was that I had found myself situated within the political and social dynamics of an ambitious world-wide transformational reform agenda designed to influence the way people, as members of the global community, think about their health and engage with health services. What was not clear yet was, whose agenda was this? I was also curious why, when health services are often reported to require convincing evidence before taking up changes, that integration was being swiftly built into public policy and planning of health services (Bartlett & Ahmed, 2017).

A possible source of my wariness was whether this was predominantly the perspective, an enactment of the power to speak on behalf of others afforded to public policy experts. A rapid scan of the literature revealed that efforts to understand what is important to an individual in relation to their daily health needs, recent health care experiences, or future health goals remains rare in the evaluation of health services, and is consequently often missing in the design or planned enhancements of health services, such as integrated care (Birrell & Heenan, 2014; Chen, 2015; Consumers Health Forum of Australia, 2013; Evans et al., 2014; Goodwin et al., 2014; National Voices, 2015; Redding, 2013; Wigens, 2016; Wilson et al., 2009). This is not to say that if the public are asked, they would not consider the changes that integrated care offers to be an improvement, or that changes to the existing public policy that preside over health system would not bring benefits. Their perspectives are just not well known.

The literature lead me to Ackoff's (2004) commentary on transforming systems in order to right something that is obviously wrong within society and is contributing to harming citizens. He voted for caution in imposing solutions upon others and would rather see cycles of testing-failing-learning supported. His words resonated with me;

> The righter we do the wrong thing, the wronger we become. When we make a mistake doing the wrong thing and correct it, we become wronger. When we make a mistake doing the right thing and correct it, we become righter. Therefore, it is better to do the right thing wrong then the wrong thing right. (Ackoff, 2004, p. 1)

Applying Swedberg's (2014) approach to what he called early or pre-theorising, I intentionally resisted approaching my initial impressions through the lens of a problem, I did not want to imply that there was a right solution or to position myself as the problem-solver. Stake (1995) also encouraged discipline, to notice what had left an impression and what was drawing me to want to explore further. In adopting these practices, what I noticed to be emerging for me was that in the absence of access to individuals' perspectives in relation to their experiences or what mattered most to them, health services would likely replicate what was already known, giving preference to the perception of value or assessment of risk held by the policy makers, funders, or health care providers (Brannelly & Matthews, 2010; Ferrer, 2015).

Next, I looked to the definitions of integrated people-centred health services outlined in the WHO's (2016a) Framework (Table 1.1). The WHO's (2016a) comprehensive definitions brought to mind the term "sharp-end-blunt-end", with the sharp end being where integration happened in the moment, which from the definitions provided would mostly be in the course of the individuals' daily living activities; while the blunt end would be the integrated care policy that determined the structure and administration of how services are organised (Hollnagel, 2015). The individual and health care provider interactions would be somewhere in-between. Simply put by Hollnagel (2015), "at the sharp end, people look at what they do themselves; whereas at the blunt end, people look at the outcomes of what others do – or what they assume others have done" (p.11). Therefore, to better understand integration, my impression was that I needed to be curious about what it was like for the individual to experience integrated people-centred health services in their context, what it meant in their everyday life.

Table 1.1: Framework on integrated people-centred health services: Definitions

Definitions	**Integrated health services**: health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation, and palliative care services coordinated across the

	different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course (WHO, 2016a, p.2).
	People-centred care: an approach to care that consciously adopts “individuals”, “carers”, “families” and “communities” perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases and respects social preferences. People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services (WHO, 2016a, p.2).

1.3 RESEARCH CONTEXT

To allow for an appreciation of the context within which this research was conceptualised, the following sections briefly outline the background and significance of health services reform and integrated people-centred care from the global, Australian, and New South Wales viewpoints.

1.3.1 Global: World Health Organization defining and guiding health service reforms

In 2009, the World Health Assembly focused their attention on strengthening primary health care and ensuring that all of the WHO’s streams of work had people embedded at the centre (WHO, 2016a). However apart from changes to public policy wording, this has been found to have minimal impact, with the community continuing to be marginalised in providing input into decisions about local health care services or health options (WHO, 2016a). In 2013, adopting participatory and iterative approaches, work commenced on the interim WHO’s (2016a) *Framework on Integrated People-Centred Health Services*.

Leveraging the calls for greater public accountability and for equity in how health resources are allocated, the WHO (2015) positioned the integration of health services as the most appropriate universal strategy for ensuring a population receives safe, timely, appropriate health care that is both responsive and cost effective. Promoting a population approach to the planning and delivery of integrated care health services means a somewhat radical shift away from services being provider-centred towards a people-centred philosophy, where services are locally developed and contextually relevant (WHO, 2015).

In recognising the significant expectations of the health workforce reflected in the framework, the drivers and guidance for action identified in the *Global Health Workforce Strategy 2030* and the *Framework on Integrated People-Centred Health Services* were aligned (WHO, 2016a). In 2016, the framework was supported by stakeholders, endorsed by the Assembly, and publicly published (WHO, 2016a; 2016b)

A key learning from their broad consultative approach to developing the framework was the heterogeneity existing across and within health systems, resulting in the recommendation that any reform efforts need to be context-specific rather than prescribing a single model (WHO, 2016a). The framework provides definitions and has five interdependent strategies designed to guide and support localising the implementation according to context and priorities (WHO, 2016a). The strategies are, empowering and engaging people, strengthening governance and accountability, reorienting the model of care, coordination of services within and across sectors and creating an enabling environment (WHO, 2015a; WHO, 2016a). Engagement is defined as when a person is involved in a process through which they harmonise information and professional advice with their own needs in order to take care of their own health (Gruman et al., 2010).

The definitions and the implementation strategies brought attention to the relationships between people, context, the model of care, and the intended outcomes. The dynamic complexities of health system transformational change were acknowledged, in that it is socially complex, subjective, non-linear, with no one definitive solution (Crowley & Head, 2017; Edgren & Barnard, 2015).

1.3.2 Australia: National health system reform drivers

At some time throughout their lives, most Australians will directly or indirectly benefit from the Australian health system, with the average Australians' life expectancy and health status being rated as comparably better than other countries (Australian Government, 2019). The structure of the Australian health care system is bound to the federal system of government and is continually restructured in accordance with constitutional changes and intergovernmental reform agreements (Australian Institute of Health and Welfare [AIHW], 2018). The system features multiple components, governed within a complex array of funding, operational and regulatory arrangements. All levels of government, non-government, private health insurers and individual citizens contribute to funding the health system (AIHW, 2018). Based on the principles of universal health coverage, the public health insurance scheme known as Medicare was introduced in 1984 (van Gool & Hall, 2024). Universal health coverage is one of the United Nations' Sustainable Development Goals and aims to protect people from financial hardship related to meeting their health and unexpected illness needs (van Gool & Hall, 2024).

Financing for Medicare is sourced through general government taxation revenue and a levy, it supports fee-free access to treatment as a public patient in an Australian public hospital (AIHW, 2018; Australian Government, 2019). However, not everyone in Australia has access to Medicare and there are some health-related services that are partially or not subsidised (Australian Government, 2019). Hence, in spite of the Australians health system being comparably described as a good system, it's complicated and fragmented governance and funding arrangements are seen as contributors to duplication and gaps in health services, including the disproportionate investment in acute services when compared to primary and community services, and for being just too difficult for the individual citizen to navigate or influence (Davies et al., 2011; Organisation for Economic Co-operation and Development, 2015; Zurynski et al., 2022).

In 2016, over seven million Australians, 35% of the population, were reported to be living with a chronic condition (Commonwealth of Australia, 2016). In 2020-21, this grew to nearly half of the Australian population, 47% or 11.6 million Australians, living with one or more chronic condition, and an increasing number are reporting multiple conditions as they age (AIHW, 2022). Living with chronic disease presents both economic and non-economic burden for the individual (AIHW, 2023). For example, over their life-course these individuals will face increasing treatment and medication costs, coupled with being less likely to maintain employment and more likely to be socially isolated and experience a loss of their independence (AIHW 2022; AIHW, 2023).

With Australians increasingly living longer, and living with chronic and complex health conditions, this is a critical driver for further reform in how health services are coordinated and where the health dollar is invested (AIHW, 2023). Supporting people living with chronic conditions in the community, requires re-imagining of the current health model away from a disease-specific focus and towards care that is personalised to the individual's circumstances and lifestyle (AIHW, 2023). In 2017, the Health Ministers agreed to collective action so that all Australians can, "live healthier lives through effective prevention and management of chronic conditions", endorsing the *National Strategic Framework for Chronic Conditions 2017-2025* as the framework that will guide the policy reforms (Australian Health Ministers'

Advisory Council [AHMAC], 2017, p. 3). The logic of the reform agenda is underpinned by guiding principles and rather than replacing the complex matrix of policies currently in place, it is intended to enable partnerships and shared accountability (AHMAC, 2017). The AHMAC (2017) framework recognises an integrated approach as an enabler for, "Strategic Priority Area 1.4: Timely and appropriate detection and intervention" (p.24). The drivers and opportunities for health system improvement identified in the framework are universally relevant, rather than unique to the Australian health system.

1.3.3 New South Wales: State health system reform ambitions and benefits

In the context of this research, the Australian state of New South Wales (NSW) has localised the WHO's (2016 a) framework and embedded it within their *Future Health: Guiding the next decade if care in NSW 2022-2032* vision of "A sustainable health system that delivers outcomes that matter to patients and the community, is personalised, invests in wellness and is digitally enabled" (NSW Health, 2022). To progress the vision, a strategic framework is in place to guide delivery against six strategic outcomes. *Strategic Outcome 2: Safe care is delivered across all settings*, includes a key objective to "connect with partners to deliver integrated care" (NSW Health, 2023). The ambition NSW Health holds for integrated care aligns to the overarching vision and strategic outcome in that it will be "leading partnerships to deliver seamless care anywhere" (NSW Health, 2023).

The proposed benefits for the people of NSW from integrated care, in particular, for vulnerable members of the community, are described as:

- program enrolment and delivery of interventions for health coaching, care navigation and care coordination to improve health literacy, self-management, and health awareness;
- linking people into primary care and community service providers who can assure continuity of care; and
- fostering patient independence by assisting them to manage their own health care and minimise their hospitalisations for as long as possible (NSW Health, 2023).

Published in 2018, the *NSW Health Strategic Framework for Integrating Care* signposts the states substantial investment in achieving their goal of delivering care that is more integrated. The framework details their journey from establishing HealthOne, a facility-based multidisciplinary service that was integrated with primary care in 2006, to their current focus on system integration as an enabler for improving individual's health experiences and outcomes, greater efficiencies in service delivery, and stronger alignment with the NSW Health's commitment to delivering value-based healthcare (NSW Health, 2018). The framework recognises the importance of stakeholder contributions, identifying people, families and carers as stakeholders that contribute to the overall success of integrated care (NSW Health, 2018). It is a future aspiration that people and communities are involved in decision making and codesign, with the frameworks immediate focus being on strengthening vertical structures and governance arrangements, including health organisations developing measurable key performance indicators (NSW Health, 2018). Monitoring and evaluation of integrated care includes internal tracking of patient activity and related health information data, and externally through patient experience surveys and record linkage systems (NSW Health, 2021).

To inform their strategy NSW Health commissioned a rapid review of the literature on healthcare provider experience and satisfaction with the provision of integrated care. The review identified 33 published articles of which most were set in the primary care context with general practitioners the participants studied (Stephenson et al., 2015). Of universal importance to healthcare providers when delivering integrated care was to know what was expected of them, with the physical environment of the clinic and its proximity as important factors. The review summarised that the providers perspectives reflected their personal preferences and beliefs about integrated care, rather than being about characteristics of the integrated care model that was in use (Stephenson et al., 2015). Their findings supported Fulop et al.'s (2005) advice that without normative integration, addressing the beliefs held about the model, structural integration of health services is unlikely to progress, or deliver the desired outcomes.

NSW Health also commissioned a rapid scoping review of patient reported measures in the integrated care context (Chen, 2015). The review confirmed that patients tend to report better outcomes when they reported to be engaged in their health care, and that in measuring patient reported outcomes the communication and shared decision making between patients and providers improved. Chen (2015) summarised that universal consensus or a static measure on what is the key dimension of the patient experience is unlikely, however developing ways to be more responsive and measuring experience over time is worthy of further consideration.

1.4 RESEARCH AIM

The WHO (2016a) position was that an ideal starting point for co-producing integrated people-centred health services is when reciprocal understandings are established that are inclusive of all perspectives. Hence, the voices of all people, how they make sense of, and realise value from, an integrated health service is critical for its iterative development. For a reciprocal relationship to be effective, all voices need to be heard.

> Voice is meaning that resides in the individual and enables that individual to participate in a community ... The struggle for voice begins when a person attempts to communicate meaning to someone else. Finding the word, speaking for oneself and feeling heard by others is all a part of this process ... Voice suggests relationships: the individual's relationship to the meaning of her/his experience and hence, to language, and the individual's relationship to the other, since understanding is a social process. (Britzman, 1990, quoted in (Connelly & Clandinin, 1990, p. 4).

With a focus on understanding meaning, my intention in this thesis is to privilege the experience and voice of the people; specifically, person(s) who reside independently in the community and who make use of an integrated health service to address their health needs. My proposition is that focusing on what matters to the person from their perspective will contribute to framing the everyday ordinary and possibly different narratives that reflect their meaning and experiences. This will then help in shaping different questions and considerations as to the potential value integrated care has to offer, and where to invest for outcomes that matter (Patterson, 2017)

Neuman (2000) described social theory as a system of interconnected abstractions or ideas that condense and organise knowledge about the social world and how it works (p.40). Reynolds, Debono and Travaglia (2024, p.4) describe that a theory, "is a way of explaining a concept or idea", that it is an interpretation of ideas rather than claiming them to be facts. My aim is to contribute in a small way to social theory through providing an interpretation of different ways in which people experience their social world, in the context of their integrated care experiences. My aim is to intentionally engage in the processes of theorising through the practical acts of the mind such as discovery and curiosity, seeking to see, feel, and express things in different ways (Swedberg, 2014).

I want to lift the voice of personal experience, to share an empathic understanding of the person's perspective and illuminate its significance, enabling those outside or observers of the experience the opportunity to hear, comprehend, and themselves theorise. I hope that the design of this research may serve to expand and contribute to better understanding of the ways in which the benefits of integrated care manifest and appear for individuals (Saldana & Omasta, 2018)

In privileging the individual's perspective and its significance as an event as well as situated within with their life continuum, I hope to offer an interpretative view of the phenomena being studied. I aim to express the phenomena in a form that will create impact, disrupting usual patterns of thinking and contribute to generating new insights and actions. In illuminating how people making meaning of, and track, in respect to their personal everyday acts of preventing and managing their health needs, light can then be shed on ways to enhance the responsiveness of an integrated people-centred health service and contribute to the iterative advancements of the wider reform agenda.

1.5 RESEARCH GOALS

The research goals were to:

- Gain a greater insight into the phenomenon, understanding the personal experience of integrated care, by adopting the perspective of the person.
- Privilege the person's voice and experience in exploring what purpose integrated care serves for people within and beyond their integrated care encounter, and how they see their role in ensuring that this purpose is served.
- Gain better understanding from people's perspectives regarding the most important elements of an integrated care service, and recommendations for improvement or innovation.
- Provoke different ways of thinking and talking about integrated care, its purpose, and ways of monitoring whether it is of service; and delivers on what matters most to people.

1.6 RESEARCH PHILOSOPHICAL AND THEORETICAL INFLUENCES

1.6.1 Research Paradigm: Qualitative, Interpretivist

This research is framed within the theoretical premises of qualitative research. Qualitative research acknowledges that there are multiple meaningful subjective realities and seeks to understand the subjective experiences, the personal and socially constructed meanings, of real-life events (Creswell, 2011). The study's focus on exploring how the participants' experienced and made meaning of a particular time and place within their social world and then reconstructing these understandings looking for consensus or divergence within their collective realities aligns with the interpretive nature of qualitative inquiry.

Qualitative inquiry is interpretative, whereby the researcher constructs meaning over time, as their mind uniquely interacts with and reflects on the study data (Saldana & Omasta, 2018). An interpretivist explanation is a secondary account of the lived experience and meaning making of another (Neuman, 2000). The researcher needs to think logically, be systematic, use their imagination, and be sensitive, ethical, and moral towards the people who are being studied (Neuman, 2000).

Interpretivist research does not try to be value free; conversely, values and meaning are seen to be infused everywhere and in everything, with any one set of values not assumed to be better or worse. The researcher takes the role of a "passionate participant" involved with those being studied (Guba & Lincoln, 1994, p. 115). A reflexive stance is encouraged, as this allows the researcher to be mindful and accountable for their impact on data generation, relationships with research participants, and data analysis (Nicholls, 2019).

1.6.2 Ontological and Epistemological Perspective: Social Constructivism

Ontology, meaning the study of being; and epistemology, meaning the theory of knowledge, are perspectives that underlie all research and any claims that are made, they guide "what you can say about your data, and informs how you theorise meaning" (Braun & Clarke, 2006, p.91). Social constructivism approaches knowledge as having dynamic properties and being relative within a person's social reality (Higgs et al., 2007). A person creates their own reality through interacting within their social world and with others, reflecting and constructing meaning that enables that person to know (Saldana & Omasta, 2018). The relationship between the researcher and the study participant is that of a "fused entity", where meaning is intersubjectively co-created through their interactions and cannot be separated (Lincoln et al., 2011).

1.6.3 Philosophical Stance: Pragmatism, Feminism

The ideological stance that underpinned this research is that there are many ways to interpret the world, with no single point of view more valid than another. This position sits within the philosophy of pragmatism, where it is the researcher's belief that being true to the research question rather than to a specific methodological paradigm is the most important (Creswell, 2011). This position is attractive, in that the axiology of pragmatism acknowledges that the researcher's values and belief systems are embedded within the research, requiring the researcher to adopt both objective and subjective stances (Teddlie & Tashakkori, 2011). The pragmatic logic for how meaning is understood in the social world is not bound or revealed by a method, rather it is an interaction that focuses "on the consequences and meanings of an action or event in a social situation" (Denzin & Lincoln, 2011, p.246). With this research being situated in the social world, in adopting a pragmatist stance, I will apply the method that will advance my understanding of the phenomenon of interest, knowing that I have the option yet are not required to use multiple methods (Denzin & Lincoln, 2011).

Feminism logic is also a philosophical dimension of this research. Denzin and Lincoln (2011) draw on Linda Steiner's work in describing feminism, as challenging the conventions of impartiality while elevating collaborative processes and empathy. Taking a feminist stance, questions are asked about power before others, paying attention to "'whose interests are regarded as worthy of debate'" (Steiner, as cited in Denzin & Lincoln, 2011, p.69). Pragmatism and feminism share some beliefs, for example, the belief that gender is socially constructed (Denzin & Lincoln, 2011). Being focused on the practices of everyday life, how they are influenced by social and political structures, and how they could be improved or made better are also shared features of feminism and pragmatism (Seigfried, 1996).

1.6.4 Theoretical Orientation: Phenomenology, Hermeneutics, and Idiography

Phenomenology is both a philosophy and a methodology often used for qualitative research (Saldana & Omasta, 2018). Phenomenology is an approach that seeks to describe the what and how of human experience, "the study of an individual's lived experience of the world" (Neubauer et al., 2019, p. 91).

Phenomena, things that make themselves known to a person through experiencing them, can occur daily. The essence is the immutable quality of that thing that makes it what it "is" or "means" and not something else (Stake, 2010, p. 31). In phenomenological research, the basic unit of analysis is the phenomena, not people (Shudak, 2018).

Hermeneutics is the connection between experience and meaning (Schwandt, 2000). Personal experience of a social phenomenon is reconstructed, made sense of, and expressed through subjective meaning (Tuffour, 2017). Meaning can be emergent, fluid, and evolving, which is congruent with the interpretive, social constructivist epistemology used in this research.

Hermeneutic phenomenologists seek meaning through interpretation, eliciting lived experience (Neubauer et al., 2019). Also known as interpretative phenomenology,

> Hermeneutic phenomenology studies the meanings of an individual’s being in the world, as their experience is interpreted through his/her life world, and how these meanings and interpretations influence the choices that the individual makes. This focus requires the hermeneutic phenomenologist to interpret the narratives provided by research participants in relation to their individual contexts in order to illuminate the fundamental structures of participants’ understanding of being and how that shaped the decisions made by the individual (Neubauer et al., 2019, p.94).

Of relevance to the aim of this research, an idiographic approach is where each person’s experiences and meanings are valued for their own merits through detailed and nuanced micro-analysis before investigating any convergence or divergence between the participant experiences (Tuffour, 2017).

1.6.5 Research Methodology: Qualitative Health Research

Early qualitative health research has been described as drawing heavily on anthropology, sociology and education theories and methods; however, more recently, it has been increasingly recognised as a specialised form or sub-discipline within the field of qualitative inquiry (Morse, 2011). Due to its unique ethical and research design issues, health research is considered different enough to warrant modification and recognition as a form of qualitative inquiry in its own right (Morse, 2011).

1.6.5.1 Qualitative Health Research: Case study and health services research

Case study research has reportedly been able to maintain relevancy over time and across disciplines because it is particularly useful in understanding and exploring practical changes, variations, and processes of complex and multifaceted interventions or program within their real-world context (Habtamu et al., 2014). The flexible and pragmatic nature of case study design is an attractive approach to answering the complex questions posed by health and social sciences researchers, practitioners, and policymakers, which usually feature context-bound phenomena with a multiplicity of variables not amenable to control (Lalor et al., 2013). Hence, case study methods are often called upon to guide health services research (Yin, 2014).

Contemporary health services are described as “messy” settings; they are complex social systems in constant transformation (Rolfe et al., 2008). Much of the contemporary need for case studies in health services research is said to be driven by global developments in the integration of health services that require multiple components to be linked in new ways, producing mega-systems of greater complexity (Yin, 2014). Therefore, studies need to take place within a high-flux state, featuring continually and rapidly changing contexts and real-life complexity (Pawson & Tilley, 1997). Case study research design helps to unfold implicit and explicit theories at play within the messy reality of the health service, interpreting, explaining, negotiating, and contesting (Greenhalgh et al., 2009). Sandelowski (2011) stated that case study research may be undertaken at any point in a program of health services research where intensive study is warranted.

1.7 CASE STUDY RESEARCH DESIGN

Supported through an integrative review of the health services research, this section provides justification for, and demonstrates application of, case study research design, exploring its appropriateness for addressing the research goals and alignment with the theoretical framework.

1.7.1 Integrative review of the literature

An integrative review of the literature was undertaken in this study to better understand why and how case study research design is applied within health services research, and to identify the challenges and lessons learned. An integrative review is described as an approach to reviewing the literature, irrespective of the research methods utilised, to better understand a particular phenomenon or issue (Whittemore & Knafl, 2005). Researchers have found the integrative review approach to be both a systematic and rigorous process (Allen et al., 2015; Mannix et al., 2013).

1.7.2 Data Collection

An advanced search via EBSCOhost Research Databases including Business Source Complete, Medline, Academic Search Alumni Edition CINAHL, and PsycINFO databases was undertaken for the period from January 2001–December 2015. This period was chosen to ensure that contemporary perspectives informed the initial design phase of this research.

The initial search term “case study” was limited to appearing in either the title, abstract, or as a keyword of papers published in English, which identified 323,680 sources. Next, the search terms “health services” and “planning” were included, refining the sample to 1,034 publications. The terms “change” and “evaluation” were added to capture studies associated with something dynamic or improving. This reduced the sample to 77. The search was further refined to full text peer-reviewed articles, duplicates were removed, and reference lists were hand searched to ensure any relevant papers were not missed, reducing the sample to 45.

Finally, with the focus of this appraisal being to understand how case study research had been applied, only empirical papers were included in the final sample of 15 publications.

The integrative review search findings were similar to a review of high-impact qualitative method journals from January 2008 to March 2013 for papers with case study in the abstract field (Hyett et al., 2014). Limiting the final sample to empirical research only was a strategy applied by Mannix and colleagues (2013), who were looking to specifically uncover research derived characteristics.

1.7.3 Quality Appraisal

Methodological reviews have highlighted the challenges of critically evaluating and comparing the rigour of case studies (Hyett et al., 2014). In recognition that diversity in focus and application are features of case study research, for this appraisal, I drew on Yin's (2014, p. 29) five critical features of case study research design:

1. the study question(s);
2. study propositions;
3. study unit(s) of analysis;
4. the logic linking the data to the propositions; and
5. criteria for interpreting findings.

To understand the benefits that researchers associate with applying the case study design in addressing their research question, the review also included a sixth feature;

6. challenges and lessons learned related to case study design.

Each of the publications were reviewed to ensure they specifically and sufficiently addressed the six features. This resulted in the sample being reduced to 13 publications (Table 1.2), with two papers not meeting the criteria.

Table 1.2: Integrative literature review – Final data set

1.	"Drivers of routine immunization coverage improvement in Africa: findings from district-level case studies" (LaFond et al., 2015)
2.	"Addressing the social determinants of health: a case study from the Mitanin (community health worker) programme in India" (Nandi & Schneider, 2014)
3.	"The crisis in human resources for health care and the potential of a "retired" workforce: case study of the independent midwifery sector in Tanzania" (Rolfe et al., 2008)

4.	“Epistemic communities in global health and the development of child survival policy: a case study of iCCM” (Dalglish et al., 2015)
5.	“Pneumonia’s second wind? A case study of the global health network for childhood pneumonia” (Berlan, 2016)
6.	“Using case study within a sequential explanatory design to evaluate the impact of specialist and advanced practice roles on clinical outcomes: the SCAPE study” (Lalor et al., 2013)
7.	“Using a case study approach to document “preferred practices” in mass drug administration for trachoma” (Habtamu et al., 2014)
8.	“Swimming upstream: The challenges and rewards of evaluating efforts to address inequities and reduce health disparities” (Hughes et al., 2013)
9.	“Role of pay-for-performance in a hospital performance measurement system: a multiple case study in Iran” (Aryankhesal et al., 2013)
10.	“Strategy deployment systems within the UK healthcare sector: a case study” (Zhang et al., 2012)
11.	“What Happened to the No-Wait Hospital? A Case Study of Implementation of Operational Plans for Reduced Waits” (Hansson et al., 2012)
12.	“Good governance and corruption in the health sector: lessons from the Karnataka experience” (Huss et al., 2011)
13.	“How Do You Modernize a Health Service? A Realist Evaluation of Whole-Scale Transformation in London” (Greenhalgh et al., 2009)

1.7.4 Integrative Literature Review Findings

Each of the 13 papers were reviewed to find the six critical features of case study research design, with the features then extracted from each publication and compared. Table 1.3. provides exemplars of the design features identified across the studies.

Table 1.3: Integrative literature review findings – Exemplars

Critical Features	**Data Abstraction and Synthesis**
Study question(s)	Some study questions were clearly stated at the outset, while others were introduced within the literature review or study background and formalised in the methods section. “How” and “why” forms of questions were most prevalent in this review. For example: How and why the Mitanins (a government community health worker (CHW) programme) were able to act on the social determinants of health, describing the catalysts and processes involved and the enabling programmatic and organisational factors (Nandi & Schneider, 2014).
	The term “study proposition” was not identified in any of the publications reviewed. However, most papers did make issue or intentional statements

Study propositions	at the outset; for example, "Assets-based evaluation strategies that focus on defining and applying effective implementation strategies are important tools for understanding the dynamic pathways of coverage improvement" (LaFond et al., 2015). This statement was supported with a theoretical model and influenced the preparatory phase of the study, where the researchers identified and categorised potential performance drivers. Other papers identified theory, such as the Haas theory of epistemic communities (Dalglish et al., 2015), or the WHO's policy and best practice guidelines as directing the scope of their study at the outset. (Habtamu et al., 2014).
Study unit of analysis	Examples of case definition included: "A case was defined as action by a CHW (Mitanin) or team of CHWs (Mitanins) on nutrition or violence against women, which has resulted in a positive change in the particular social determinant of health in the context of the village/cluster of villages for which the CHW/s are responsible" (Nandi & Schneider, 2014, p. ii73) In defining their unit of analysis, Lalor and colleagues (2013) definition was structured in consideration of their study being structured as a nationwide study where data were to be collected within the context of healthcare delivery with a large research team and multiple case sites (pp. 1–10). The case was deemed to be the organisation or institution where nurses or midwives worked; for example, a ward or community clinic. In keeping with an instrumental case design, the cases were purposively selected for the informational representativeness they could yield.
Logic linking the data to the propositions	Yin (2014) described five techniques often used in case study research – pattern matching, explanation building, time-series analysis, logic models, and cross-case synthesis. Examples of each of these techniques were identified, with some case studies applying more than one technique. For example, Dalglish and colleagues (2015) applied the analytic techniques of explanation building and time – series analysis, whereby preliminary data analysis began with the document review, which was used to populate a timeline capturing key events and compared how policy and related topics were framed by individuals, groups, and institutions. LaFond and colleagues (2015) applied

	a positive deviance lens in three countries, meaning they explored cases with positive outcomes and compared the experience of districts where coverage improved with districts where coverage remained unchanged. The techniques used included pattern matching and cross-case synthesis.
Criteria for interpreting findings	Each of the case studies applied strategies and collected data to address possible rival explanations. All case studies anticipated that investigator bias would be a potential rival explanation, and most collected both qualitative and quantitative data as strategies to minimise the possible "other influences" on the study findings. Lalor and colleagues (2013) clearly detailed their anticipatory strategies (p. 4). Their case study design included both as shown below "Using four research assistants trained in using the tools to identify activities that represent specialist or advanced practice, regular research team meetings, analysts worked in pairs, and all findings were reviewed by one principal investigator for consistency" and "Using independent research assistants not linked with the clinical case sites or data analysis, selection of cases to ensure generalisability of the findings within the publicly funded health service in Ireland, ensuring data were categorised using a framework that would allow for international comparison".
Lessons learned and the limitations of the case study design	The key challenges included the difficulties in establishing linear or causal relations in the messy "shifting sands" of the health service. Study participants found it hard to clearly articulate in the moment what they were attempting to achieve, the how, or why; that concepts and interpretations do not "fall out of the data'; everyone holds a different view as to what is "rigour"; trying not to pass judgment on a program's overall "success"; study participants tended to reflect well on themselves or the group they represented. Other issues included what to do when the researcher is affiliated with the organisation or "case" being studied or when the researcher is an outsider; that with limited resources, especially time, it is not always possible to interview all the key informants, address all program objectives, or conduct in-depth analysis of all key contextual factors. The

	lessons learned (not listed in this paper) were also analysed and found to be transferrable across the studies.

1.7.5 Critical Reflections

To explore the appropriateness of case study methodology for the design of this research, the aim of the integrative review was to appraise the "how" and "why" case study research design has been applied in health services research. Each paper was carefully scrutinised several times using Yin's (2014) critical features of case study research design. Having to draw out each feature enabled me to appreciate the individual and collective significance within the overall case study design.

In examining each paper for the logic and linking the data to the propositions and criteria for interpreting findings, I appreciated that I was forced to ask "why" and "how" questions about the case study design. Careful consideration of the strategies and techniques for analysing and interpreting data sets to ensure the data collection sources and methods are appropriate and adequate is important to the design and credibility of future case study research. Pragmatically, it is critical, as it is near impossible to "go back" and collect data after the fact within a case study design.

This review undertaken for this research provided insight into case study research and its application in the context of health services. The complexity and unpredictability of the health setting was a universal, but not unsurmountable, challenge within the case study research design.

1.8 INTERACTIVE RESEARCH MODEL

1.8.1 Design Map

The research goals, theoretical framework, and design options were outlined in this introductory chapter. I adopted a reflexive, iterative approach to the overall research design. This meant that rather than committing in advance to a sequence of steps, I was aware that I may need to make adaptions or modifications to the research design (Maxwell, 2013). Joseph A. Maxwell (2013), a thought leader in applied social research method, proposed an interactive model for the design of qualitative research. He recognised that different components may interact with and be affected by one another as the research proceeds; therefore, his model enables flexibility within the structure (Maxwell, 2013). This aligns with the pragmatism stance I hold within the research theoretical framework. Applying the "rubber band" metaphor often associated with qualitative research, the design can be viewed as elastic rather than rigid, which allowed for flexibility while providing resistance to ensure the rigour of the design was protected. What was critical for the quality of research was that I carefully deliberated the interactivity of the selected methods, with the process for data collection and criteria for data analysis clearly identified (Stake, 2010).

1.8.2 Research Design: Exploring “a case of”

The goal of this research is to gain a greater insight into a phenomenon – understanding the personal experience of integrated care – by adopting the perspective of the person. This phenomenon could be framed as “a case of”. The case is a real situation, it is specific and bounded by the literature, and by geographical and by bureaucratically defined boundaries (Luck et al., 2006; Stake, 1995; Yin, 2014). In an instrumental case study, the case is selected because it facilitates the opportunity for the researcher to gain greater insight into the issue of interest, something embedded within the case and its context (Stake, 1995).

Case study research design is a dynamic balance of seeking data particular to the case. While holding gently, in knowing that as “a case of”, this is a theoretical construct that will emerge as a process and product of the research and become known following data analysis (Ragin, 1999). While there may be a number of individual participants within the case, the case and the “case of” are singular. Taking Stake’s (1995) position, each case study is selected with the aim of knowing it well, what it is, what it does, emphasising its uniqueness. The intent is not to compare how it differs from others; however, it is recognised that making generalisations with what is known when trying to make sense of new information, is accepted as being unavoidable.

In considering the research design, what data were pertinent and added value to the understanding of the phenomenon, I took the time and opportunity to get acquainted with the case prior to determining the final data collection and analysis processes (Stake, 1995). I also took advantage of my own knowledge in relation to the phenomenon of interest, and considered the approach that would best enable me to truly, deeply listen, allowing me to be targeted, yet open to discovery in advance (Stake, 2010). With the aim of understanding local and specific experiences and co-constructing the social understandings held by individuals, my approach aligned with the perspective of social constructivism and supports intersubjectivity.

I acknowledge that social constructs can be influenced by external inputs and shaped by new understandings; they are being continuously appraised and reappraised. When planning to research within complex multilayered environments, Stake (1995, p.22; 2010, p.130) referenced the work of sociologists Malcolm Parlett and David Hamilton, who described the concept of progressive focusing, as three overlapping stages that I could adapt or build into the research design. The stages were observation, renewed inquiry and seeking to explain.

Swedberg (2016) encouraged social researchers to draw on their intuition and different habits of thinking as a means of exploring an existing phenomenon from another or novel perspective. Swedberg's (2016) approach to the research process referenced Charles Peirce, a philosopher credited as the founder of pragmatism. Peirce's model included three thinking approaches, through which I could engage in "abduction, deduction and induction" forms of thinking (Swedberg, 2016, p.14). Like Stake (2010), Swedberg (2014) positioned the researcher as being both disciplined and creative thinker, open to accessing the deeper subconscious mind and engaging in activities such as visual thinking to reveal insights and explanations of what was being observed, heard, or felt.

1.8.3 The Emerging Research Question

The research questions sit at the centre piece of Maxwell's (2013) research design, they focus the research and guide the researcher in how to conduct it. This does not mean that the research question is set or fixed from the commencement of the research. However, it does mean that if they are refined or expanded during the research, that all other components of the research design also need to be re-considered.

What I found to be of specific interest and motivation was the privilege this research presented to contemplate and theorise about how the world appeared from another's point of view. With an appreciation that moving towards an integrated people-centred health service offers universal advantages for people and health systems, it is still an ambitious transformation in how roles of the person and the health service are negotiated. I was curious to listen and learn from the people who had recently experienced an integrated care health service within their life's course.

This research was designed to gain a greater insight into a phenomenon, "a case of". The question then became; *"How do individuals living in the community who engage with an integrated care health service make sense of this experience as part of their everyday health needs and goals?"*.

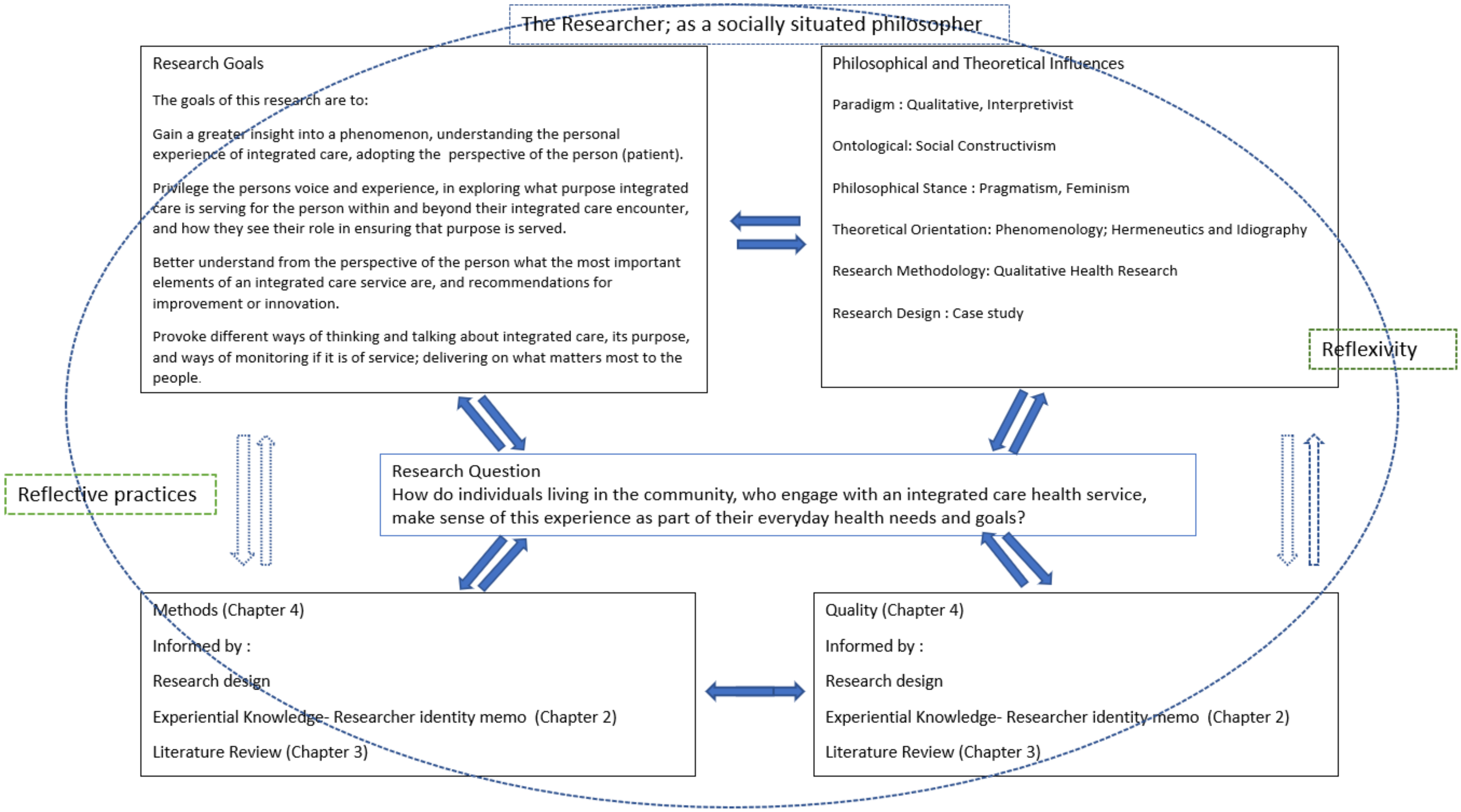
To ensure the research design served to answer the research question, it was important that all the design components were connected and interconnected. I was reassured by Maxwell

(2013) that “the value and feasibility of your research methods cannot be guaranteed by your adhering to methodological rules; rather, they depend on the specific setting and phenomena you are studying and the actual consequences of your strategy for studying it” (p.233). I was also conscious that this research was set in the context of a desire to shift or rethink old ways, meaning that new methods may need to emerge to disrupt old ways. Hence methodological flexibility was an attractive feature of Maxwell’s (2013) approach to research design.

1.8.4 A Tentative Plan

To frame a tentative plan of the overall research, acknowledging that it was still under refinement, I adapted Maxwell’s (2013) “research on a page” approach. This tentative plan was my guide in the formative phases of designing the research. It ensured coherence as I progressed from the thinking components to considering the doing components of the research design. As illustrated in Figure 1.1, Research on a Page – A Tentative Plan, I populated the research goals, conceptual framework, and research question, while the method and research quality components took shape following self-examination of my position as the researcher (Chapter 2) and its potential influence on the research and the systematic review of the literature (Chapter 3). In Chapter 4, I discuss how I revisited the research question and constructed the next version of the research design. Reflexive practices were embedded throughout the research to ensure that the design remained dynamic and responsive to new understandings if or when they emerged. The research on the page approach has been recognised as effective tool for communicating to the reader the iterative entanglement of thinking and doing that underpins robust research design (Maxwell, 2013).

Figure 1.1 Research on a Page – A Tentative Plan



Research Goals

The goals of this research are to:

Gain a greater insight into a phenomenon, understanding the personal experience of integrated care, adopting the perspective of the person (patient).

Privilege the persons voice and experience, in exploring what purpose integrated care is serving for the person within and beyond their integrated care encounter, and how they see their role in ensuring that purpose is served.

Better understand from the perspective of the person what the most important elements of an integrated care service are, and recommendations for improvement or innovation.

Provoke different ways of thinking and talking about integrated care, its purpose, and ways of monitoring if it is of service; delivering on what matters most to the people.

Philosophical and Theoretical Influences

Paradigm : Qualitative, Interpretivist

Ontological: Social Constructivism

Philosophical Stance : Pragmatism, Feminism

Theoretical Orientation: Phenomenology; Hermeneutics and Idiography

Research Methodology: Qualitative Health Research

Research Design : Case study

Research Question
How do individuals living in the community, who engage with an integrated care health service, make sense of this experience as part of their everyday health needs and goals?

Methods (Chapter 4)

Informed by :

Research design

Experiential Knowledge- Researcher identity memo (Chapter 2)

Literature Review (Chapter 3)

Quality (Chapter 4)

Informed by :

Research design

Experiential Knowledge- Researcher identity memo (Chapter 2)

Literature Review (Chapter 3)

1.9 THESIS OUTLINE

This chapter outlined the context and overall intent of the research. My interactive, qualitative, interpretivist theoretical orientations and the research design were introduced. The tentative plan (Figure 1.1) illustrated the connections between the components of the research design. Congruence between the components was critical in achieving the research goal of privileging the lived experience and meaning of the research participants.

This thesis has been constructed to take the reader with me as the research unfolds. Aligned with adopting a reflexive and iterative approach to designing the research, rigour has been enhanced through the sharing of my interpretations and demonstrating my responsiveness to what was being revealed throughout the explorations, rather than their compliance with a pre-determined design sequence. Reflexive practices are built into the research design and are signposted within each chapter.

Chapter 2 focuses on me as the researcher, providing the reader with a curated exploration of my personal biography. As described by Swedberg (2014), the practical first stages of theorising are about being curious, discovering without analysing, learning what it is that interests you, then focusing in on what surprises you. Adopting an abductive form of thinking served to prepare me to be vulnerable, emotionally empathetic, and build a level of readiness to see and explain the world "in a new light". These insights and understandings mature throughout the research and were considered in the context of the research design.

The literature is examined in Chapter 3. The aim was to establish what was known empirically about the phenomenon, the personal experience of integrated care, from the perspective of people living at home and attending to their health needs within the context of their life's course. The initial literature search was completed for the period 2008–June 2018. I critically reviewed the literature to understand how others had approached their research, I searched for insights and new knowledge that had been generated and appraised how the ethical integrity of the research had been maintained. These understandings were drawn on to refine the research rationale, questions, and impact.

The research methodology forms the focus of Chapter 4. My aim was to strengthen the congruence within the thinking and doing components of the research design. To do this, firstly I draw on the empirical data and insights from the literature review to progressively refine the research goal to ensure my intentions were clear for the reader. I also adopt a tight-loose approach, crafting an overarching framing question and then focusing questions that would guide my explorations (as demonstrated in Table 4.1). I then focus on construction of the method and quality components of the research design. This chapter includes a detailed description of the participant sampling, data collection, data analysis, and how issues of ethics and rigour were addressed.

Guided by the overall qualitative data analysis plan for the research (Figure 4.2), in Chapter 5, I detail the first and most significant phase of findings. The interpretive accounts re-presented for each of the study participants I constructed from engaging in the iterative and analytical synthesis of my interpretations, impressions, researcher journal notes, participant transcripts, and codes. The iterative processes of coding, classifying, and sorting resulted in entangling the participants' and my thoughts and words until a fused interpretation took shape. This chapter presents my interpretative responses to the first three research focus questions.

In Chapter 6, I present the second and final phase of analysis and respond to the fourth research focus question. My drivers were to gain deep and rich insights from a little referenced source and offer an empirical perspective capable of contributing to or refining the existing theories in use. My approach included immersing myself, with methodological integrity, in the study participants accounts of their lived experiences in order to construct master themes, a meso-metaphor, and an interpretive claim to support theory development.

Chapter 7 provides the conclusion to the research. Here, I respond to the final two research focus questions, so that all six questions are now addressed. In acknowledgement of the time span that the research covered and the interruptions of the global pandemic, I returned to the literature to ensure my findings were considered in the context of the contemporary literature. To make it easier for the reader, the research findings are organised alongside the original literature review findings and the more recent review. This is followed by an exploration of the study findings within the context of what aligned and what contrasted with the literature. This discussion is organised under three headings, starting with the individual level findings, then group level, and finishing with the societal level findings. The thesis concludes with my "so what", the strengths and limitations of the study, and my concluding comments.

1.10 CONCLUSION

This chapter laid the foundations of, and motivations for, this novel research study. It is important to note that while the co-production of integrated people-centred health services has been promulgated on a global scale, progress against this ambitious proposition has been dependent on stages of transformation and reform that extend within and across varied social, political, professional boundaries. My focus was on those at the sharp end, those individuals who had the lived experiences of navigating these boundaries and spanning systems as they attended to protecting and managing their health in the day-to-day, who to-date have been predominantly silenced. Whilst those at a distance from these experiences, the policy maker and the professional, have been more likely to be the privileged voices. Voices that, with likely good intentions, spoke on behalf of the silenced. This research presented me with the support and opportunity for personal and professional growth way beyond my initial impressions and expectations.

The following chapter provides a deeper introduction to my biography as a person, a health professional, and a researcher. I am conscious that I am the greatest influence and threat to the philosophical and theoretical integrity of this research; hence, my first contribution to research was to adapt Maxwell's (2013) model to include my role as the researcher as an organising and reflexive system that this research sits within.

Chapter 2: The Researcher

2.1 INTRODUCTION

In Chapter 1, I introduced the key definitions, context, and focus of the research, concluding with a tentative map of the research design. Maxwell’s (2013) interactive research design was shown to be a useful structure for surfacing and guiding my reflections and my working theories. Rather than being prescriptive, Maxwell’s (2013) research design approach has been credited as being designed to serve the research, meaning that over the course of the research, it can be further adapted as the realities of the research emerge.

Why this research is required, the theoretical and philosophical views that framed the research, and what I specifically hoped to learn and understand better through doing the research were introduced in Chapter 1. Qualitative health research, in particular case study design, was appraised for its suitability to be integrated within the study design. The selection of research methods and quality strategies have not yet been discussed. Although my influence as the researcher was not, as a rule, formally identified as a component of Maxwell’s (2013) research design, it is my belief that my presence and involvement had an influence on every aspect of the design. This chapter focuses on my roles and relationships as the researcher within the research.

2.2 THE ROLE OF THE QUALITATIVE RESEARCHER

Qualitative inquiry positions the researcher as a socially situated philosopher. It is a requirement for the researcher to be open to self-examination and to adopt a reflexive stance (Guba & Lincoln, 2005). In taking on the role of researcher, I am inseparable from the research (Denzin and Lincoln, 2011). In my research role, I am committed to the best of my ability to openly acknowledge my position and the accumulative meaning that I make of my everyday life. In being a reflexive practitioner, I am mindful of the principals and beliefs that frame the ways in which I see and interpret the world around me, and how this guides my actions.

Interpretivist research is value infused rather than value free. I adopted a subjectivist approach, inquiring as a “passionate participant”, followed by intersubjectively, whereby I co-created meaning through my interactions with the research participant and their meanings, which are also inseparable (Lincoln et al., 2011, p. 101).

2.2.1 Staying Connected to What Matters.

It is critical that as a qualitative researcher, I maintain a clear line of sight of the reasons why the phenomenon being studied matters to me. Researchers in this field have been encouraged to engage in regular reflection, critique, and self-analysis throughout the course of their research. It is important that I maintain my connection to the “motives, desires, and purposes” that lead me to want to change something or be curious to understand something better (Maxwell, 2013, p. 35). I am mindful that my desires and needs may also be deep rooted and distanced from the actual research I engage in. Therefore, it is important that I am aware that personal reasons, experiences, and perspectives can be both sources of distraction and sources of insight. Revealing and being more consciously aware of why this research mattered to me enabled critical reflection on the external and internal influences that both shaped and were possible threats to the research (Maxwell, 2012).

The researcher’s identity memo is in essence a “thinking on paper” reflective exercise (Maxwell, 2012, p. 99). It is an explicit technique that Maxwell (2009) offers researchers for “reflecting on, and writing down, the different aspects of your experience that are potentially relevant to your study”, including examining potential advantages and disadvantages for their research (p.225). The intent here was that rather than a one-off reflection, the exploration of my “identity and perspective in relation to the research” was iterative, and that it could change over the course of the research (Maxwell, 2012, p. 99).

Figure 2.1 Maxwell’s (2013, p. 45) Exercise 2.1 Researcher’s Identity Memo

> **Exercise 2.1 Researcher’s Identity Memo**
>
> The purpose is not to write a general account of your goals, background, and experiences. Instead, specifically describe those experiences, and the beliefs, goals, and expectations that emerged from them that are most directly relevant to your planned research project and reflect on how these have informed and influenced your research.
>
> Two broad sets of questions are productive to reflect on in this memo. In your answers to these, try to be as specific as you can.
>
> 1. What prior experiences have you had that are relevant to your topic or setting? What beliefs and assumptions about your topic or setting have resulted from these experiences? What goals have emerged from these, or have otherwise become important for your research? How have these experiences, assumptions, and goals shaped your decision to choose this topic, and the way you are approaching this project?
> 2. What potential advantages do you think the goals, beliefs, and experiences that you described have for your study? What potential disadvantages do you think these may create for you, and how might you deal with these?

2.2.2 Researcher’s Identity Memo

Drawing on the reflective framing questions that Maxwell (2013) recommended in his memo exercise (Figure 2.1), I undertook a self-examination of my personal goals, experiences, assumptions, feelings, and values as they related to this research. The aim was to provide the reader with insight about why I was undertaking this research and to introduce myself as a person and a researcher, surfacing my own meanings across my life course.

In adopting an interpretative phenomenological approach, in this thesis the research phenomenon was explored through listening to and seeking to understand individuals’ meanings and experiences. In the researcher role, my personal meanings were also embedded in the research. Just like my research participants, I bring my life world, my reality influenced by the world I live in, to the research (Neubauer et al., 2019).

2.2.2.1 Researcher’s Memo

The researcher’s identity memo is both personal and professional (Maxwell, 2013). The memo lays bare my context and critical reflections on the experiential knowledge I held as relevant as I prepared for this research (see Appendix A: Researcher’s Memo). My intent was to be as open and transparent as I could be. The researcher’s memo was my guide for unearthing and sharing insights from my personal experiences, assumptions, roles, and how these might impact on the research and the application of the research design. Table 2.1 summarises the results of my critical reflections, including practical considerations for this research’s design.

Table 2.1 Summary of research memo insights and practical considerations

As a researcher:	Practical considerations:
I need to be aware of being polite and needing to fit in as being deeply engrained in my biography.	The research method should include researcher engaging in mindfulness in preparation for and post interviews. The researcher will journal directly after interview and make notes, including my impressions, feelings, and questions as they arise. The researcher will establish a trusted critical companion relationship with someone not directly working in healthcare to support and challenge the researcher’s reflections and reflexivity.
I need to be wary that I have blind spots, that I do tend to trust people and that their actions are with good intentions, until proven otherwise.	
I need to recognise that I have been colonised, with decades of exposure to the culture and practices of Australian public healthcare.	
I associate feelings of shame with some of my earlier experiences. I likely have deeply embedded mental models and mechanisms	

that may interfere or influence what I hear and the meaning I make.	The researcher will engage a supervision panel as a peer group to continuously critique the research process, the researcher's position and the theories in use
I need to be open, non-judgmental, and empathetic of different ways of knowing and how and why a person sees their role, understands what is important to them, and the actions they take.	
I may not be received as the positive force for change that I intend to be. Rather I may be seen as a threat or an enforcer. People may just tell me what they think I want to hear or to please me.	
I am conscious that social hierarchy exists, and that the dynamics of power are often subtle, embedded, made sense of in different ways and mostly not openly addressed.	The research method will include consideration of power dynamics. The participant must be provided options within the interview process.
I aim to be trustworthy, recognising the importance of establishing trust with participants.	The researcher will be prepared to model the openness expected from participants by allowing time to be introduced to each other and for the participant to feel ready to participate. They will invite the participant to influence the environment or to share what trust would look or feel like to them.
I must be attuned and empathetic when exploring others lived experiences. I must respect that others may have had experiences that range from something they are not proud of, holds residual trauma, feel at peace with, or have not ever really thought about before.	This relates to trust. The researcher needs to create time and safety – space for participants to share their experience and views in their words, in their time. The participant should be provided with the opportunity to pause, stop, or seek counsel with an appropriate person.
I believe that people hold preconceived expectations of life, health, themselves, others, of something. These are connected to the person, their history, what's happening now, and their goals, which influences how people interact and respond. Raising these to the surface could be seen as exposing people, making people's thoughts and actions vulnerable to being judged or criticised.	This is related to trust and trustworthiness. It is critical the researcher respects the person, keeps the data connected to the person, in particular, when analysing for patterns across the cohort and is disciplined and intentional in their approach. All assumptions should be checked and re-checked.
I need to be clear about my interests and show that I am really interested in people as people, and that I appreciate that there may be layers of innate protective mechanisms that get in the	The researcher should draw on their

way of telling things how they are. However, I will walk with them and follow their lead, we have a path to get us started, and that we should see where we go.	experience and commitment to being authentic.
I feel that the culture and presence of health care is so strong, understanding what really matters to the person is at the risk of getting lost or being misconstrued. I propose that in focusing on the person, the distraction of the healthcare provider and the healthcare setting can be minimised.	It will be a challenge for the researcher to compartmentalise their thoughts while working full-time in healthcare. Critical companion and journalling should be used to surface thinking and the mental models in use. The researcher will need to be disciplined.
I have a better understanding now that my goal is to get a sense of what is really going on for people from their perspective, their reality, and that I must privilege their perspective, not to use it to validate someone's else's view or practices.	The research's conceptual framework and methodology are critical to achieving this goal. Consideration of applying different perspectives to the study will contribute to the rigour of the research.
I hope that I can bring the meaning people are making and what matters to them to the surface, not because people are not capable, or they need help, but because I believe people are innovative within their own circumstances. Sharing or normalising people's resourcefulness will give other people options or ideas to build from. Perhaps this may enable or empower different ways of thinking and talking that will then lead to different behaviours.	This could be linked to the earlier mentioned blind spot the researcher identified about their positive outlook. Reflexive practice will be critical, as will keeping the data connected to the person, noting what is the person's words, and what is the researcher's interpretation. Inviting independent people to review and provide comment on the research may assist with research transparency and rigour.

2.3 CREATIVITY AND HEURISTICS – METHODS OF DISCOVERY

With deeper insight into my biography, a practical method for discovering and engaging with my research, whilst continuously monitoring how my identity was influencing the research and how the research was influencing me, was to theorise. Swedberg (2014) defined theorising "as the process through which a theory is produced", while a theory was defined as "a statement about the explanation of a phenomenon" (p. 17). Maxwell (2009, p. 255) cited Reason's (1988) reference to critical subjectivity when referring to being intentional in drawing on experiential knowledge and applying these insights when theorising,

> A quality of awareness in which we do not suppress our primary experience; nor do we allow ourselves to be swept away and overwhelmed by it; rather we raise it to consciousness and use it a as part of the inquiry process (Reason, 1988, p. 12)

Theorising was applied as a heuristic approach in this research, consciously situating the researcher. Swedberg (2014) maintained that each researcher's heuristic stance, how they approach discovery and problem solving, was unique, instinctive and it influenced everyday thoughts and decisions. In order for researchers to think differently and be open to the creativity of thinking that theorising offers, Swedberg (2014) recommended that they reflect on the heuristic rules they tend to follow, and to self-observe throughout their research. With this thesis framed as interpretative research, as the qualitative inquirer I am the primary research instrument, so I have embedded reflexive strategies that enable critical self-examination of my "creativity and heuristics methods of discovery" as an element of the research design (Saldana & Omasta, 2018, p. 7).

2.3.1 Exploring Theorising Further

Inspired by the early work of the American philosopher and scientist Charles Sanders Peirce (1839–1914), who was credited as the father of pragmatism, Richard Swedberg (2017), a Swedish sociologist and Professor Emeritus of Sociology, described theorising as an evolving, contemporary, and practical thinking process. Theorising invites the researcher to be creative yet intentional in their thinking processes, requiring the researcher to be ready and able to let go and let in, a readiness to feel, see, and explain the world in a new light (Scharmer, 2009).

Like Maxwell's (2013) thought experiment exercises, which were designed to creatively engage the qualitative researcher in looking beyond what was published, to critically challenge the authority of the literature, and seek out different sources of information, I propose that theorising was fundamental to the iterative design of this research. Rather than viewing theorising as a rule bound process, Swedberg (2014) argued that when approached within a relaxed, playful, open mindset, abductive-oriented thinking would generate novel thoughts and tentative explanations from the everyday.

Swedberg (2014) referenced Pierce's (1935) writings and practical exercises as reinforcing the importance of the art of thinking, exercising the mind, and ridding yourself of old mental habits to form new ones. Pierce was said to recommend training exercises that refreshed the mind's child-like simplicity in what he called "the Play of Musement' (Swedberg, 2014,p. 245). Pierce also suggested that as recreation, "the dawn and the gloaming most invite one to Musement" (Hartshorne & Weiss, 1960, p. 459), which Swedberg (2014) translated to advocating for taking a walk for about an hour a day, at dawn and dusk. Peirce used the skiff as a metaphor:

> Enter your skiff of Musement, push off into the lake of thought, and leave the breath of heaven to swell your sail. With your eyes open, awake to what is about or within you, and open conversation with yourself; for such is all meditation (Hartshorne & Weiss, 1960, p. 461).

In Peirce's view, abductive-oriented thinking was the first stage of inquiry and required engagement with "a series of mental performances", including conjecture, scrutiny, and wonderment, which lead the researcher towards a plausible explanation that should still be tested; the prelude to scientific knowledge generation (Hartshorne & Weiss, 1960, p. 469). The second stage of inquiry was where deductive thinking takes the researcher from the general to the specific, transforming ideas into a testable hypothesis. Inductive thinking was what Peirce named the third stage of inquiry, whereby the researcher appraised the hypothesis, as components and as a whole, "then makes self-appraisal of these very appraisals themselves" before passing judgement (Hartshorne & Weiss, 1960, p. 472).

Swedberg (2014; 2016) claimed that his creative theorising approach was closely related to Peirce's abductive thinking processes, he also cautioned that Peirce's division of the research process into a three-stage inquiry scheme may be restrictive, and in response, offered a modified approach where the research is divided into a pre-study and the main study. Swedberg's (2014) pre-study, or preparation phase for the research, occurs alongside and interacts with the research design process; rather than being separate research, it belongs together with the main study. Accordingly, theorising took place iteratively throughout the planning, implementation and writing of this research.

With a goal of this research being to offer novel perspectives, theorising created the space and invited me to let go of rules, to play, and be open to pausing and musing. Maxwell's (2013) researcher's identity memo helped to position the researcher and reveal some of my heuristic rules that had the potential to influence or blindside my thinking. Heuristic rules are also known as mental shortcuts and have the potential to undermine creative thinking, in that the individual may instinctively follow a known decision pathway when uncertain, and do what they would normally do in a similar situation (Swedberg, 2014). Learning how to recognise these rules, is part of the discipline of the qualitative researcher. Stake (2010) encouraged the researcher to recognise, anticipate, or to "set up traps to catch" any instinctive biases and to be deliberate in their thinking (p.164).

Opening up your senses, closing your eyes, feeling, exposing yourself to information from a wide range of sources and, most importantly, engaging in self and peer observation are encouraged to be embedded within your daily repertoire as a researcher (Swedberg, 2014; Swedberg, 2016; Swedberg, 2017). Embedding theorising practices into my daily routine and ways of thinking allows me to continually surface existing thinking practices and enables me to recognise, adjust, and practice different ways of thinking. In acknowledging my biography and associated mental shortcuts, I can consider in advance the approaches and conditions that will best enable me to truly, deeply listen, and be open to discovery (Stake, 2010). Theorising relates to both the thinking and doing components of Maxwell's (2013) interactive research design; hence, I embedded this within my research design.

2.4 SIGNIFICANCE IN THE CONTEXT OF THE RESEARCH

Expanding momentarily from the micro-analysis of my biography and thinking habits as the researcher, I believe it is important to pause and recognise the broader structural and cultural reframing of health systems that the WHO (2016a) integrated people-centred framework was calling for. It is apparent that there would be far-reaching benefits in taking the time to surface and understand the many and varied heuristics that underpinned how decisions were being made about the design of health services. I recognised that the macro-level of analysis required to do this would be beyond the scope of this research; however, it is important to acknowledge the complexity of the wider social world within which this research is situated.

The focus for this research, was to bring forward an understanding of the thinking and decision-making processes that everyday people engaged with in relation to managing their health as a part of their daily living. In preparation for engaging with the research I have identified in Table 2.1 practical considerations that will assist me in being conscious of how my meaning and life world experiences are interacting with the research. Below I will further consider how my identity may interact with and shape the research processes and findings, including strategies for surfacing and acknowledging across the course of the research.

2.4.1 Empathic Inquirer

In planning to understand the personal experiences of people within a particular situation, it was also important that I noted my own and the research participants' emotions, positive or negative, associated with a memory or situation that could also be transferred to new or like-situations, therefore influencing how a decision or judgement was made (Swedberg, 2014). A special characteristic of qualitative interpretative research where humans study humans is its personalistic orientation, "it is empathic" (Stake, 2010, p. 15). Stake (2010) described empathy as a "matter of perception more than emotion" and reminded the empathic researcher that humans are complex, similar yet unique to others, continuously experiencing new insights, hence attempts to ever understand fully are not possible. (Stake, 2010, p. 47)

Supporting a feminist perspective, England (2002) stated that, “some of our deepest insights come from the ability to empathize” rather than keeping separate from those who we are studying and argued that emotional connections are the facilitator’s way of developing “empathy, altruism, and a subjective sense of social solidarity” (p. 160). Significant for this study, it is proposed that “imagining how someone else feels in a given situation implies the possibility of translating between one’s own and another person’s metric for utility” (England, 2002, p. 158). This proposition supported my assumption that I could co-create a shared understanding of relative advantage or disadvantage of their situation with the research participants. Sharing what is important or of utility with someone places that person in a vulnerable position. This reinforces the importance that I invested in considering strategies that this would contribute to establishing trust and trustworthiness with the research participants. This was relevant to the goals of this research and the overall research design.

2.4.2 Facilitating Expression of Meaning.

In adopting an interpretative phenomenological orientation, I sought to understand how the participants’ made sense of their experience, and how their meaning influenced their behaviours or choices (Neubauer et al., 2019). To support the research participants in telling their story, what mattered or held value, I took responsibility for creating an environment where the participants could feel safe, and where they could express and question their own meaning making processes (Titchen & Higgs, 2007). A psychologically safe environment is one where people feel confident to voice their views, to listen actively, empathise, and support others who might hold different views (Evans & Baker, 2012; West et al., 2017). I hold the belief that both the research participants and myself as the researcher, stood to benefit from these conditions.

Dialogue has often been described as a communication process that facilitates safety and “the free flow of meaning between people”, building a pool of shared meaning (Patterson et al., 2012). Enabling open dialogue within the research begins with the researcher’s communication capabilities. William N. Isaacs (1999) termed dialogic leadership as an intentional approach “to evoke people’s genuine voices, to listen deeply, to hold space for and respect as legitimate other people’s views, and to broaden awareness and perspective” (p. 2). He proposed that when viewed as a dialogic system, the researcher and the research participant are continuously shifting their stance from initiating ideas, to supporting, challenging, or observing and providing perspective (Isaacs, 1999).

In explaining their personal meaning, a person is said to be sharing their thinking processes and how they make sense of and experience their world (Glaw et al., 2017). In general, a person's mental model is said to be shaped by the societal forces they are exposed to and grounded in their beliefs, what they think they know, their predictions, not necessarily on facts. Senge (1990) described mental models as "deeply ingrained assumptions, generalisations, or even pictures or images that influence how we understand the world and how we take action" (p. 8). A type of heuristic, mental models provide an explanation, that shapes the stories we tell ourselves and others. Mental models are hard to recognise in yourself or others, however they can be externally recognised through the words used, behaviours, and actions taken (The World Bank, 2015). Creative expression, using arts, media or metaphors, has been reported to be effective in facilitating expressing the meaning of meanings (Swedberg, 2014; Titchen & Higgs, 2007). This has relevance to the method and quality components of this research and the overall research design.

2.4.3 Reflexivity

As a qualitative researcher, I am in a privileged position. In engaging in human inquiry, Lincoln et al. (2011) proposed that the researcher experiences the research and comes to know the self through the process. Adopting a feminist lens, in her essay "Who Am I? The Need for a Variety of Selves in the Field", Shulamit Reinharz (1997) argued that a social researcher has many selves that are both brought to and created within the research processes. Reinharz (1997) organised those selves into three categories; the research-based self, the brought self (those selves that create our stance, historically, socially and personally), and the situationally created self (p. 5). These selves interact within the research, the processes of discovery, interpreting, and analysis (Reinharz, 1997). Building reflexivity, the process of reflecting critically on the self, into the research design and extending this critique to be inclusive and open to the varied selves that emerge throughout has been widely recommended and was embedded into this research (Lincoln et al., 2011)

2.4.4 Brought Self

Further to the prior personal and professional experiences relevant to this research outlined in Appendix A: Researcher's Memo, since enrolling in this research program I have worked in a variety of employed and voluntary health related positions including:

Health – NSW Health (Employed)

2010–2015: Head Practice Development, Justice Health and Forensic Mental Health Network, NSW Health

2017–2019: District Organisational Development Unit Manager, South Eastern Sydney Local Health District, NSW Health

2019–Ongoing: Executive Director, Capability and Culture, Clinical Excellence Commission, NSW Health

Health – Professional Associations (Voluntary)

2010–ongoing: Australasian College Health Service Management (ACHSM) Fellow

2019–2023: ACHSM President NSW Branch

2022–ongoing: ACHSM Board Director

Health–Community Associations (Voluntary)

2021–ongoing: The Circle Foundation Cooperative (Eurobodalla)

2022–ongoing: Health Council (Mudgee)

Relevant to this research, I have demonstrated commitment to building my capabilities to facilitate safe and effective learning environments and the authentic expression of meaning through:

- VitalSmarts Crucial Conversations Accreditation: I am a trained facilitator in the skills of effectively navigating conversations and expressing what matters in crucial moments.
- Gallup Strengths Coach – individuals and teams: I am certified to coach people to identify and tap into their strengths and natural talents in order to do what matters most and improve their quality of life.
- Kings Fund UK and Consumer Health Forum Australia, Collaborative Pairs Program Facilitator: I brought health consumers and citizens together with health managers and clinicians to develop collaborative and relational capacities to strengthen capacity to work together to transform and reform health systems.

- Practice Development Facilitator: I supported individuals and teams to create transformational cultures of effectiveness and co-construct new knowledge and practices about person-centred, evidence- informed healthcare.

I have included these roles, experiences, and capabilities as they contribute to the self that I bring as the researcher to this research. Being aware of and reflecting in and on my contributions and influences on the research formed part of the processes of discovery, surfaced through practicing reflexivity and recognised within the research findings.

2.5 WHY WHAT MATTERS TO THE PATIENT MATTERS

The publication, "Why understanding what matters to the patient" (Patterson, 2017) triangulates my researcher identity, experiential knowledge, and published and unpublished literature relevant to this research's phenomenon. The paper was written in the formative phase of this research and describes how I was making sense of, and being challenged by, how integrated health was evolving within the Australian context at that time. The full paper is in the appendices (see Appendix B: Why understanding what matters to the patient matters).

2.6 CONCLUSION

This chapter shared insights into my identity and why this research matters to me. These are important insights in conceptualising my research stance and monitoring how my positionality influences the research processes and findings. Adopting the role of a qualitative, interpretative researcher meant that I played a significant and influential role within the research. It was critical that I was prepared, to be able to be responsive to the research participants, and that I considered the research environs at all stages of the research process. My philosophical and theoretical position aligned with the research. Just as a goal of this research was to engage people in different ways of thinking, I also challenged myself to experience new and different ways of thinking and to share my novel ideas through publication. I committed to continuing to draw on my knowledge and experiences, and be open to learning, and unlearning, throughout the research. The importance of embedding reflexivity into the study design has been argued.

In Chapter 3, I look to the literature to establish what is known empirically about the personal experience and meaning of the benefits of integrated care for people living at home, managing their health needs within the context of their life's course.

Chapter 3: Literature Review

3.1 INTRODUCTION

In Chapter 1, I introduced the WHO's (2016 a) *Framework for Integrated People-Centred Health Services* which was calling for health systems to "rethink health care". The WHO's (2016 a) ambition was a transformed, relational, and co-produced model of healthcare that centred on the needs and goals of the person, placing them in a better position to meet their immediate day-to-day health care needs and, potentially, their future health needs.

With input from the literature, technical consultations, and expert opinions, the WHO's (2016 a) framework provides universal guidance across five interdependent strategies: (1) empowering and engaging people and communities, (2) strengthening governance and accountability, (3) reorienting the model of care, (4) coordinating services within and across sectors, and (5) creating an enabling environment. There are also foundational conditions for success that cut-across the strategies: participatory approaches, co-production, mutual accountability, partnership and transformational change, and action (WHO, 2016 a). Person level outcomes are listed as essential for ensuring the perspectives and experiences of individuals and communities inform the reorientating of the models of care and that the governing metrics reflect what matters most (WHO, 2016 a).

As stated in Chapter 1, my curiosity was sparked, as at the time the WHO's (2016 a) framework was launched, the literature was also reporting that it was rare for the perspectives of the individual or what was important to them to be collected or considered in the design and evaluation of health services (Birrell & Heenan, 2014; Evans et al., 2014; Goodwin et al., 2014; Redding, 2013; Wigens, 2016; Wilson et al., 2009). This suggests that the perceived benefits of receiving integrated care are unsubstantiated by the individual, and likely reflect the views of policy makers or experts.

This is not to say that efforts are not being made to measure the effectiveness of health services in returning positive impact on population health metrics or understanding which interventions produced benefit, at what cost, and at what gain or value at the individual and population level (Baker et al., 2008; Berwick et al., 2003). However, it is reported to be difficult to capture reproduceable measures within the dynamic complexity of the real-world setting, with the tactics used in the hospital settings such as inputs, outputs, and causal relationships found to be less reliable when out of context (Sansoni, 2016).

As I revealed in the researcher's identity memo in Chapter 2, I developed awareness through my master's research that understanding the individual's perceptions of their patient care experiences is not easy to capture using mail-out surveys, and that health care professionals place little value on documenting these occasions in medical records (Patterson, 2005). The charismatic medical champion for health care quality, Dr Donald M. Berwick (2016), has had success in drawing attention to the benefits of directly engaging with individuals and communities to identify what matters most to them. He promoted the incentives of the cost savings from reducing waste, increasing reliability, and improving outcomes of health care, known as the Triple Aim (Institute for Healthcare Improvement, 2016). This approach represents a philosophical shift from focusing on what is important to the health provider or on health expenditure and cost containment, towards delivering value for individuals and communities (Porter & Lee, 2016). When individuals evaluate their own experiences, their role, and the degree to which the health service has supported and improved their health and functioning, this will result in a measure of the value created for the patient and the health service could triangulate this with other measures for improvement (Barnet & Shaw, 2013; Bywood et al., 2011; National Voices, 2015; Porter & Lee, 2016). Conversely, the absence of engaging individuals as an informed co-producer and evaluator contributes to negative patient experiences, adverse clinical outcomes, and a quasi-indicator that health services are poorly designed, inefficient, and costly (Banfield et al., 2017; Berwick, 2016; Leijten et al., 2018; WHO, 2015; WHO, 2016a;). These arguments present a strong case for change.

WHO (2016 a) and Berwick (2016) have both championed the need to rethink how health services are organised and measured. However, using French and Raven's (1959) bases of social power to explain, even though WHO (2016 a) holds globally legitimate power, and Dr Berwick (2016) has personal referent and expert power, they are not powerful enough. The literature continues to report that the bureaucratic, organisational endorsed legitimacy, informational and reward powers continue to dominate the tactics used by health services, including privileging the perspectives of the health service managers and providers, prioritising system and organisational measures, and rarely measuring or reporting on the individual's experiences of care or how the individual perceived they had benefit from their care (Birrell & Heenan, 2014; Evans et al., 2014; Goodwin et al., 2014; Redding, 2013; Wigens, 2016; Wilson et al., 2009). The participatory approaches desired as conditions for an integrated model call for a shift in traditional power bases. Shifting towards adopting an open and exploratory approach to understanding from the individual's perspective what they see to be the immediate and longer-term benefits and consequences is in tension with the embedded reductionist approaches that provide health service decision makers with familiar, immediate, discrete data points that they can use to guide their decision-making (Caine, 2014; Edgren & Barnard, 2015; Hardwick, 2013).

Rather than the individual's needs and perceptions being at the centre of the early development of integrated health services, research papers tend to report that it is difficult and rare to identify how and where the voices of individuals have contributed, and that this then limits their ability to explain any impact on the service design (The George Institute for Global Health, 2014; Greenfield et al., 2014; McDonald et al., 2015; Wodchis et al., 2015). Rather than participatory approaches, health services tend to favour the use of patient surveys that collect responses to forced option questions that are developed locally based on expert opinion or published frameworks as their method of receiving input or feedback from individuals or the community (Singer et al., 2011; Anhang Price et al., 2014; McMurray et al., 2016; Tonges et al., 2018). A deterrent for directly engaging individuals as evaluators is that the often subjective, emotive, and at times, seemingly unrelated descriptions provided by individuals makes it difficult for health services to identify specific or causative themes, or to generalise beyond that individual's experience (Dudley & Garner, 2011; Ebrahimi et al., 2017; Jackson et al., 2012; Walker et al., 2016).

Over reliance on quantitative tools in the context of evaluating integrated health services has resulted in the model of care demonstrating limited to no impact for the individual (Low & Fletcher, 2015; McMurray et al., 2016). This brings me back to Ackoff (2004), who I referenced in Chapter 1, as suggesting that we can unintentionally make things "wronger". I took this to mean that in the absence of any other mechanism of understanding the individuals experience, a health service may use the information they are familiar with and have readily available to decide what or whether to invest or disinvest in the integrated care health service model of care (Harvey et al., 2017). Having access to patient survey data may be a disincentive for being curious about better ways to capture their voice, and therefore better understand the meaning of the individual's experience.

Co-producing and being responsive to the changing day-to-day health and socio-economic realities across the person's life course sets an ambitious goal for integrated care, which requires a significant paradigm shift that challenges currently held assumptions, practices, and policies in how health and health services are understood, organised, and funded (Bartlett & Ahmed, 2017). The impact of not engaging the individual as an evaluator, keeping them silent, would likely sustain the practices that individuals must abide by the authority of the health service, rather than co-producing services that consider the individual's world and needs, limiting the universal economic and social benefits associated with the integrated people-centred health services framework (Greenfield et al., 2014; Lewis, 2014; Rifkin, 2018; Walker et al., 2016). The need for pragmatic ways to engage and meaningfully capture the individual's voice to better understand what matters most to them is essential for destabilising the power dynamics that maintain the status quo and for elevating alternate sources of informational and expert power that could ultimately drive the desired health and social reforms.

The research discussed in this chapter helped me to understand and then to build on from what was already known empirically about my phenomenon of interest, being the experience of integrated care from the perspective of persons living independently in the community who had recently had direct access to the health service within the context of their life's course. I appreciated that this was an under-developed area of research; however, I wanted to learn from those who had specifically privileged the voice of the individual in order to understand the meaning and value of their integrated care experiences from their perspective. I was curious for examples of the research methods used and what researchers found and how these findings could be useful steps in co-producing an integrated people-centred health service.

3.1.1 Literature Review Objectives

The objectives of the systematic review were:

- To identify pragmatic approaches (that had been applied in real-life settings) to examine how individuals construct their expectations and/or experiences of an integrated health service across a range of settings.
- To identify how person-level outcomes that describe issues and outcomes important to the individual could shape integrated health services.
- To propose recommendations about the benefits and insights that person-level outcomes offer integrated health services across a range of settings.

3.2 LITERATURE REVIEW STRUCTURE

The *Preferred Reporting Items for Systematic Reviews and Meta-Analysis* (PRISMA) statement and checklist were used to guide the structure of this systematic review and to develop the objectives of the search strategy (Liberati et al., 2009). For the purpose of this review, individuals were all adults (18 years of age and over) living in the community attending to their health care needs that were appropriate for or had been exposed to an integrated health service setting.

3.2.1 Literature Search Strategy, Data Sources and Screening

I engaged an experienced research librarian specialising in health sciences to guide me in the development of the final search strategy. To avoid any potential replication, an initial search was conducted to establish that no other systematic reviews existed or were currently in progress. Following this initial enquiry, a three-step search strategy was designed to identify relevant published studies. Stage One involved searching online databases using preliminary keywords, Stage Two involved using additional search words identified in the title or abstracts found in Stage One, and Stage Three involved hand searches of reference lists and bibliographies.

A search was performed in Ovid MEDLINE, EBSCO CINAHL, SCOPUS Elsevier, and ProQuest Health and Medicine databases. A combination of keywords and MeSH terms for delivery of health care, integrated, individual, patient outcome, patient perspective and people-centred were used to retrieve studies (see Appendix C: Ovid Medline Search Strategy)

3.2.2 Literature Screening: Inclusion criteria

The mnemonic of population, interventions, comparators, and outcomes (PICO) is widely used as a way of breaking down a research question into searchable keywords (Richardson et al., 1995). Studies were included in the literature review if they met all the following inclusion criteria:

Population – Adults (18 years of age and over) living in the community with health care needs that were appropriate for or had been exposed to an integrated health service setting.

Intervention – Eligibility for or exposure to an integrated health service where more than one provider of care or health care service aimed to provide a coordinated, multidisciplinary, person-centred experience of care in an outpatient, primary health, community or home setting.

Comparator – usual or standard models of health care delivery designed primarily to meet the preferences of the service or provider, or was disease focused. Providers deliver care in isolation and, at times, in competition with each other. Service and provider metrics were the primary data source for evaluating the delivery model.

Outcomes **–** personal level outcome measure **–** An individual's description of what was important to them, what was considered a benefit or good outcome, when experiencing an integrated health service

Study Design **–** Any empirical research published in peer review journals. The design of the study had to be appropriate for the research question. Excluded studies included literature reviews, protocol development, descriptive studies, and opinion pieces.

3.2.3 Literature Screening: Exclusion criteria

Non-English studies that theorised, described, or narrated were excluded, including literature reviews, protocol development, descriptive studies, dissertations, abstracts only, editorials, reports or clinical opinion articles. Studies addressing attributes of the model of care about the way it was structured, health care providers behaviours and attitudes, or the design of a specific clinical intervention were also excluded, as the focus of this review was studies that investigated the individual's perspective and the significance at the person-level (issues and outcomes important to them).

3.2.4 Literature Eligibility

Each abstract was reviewed for inclusion, with all duplicates being removed in the first screening. Discussion and agreement of inclusion and exclusion criteria occurred prior to screening the potentially relevant full text articles. Each potentially relevant full text article was read at least twice and assessed for inclusion. My academic research supervisors reviewed papers upon request, and additional faculty members were available to be consulted in the event of a disagreement that could not be negotiated. The full text articles assessed as eligible were then screened again, with articles eliminated if they did not meet all inclusion criteria.

The following data were extracted to assess the eligibility of all studies: title, author, year, journal, study aim, setting, sample, method, validity, findings, conclusions. The results were organised in a table and discussed during research supervision.

3.2.5 Literature Quality Appraisal

The systematic review resulted in five eligible studies being identified, and they were all qualitative research. The Critical Appraisal Skills Programme (2018) Qualitative Checklist was selected for systematically appraising these. The screening tool had been widely used in a variety of systematic reviews (Long et al., 2020). Where it was unclear whether the article should be a positive or negative response to the appraisal questions, I sought clarification from my experienced research supervisory panel.

It is of note that across the included studies, none were able to provide a level of certainty that the researchers had critically examined their own roles, or explored their potential impact or influence on their research, as an iterative process from commencement to completion of the study (see Appendix D: CASP Checklist). No studies were excluded following the appraisal, as the methodological quality of the studies included in the review was not an inclusion criterion.

3.3 QUALITATIVE LITERATURE REVIEW

3.3.1 Inclusion Criteria

The five eligible studies had met the general (PICO) approach as detailed above in section 2.2. With most of the studies in the review using qualitative methods, I also took the opportunity to apply Lockwood and colleagues (2015) approach in framing the inclusion criteria under the headings of population, phenomena of interest and context (PICo). Lockwood et al., (2015) reported that this approach was suitable when reviewing interpretative studies looking, “to understand the meaning of a phenomena and their relationships” (p.181). I found the PICo approach provided a clear and pragmatic criterion that was easy to apply when searching qualitative studies. There were no further studies identified using this approach, however each of the five studies identified using the PICO also met the PICo criteria;

***Population*:** Adults (18 years or greater) living independently in the community.

Phenomena of Interest: studies that investigated the perspectives of individuals whose health needs were suitable for or who had accessed an integrated health service. These studies examined how individuals constructed their needs and wants (what was important to them) and/or their experience of the model of care, focusing on issues and outcomes important to the individual.

Context: studies that described primary or secondary level health care service as being an integrated health service: an outpatient, primary health, community, or home setting where more than one provider of care or health care service aimed to deliver a coordinated, multidisciplinary, person-centred experience of care. These settings could be located in any country or cultural or geographical context.

3.3.2 Qualitative Literature Review: Synthesis

Synthesis is recognised as not being a straight-forward process; however, bringing together the findings from primary qualitative studies is important to gain insights and deepen understanding across contexts and participant groups (Tong et al., 2012). Preserving the meaning and richness of study data is both a feature and a complication of qualitative research. This means that researchers present or report their qualitative findings and results in a variety of ways. There has been ongoing debate as to the best approach or most reliable methodologies for the synthesis of qualitative research (Sandelowski & Barroso, 2002; Tong et al., 2012). A criticism has been the lack of transparency in the processes taken to bring studies together, making it difficult for the reader to assess whether the data were managed in a systematic way or the dependability of the findings (Tong et al., 2012).

The purpose of this systematic review was to propose recommendations on the benefits and insights that person-level outcomes offered integrated health services across a range of settings. The methods of synthesis in meta-aggregation methodology were selected as most appropriate for meeting this systematic review's pragmatic objectives. This approach has been reported as robust when used in qualitative reviews, as it can incorporate any number of studies, including very limited numbers, and complex phenomenon (Lockwood et al., 2015). Lockwood et al. (2015) described data synthesis in a meta-aggregative review as a three-step process: Step 1, findings are identified and extracted, along with a unit of data (e.g. a quote from a participant) that support each finding; Step 2, findings are collated into groups of similar findings, with at least two findings known as a category; Step 3, one or more synthesised findings of at least two categories are developed (p.184). Relevant to this study, meta-aggregation has been recommended for reviews that aim to produce synthesised findings that are meaningful and pragmatic, findings that would inform practice-level theory or be applicable to health care policy (Lockwood et al., 2015).

3.3.3 Meta-Aggregative Review: Data Extraction

Adopting this systematic approach to the literature review provided a logical flow that enabled the reader to appraise the analysis processes undertaken by the reviewer. To maintain transparency, all text labelled as results or findings were extracted from each study (Thomas & Harden, 2008). Each extraction was accompanied by an example or illustration, such as quotations from study participants, observational data, or other supporting data. In the event a unit of data (e.g. verbatim quote) was not able to be found that adequately summarised the finding, Allen and colleagues (2018) supported a modified approach that included rewording findings slightly to reflect the context of the report in which the findings were identified. This approach enhanced transparency in the synthesis of qualitative research and was supported by Tong et al.'s (2012) recommendation to include quotations that illustrated themes or constructs identified through the analysis process. Lockwood et al. (2015) also recommended this approach as a mechanism for enabling the reviewer or the reader to discern whether there was plausible congruency between the data, the illustration, and the study findings.

3.3.4 Meta-Aggregative Review: Categorisation and Synthesis

The second step in data synthesis involved developing categories for findings. Lockwood et al. (2015) described creating a category as an iterative process of examining all findings from the included studies, looking for at least two findings with similarity in meaning or underpinning concepts, and combining them. Synthesis in meta-aggregation is progressive, concentrating from a large number of findings towards a smaller number of categories, it does not involve re-interpretation or re-conceptualisation of findings (Lockwood et al., 2015). For this review, I provided a descriptive summary for each category. The categories were then reviewed by my academic supervisors and any comments discussed, aiming for consensus.

The final stage of the meta-aggregative approach was synthesis of the findings in an overarching description of a group of categories. Lockwood et al. (2015) labelled the synthesised findings as being indicatory statements or recommendations, appropriate for informing policy or practice development.

3.4 LITERATURE REVIEW FINDINGS

3.4.1 Study Selection

The electronic data search with selected key words yielded 707 records. Thirty-eight records were added following a review of titles, abstracts, and reference lists. Sixty-one duplications were removed, leaving 684 potentially relevant records. Initial screening excluded

490 records. The remaining 194 records were screened against the inclusion criteria, excluding 121 records for the reason of study design (68), participants (25), intervention (21), or not full text (7).

An in-depth review of the 73 records assessed as addressing the research question resulted in 19 records being omitted for study design and 49 omitted as the study's focus was an attribute of the service, service provider, or intervention rather than the individual. Five papers were determined eligible and included in the review (see Figure 3.1 and Table 3.1).

Figure 3.1 PRISMA Flow Diagram

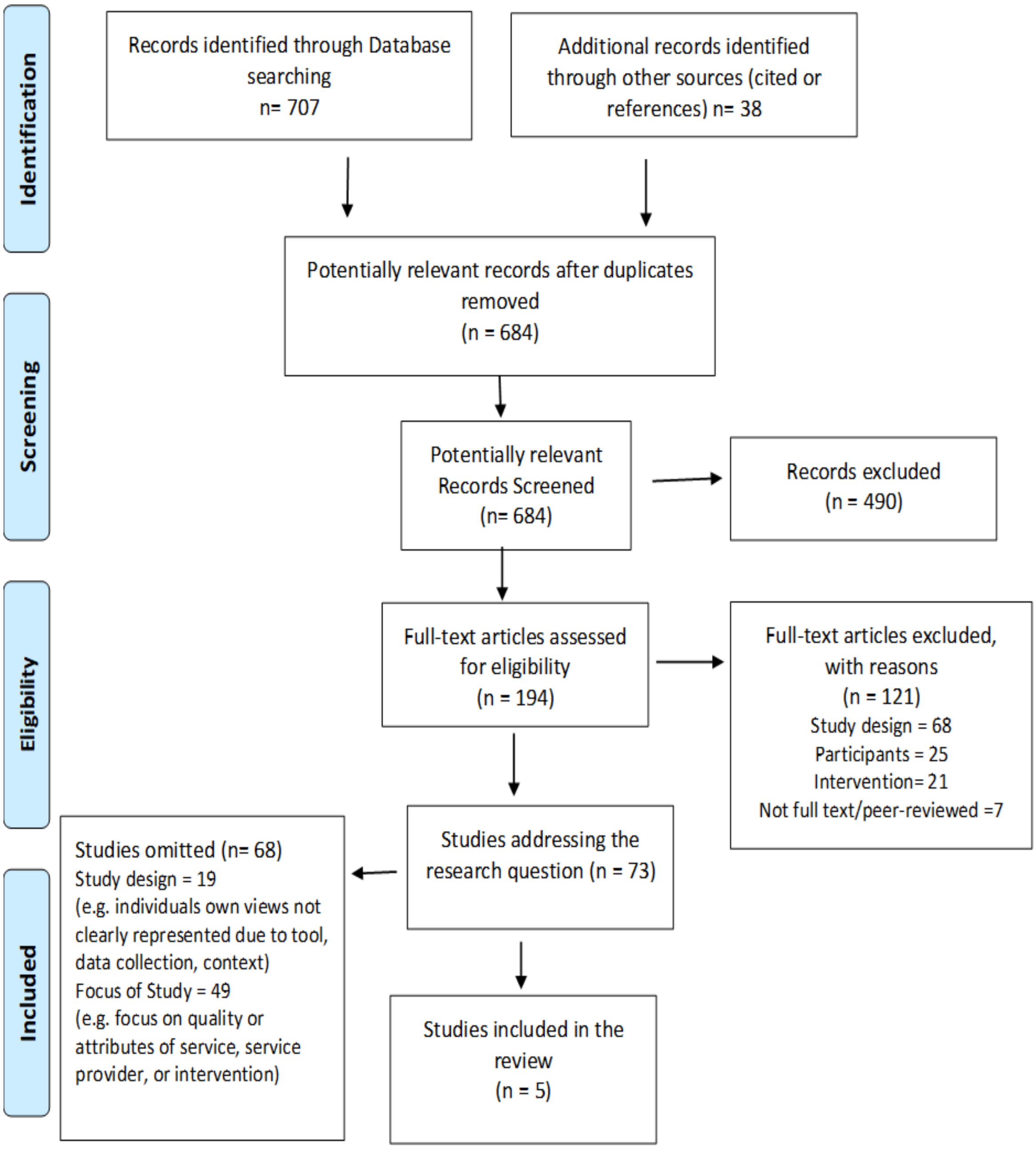


Table 3.1: Five eligible studies included in the review

1	Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2016). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations, 19*(1), 74–86. https://doi.org/10.1111/hex.12331
2	Petch, A., Cook, A., & Miller, E. (2013). Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health and Social Care in the Community, 21*(6). 623-633. https://doi.org/10.1111/hsc.12050
3	Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015). What outcomes are important to people with long-term neurological conditions using integrated health and social care? *Health and Social Care in the Community, 23*(5), 559-568. https://doi.org/10.1111/hsc.12171
4	Spoorenberg, S. L., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS One, 10*(10), e0137803. https://doi.org/10.1371/journal.pone.0137803
5	Yarborough, B.J.H., Yarborough, M. T., Janoff, S. L., & Green, C. A. (2016). Getting by, getting back, and getting on: Matching mental health services to consumers' recovery goals. *Psychiatric Rehabilitation Journal, 39*(2), 97–104. https://doi.org/10.1037/prj0000160

3.4.2 Data Extraction

3.4.2.1 General Characteristics

All eligible papers were qualitative studies exploring individuals' views using in-depth interviews and focus groups. The studies originated from United Kingdom (2), Australia (1), Netherlands (1), and USA (1). Participants were all community-living adults, with the sample size ranging from 23 to 230.

Using Lockwood and colleagues' (2015) approach to data extraction, general characteristics were the first to be extracted. This included the citation details, setting, participants, aim/research question, and methodology for each study (see Table 3.2)

Table 3.2: Data extraction: General characteristics of included studies

	Author(s), Year, Title, Journal, Country	**Setting**	**Participants**	**Aim/ Research Question**	**Methodology**
1	Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2016). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations,19*(1), 74–86. Australia	Two specialist GP-based complex diabetes services in primary care. Co-located multidisiciplinary team, urban setting.	Thirty purposively selected people living in the community with Type 2 Diabetes (T2DM) participants in an RCT who had been randomised to receive GP-led diabetes care and consented to a potential interview. Mean age 60.2 years.	To investigate patients' perceptions and experiences of T2DM self-care and engagement with GP-led integrated diabetes care. This study focused on the first interview with patients and specifically, the sense they made of diabetes, their self-care and their interactions with health professionals.	Qualitative study, in-depth interviews, audio-recorded, normalisation process theory was used to orientate thematic analysis and interpretative processes.
2	Petch, A., Cook, A., & Miller, E. (2013). Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health and Social Care in the Community, 21*(6). 623-633. Scotland and England.	Fifteen health and social care partnerships (three Scotland/12 England) operating as a partnership for at least a year. The sample included a mix of urban/rural sites, varied socio-economic backgrounds and sites more likely to include people from black and minority ethnic populations.	People using services delivered in partnership between health and social care, including 63 older people, 87 people with an intellectual disability, and 80 people using mental health services. A diverse sample in terms of age, gender, ethnicity, living circumstances, and need were recruited.	To assess the extent to which health and social care partnerships delivered the outcomes that people who used services valued, and to determine the features of partnership working associated with the delivery of these outcomes.	An exploratory, qualitative approach, including extensive development and piloting phases. Focus groups, partnership mapping and semi-structured interviews. Builds on the Social Policy Research Unit (SPRU), University of York outcomes important to service users framework. Audio-recorded interviews and service mapping data were entered into NVivo. Three stage analysis-by fieldwork site, across services, and within client groups.

	Author(s), Year, Title, Journal, Country	**Setting**	**Participants**	**Aim/ Research Question**	**Methodology**
3	Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015). What outcomes are important to people with long-term neurological conditions using integrated health and social care? *Health and Social Care in the Community, 23*(5), 559-568. England	Four English primary care trusts and their five community neuro-rehabilitation teams integrated in different ways and to different degrees.	A purposive sample of 35 participants, living with a long-term neurological conditions (LTNCs), existing client or had been client of the NRT within previous six months, aged 18 or over, and cognitively able to give informed consent and participate in an interview	To explore how service user-derived outcomes could be used in integrated health and social care practice for those with LTNCs. This study was part of a wider case study and focuses on Stage 1 to identify outcomes important to people with LTNCs.	Qualitative study using in-depth, semi-structured interviews. Audio-recorded and transcribed, an adapted version of the framework approach was used to manage interview data. This approach comprised four stages of management: familiarisation and identification of themes, constructing a thematic framework or index, indexing and charting the data on the framework.
4	Spoorenberg, S. L., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS One, 10*(10), e0137803. Netherlands	Fifteen elderly care multidisciplinary teams from three municipalities trained in working according to the embrace model (a population-based integrated care model for community-living older adults), semi-rural setting.	Maximum-variation sampling was applied to the 755 community-living older adults receiving integrated care and support according to the model, yeilding a sample of 23 community-living participants between the ages of 75 and 89.	To evaluate the opinions and experiences of community-living older adults with regard to integrated care and support, along with the extent to which it met their health and social needs. The study focused on the following research questions: 1) How do older adults experience the effects of aging? and 2) How do older adults experience the care and support offered by a chronic care model-based integrated care model?	Qualitative study using a semi-structured interview guide. Qualitative analysis using a modified grounded theory approach and constant comparative method. Transcribed interviews were analysed using Kwalitan 6.0 software.

	Author(s), Year, Title, Journal, Country	**Setting**	**Participants**	**Aim/ Research Question**	**Methodology**
5	Yarborough, B. J. H., Yarborough, M. T., Janoff, S. L., & Green, C. A. (2016). Getting by, getting back, and getting on: Matching mental health services to consumers' recovery goals. *Psychiatric Rehabilitation Journal, 39*(2), 97–104. USA	Health services providing inpatient and outpatient medical, mental health, and addiction services and a not-for-profit. An integrated health plan that maintains an integrated electronic medical record.	Participants (177) were stratified based on diagnosis and gender and randomly selected within those groups to achieve even representation of genders and individuals with schizophrenia spectrum (schizophrenia, schizoaffective disorder) or mood (bipolar disorders, affective psychosis) disorders, with 96% (164) of those living at the time of the 24-month interview completing the interview (three participants were deceased).	To explore mental health consumers' definitions of recovery from serious mental illnesses to identify the recovery goals and outcomes they deemed most important, to make recommendations to enhance services, and to suggest possible consumer centered outcome measures	Qualitative study, semi structured interviews, audio-recorded. Transcripts were coded using Atlas.ti, and definitions of recovery were further subcoded. Qualitative analysis used a modified grounded theory approach and constant comparative method. Part of a larger mixed-methods, longitudinal, exploratory study.

3.4.2.2 Verbatim Extracts of Study Findings

The next step was to carefully examine the meta data set of all 115 findings looking for at least two findings with similarity in meaning or underpinning concepts and combining them to form a category. This iterative process resulted in 27 discrete categories being developed. Throughout the synthesis processes, I corroborated the findings regularly with my academic supervisors, who had expertise in qualitative research, to ensure I was not compromising the meaning or losing the richness of the study findings. To protect the integrity of the evidence trail, my decision-making process throughout the synthesis is comprehensively detailed in Appendix E: Extracted findings and illustrations for each of the included studies

The final step was to develop an overarching synthesised description for those categories that demonstrated similar features. This approach resulted in the framing of an indicatory statement for each group of categories that was both meaningful and pragmatic, in that it could be of service to support either policy or practice development. The systematic approach taken to connect each of the 115 qualitative findings to one of the categories and then one of the ten synthesised statements is illustrated in Appendix F: Literature Review Synthesised Findings

This research aims to contribute to an under-developed field of research. The purpose of this systematic review of the literature was to surface what had been published and presented as individual (person) level outcomes associated with an individual's experience of an integrated health service. The methods of synthesis in meta-aggregation methodology were selected as most appropriate for synthesising qualitative data collected from different people, in different settings, via different methods, by five different researchers, whose participants were purposively selected based on them having experienced an integrated health service.

The synthesised findings from this review of the empirical research available, are presented below in the format of 10 indicatory statements in Table 3.3. These statements provide a point of reference for my iterative refinement of this research's design and will be drawn on when seeking to understand the implications of the research findings.

Table 3.3: Literature review synthesised findings –Ten indicatory statements

Ten indicatory statements resulting from the meta-aggregation of five qualitative studies
People may have common needs, wants, and fears; however, what matters most is knowing and respecting them as a person and their right to self-determination.
Social contact with other people is highly valued; experiencing the giving and receiving of support and companionship that is meaningful for that person at that time.

It is important that the cognitive, physical, and emotional effort of change is recognised, and to understand that a person’s perception, acceptance, and engagement with change is personal, and may vary over time.
Having basic daily living needs met is consistently the first priority. A person is unlikely to feel motivated or able to engage until basic needs are met.
Mobility and accessibility are highly valued, they are associated with a person’s sense of independence, autonomy, and freedom.
A person’s perspective on their independence influences their sense of self and their social value.
You cannot predict what matters most to a person or what their focus should be with confidence. Every interaction or intervention may result in intended or unintended consequences. Developing skills and techniques that enable a person to actively engage in iterative processes of planning, implementing, and evaluating change is empowering.
Self-development and learning new skills are important for preserving and achieving a sense of control, choice, confidence, and well-being.
Regular contact with a trusted professional is important.
There are core elements of an integrated model of health care delivery that matter from the patient’s perspective.

3.4.3 Findings Relevant to Literature Review Objectives

This systematic review of the literature was designed to address three primary objectives. The data extracted from each study and their relevance to the literature reviews objectives are outlined below, and summarised in Table 3.5.

3.4.3.1 Literature Review: Objective 1

This objective focused on providing insights into pragmatic approaches used to organise research studies within a practice setting to ensure the participants’ perspectives were the primary source of data. The research design characteristics of the five included studies is illustrated in Table 3.4. All included studies applied a qualitative approach. To answer their research question, they all used in-depth structured interviews. Each study’s design varied slightly; however, each approach included speaking directly to people who had experienced an integrated health service. Each study adapted an existing methodology to align with their study design and research questions. Three of the studies used data management systems to aid coding and organising data.

Table 3.4: Research design characteristics of the five eligible studies

Design Qualitative research (1,2,3,4,5)
Sampling Purposive sample (1,2,3) Maximum-variation sampling (4) Stratified sampling (5)
Methodology Deductive approach applying normalisation process theory (NPT) followed by Inductive processes and constant comparison (1) Outcomes important to service user's framework (2) Modified framework approach (3) Modified grounded theory approach and constant comparative method (4,5)
Method In-depth semi structured interview guided by purposively designed questions (1,2,3,4,5) Face-to-face interviews in home (1,2,3,4,5) within 3 months initial appt (1); eight to ten months after initial (4); 24-month follow-up visit
Data Management systems NVivo (2) Kwalitan 6.0 software (4) Atlas.ti (5)

3.4.3.2 Literature Review: Objective 2

This objective focused on understanding how the study method elicited personal meaning in order to identify person-level outcomes that reflected issues and outcomes important to the individual. The use of an interview guide was a common feature of the included papers. Interviews took place in person in a familiar place, such as the home or clinic that the person had previously visited. The interviews ranged from 20 mins to 90 mins duration. Question framing varied from a codesign approach, which included initial service user focus groups being held to inform the question guide design (Petch et al., 2013), to applying an existing outcome framework to organise the questions (Spiers et al., 2015). All included papers explored the individuals' views about their health and related health care experiences in person. Other questions included exploring what the individual had expected and what was important to them in general, not health specific (Burridge et al., 2016). Participants were prompted to describe the service in their own words, what it offered the person, and what a better or ideal model might look like for them (Petch et al., 2013; Spoorenberg et al., 2015). For example, "What is important to you in life? What can services do for you? And what do good services look like?". Another approach encouraged reflection on previous experiences and asked questions that explored how the participant made sense of their experience. For example, "After all this reflection, would you tell us what “recovery” means to you? Or choose the word you prefer if you do not like “recovery,” and tell us what that means to you?” (Yarborough et al., 2016).

3.4.3.3 Literature Review: Objective 3

The purpose of Objective 3 was to propose recommendations about the benefits and insights that person-level outcomes offered integrated health services across a range of settings. Each study provided unique insights of relevance to any setting offering an integrated health service. The data synthesis showed that study participants who had experienced an integrated health service described the following elements as important:

- Respect for the person, their lived experiences, their situation and their perspective.
- Valuing the person’s health and social care needs equally.
- Commitment to working as partners in multidisciplinary teams and fostering collegiate working relationships across the health and social care systems.
- Genuine engagement with the community as partners and assets, inviting collaboration through codesign and seeking input and feedback in the co-production, delivery, and continuous improvement of health services.

Table 3.5: Mapping each included study to the literature reviews three objectives.

	Study	**Objective 1 – How individual perspectives were explored**	**Objective 2 – What is important – how are person-level outcomes expressed**	**Objective 3 – What are the insights as to the benefit person-level outcome offers integrated model HC**
1	Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2016). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations,19*(1), 74–86.	Face-to-face interviews in the home. Interview held within three months of initial appointment. Interview guide included asking about how they viewed their health, how they viewed their diabetes, diabetes care experiences, expectations over next 12 months, and anything else of importance to them.	Personal change processes involved in diabetes self-care, and what was important included: diabetes care alliances – relationships with multiple providers; diabetic life – the “‘work”‘ of balancing what was important in their life and living with diabetes; sensibility of change – making the changes that had to be made in the reality of day-to-day life.	The experience was personal and complex, patients responded to advice in ways that seemed rational to them and their life. Perceptions and experiences influenced engagement with treatment routines and health professionals. Learning to manage relationships with various health professionals added to patients’ diabetes-related work. Providers need to adopt a flexible, interactive approach and foster trust to enable better diabetes care.
2	Petch, A., Cook, A., & Miller, E. (2013). Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health and Social Care in the Community, 21*(6). 623-633.	Three service user focus groups. Focus group questions: What is important to you in life? What can services do for you? And what do good services look like? Focus group data informed the semi-structured interview guide, interviews lasted between 20 and 40 mins.	Personal level outcomes important to service users: quality of life – feeling safe, having things to do, seeing people, staying as well as you can be, living life as you want, living where you want, dealing with stigma (mental health). Process: listened to, choice, treated as an individual, reliability, responsiveness. Change – improved confidence and skills, improving mobility, reduced symptoms.	All participants indicated that how they were treated by staff was at least as important as what services were achieved with regard to quality of life and change outcomes. Four important operational features that contributed to good outcomes to users: 1. Co-location of health and social services staff. 2. Users and carers valued services that simultaneously met their health and social needs. 3. Specialist partnerships, in that they supported a specific user group and that staff understood the needs of that particular group. 4. Health and social care partnerships extended into other sectors, including housing and/or the voluntary sector.

	Study	Objective 1 – How individual perspectives were explored	Objective 2 – What is important – how are person-level outcomes expressed	Objective 3 – What are the insights as to the benefit person-level outcome offers integrated model HC
3	Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015). What outcomes are important to people with long-term neurological conditions using integrated health and social care? *Health and Social Care in the Community, 23*(5), 559-568.	Face-to-face interviews between 30 and 90 minutes. Interview guide was informed by Harris et al.'s (2005) outcomes framework and explored the outcomes that were important at the person-level. This covered outcomes relating to autonomy, personal comfort, economic and social participation.	20 "key" outcomes were identified grouped across three domains: personal comfort, autonomy, and social and economic participation. Emotional well-being and maintaining social relationships and activities were considered important outcomes. Three relationship types were key: intimate and personal, family and social.	Outcomes important to people with Long-Term Neurological Conditions (LTNCs) have shifted from earlier research by Harris et al. (2005) which had provided a useful outcomes framework for a widerange of user groups. A key insight was that nter-relationships between and within what was important to people can be observed throughout the outcomes. It should be avoided considering outcomes in isolation. Taking a holistic approach to assessing an individual's needs is highlighted as important.
4	Spoorenberg, S. L., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS One, 10*(10), e0137803.	Face-to-face interviews eight to 10 months after started receiving Embrace care. Interviews during home visits lasted 60 to 90 minutes. Open-ended questions explored the experience of aging, experience and views of benefits of model of care, and what would constitute an ideal healthcare situation?	What mattered was the prospect of becoming dependent and losing control, the importance of social interaction and narrowing of their social network, and fear of becoming dependent on/being a burden to others.	The design of the Embrace model enabled participants to stay in control, even if they were dependent on others. Four types of interactions: being supported, being monitored, being informed, and being encouraged provided participants with a sense of being in control and of being safe and secure. Integrated care can be beneficial to robust older adults – not just the frail or those with chronic conditions
5	Yarborough, B. J. H., Yarborough, M. T., Janoff, S. L., & Green, C. A. (2016). Getting by, getting back, and getting on: Matching mental health services to consumers' recovery goals. *Psychiatric Rehabilitation Journal, 39*(2), 97–104.	The interviews were held at the 24-month follow-up visit, either in medical/research clinics or participants' homes. Asked explicitly, "We know we've asked you to do a lot of thinking about your life these last two years. After all this reflection, would you tell us what 'recovery' means to you? Or choose the word you prefer if you do not like "recovery," and tell us what that means to you?"	Recovery was described as a moving, non-linear process including i)"Getting by" meant coping and meeting basic needs. ii)"Getting back" meant learning to live with mental illness. iii) "Getting on" meant living a life where mental illness was no longer prominent. What was important was regaining control and recouping losses.	Mental health recovery is complex and dynamic; individuals' recovery goals can be expected to change over time. Person-centered care must accommodate changing consumer priorities, services must be flexible and responsive, and any outcome measures need to match consumers' objectives.

3.5 DISCUSSION

3.5.1 Unexpected insights for consideration in this, and future, research

The literature review systematically identified published empirical research between 2008 and 2018, resulting in five papers being determined eligible and included in the review. The review focused on studies that investigated the perspectives of adults living in the community whose health needs were suitable for or who had accessed an integrated health service. The phenomenon of interest was to understand how individuals constructed their needs and wants (what was important to them) and/or their experience of the model of care focusing on issues and outcomes important to them. The data extracted and synthesised from the included studies met the literature review objectives. Furthermore, the literature review processes and data synthesis provided other important and unexpected insights for consideration in the design of this, and future, research.

3.5.1.1 Research Trends Over Time

The processes of systematically searching empirical databases and reading potentially relevant papers, revealed that the early conventions of this field of enquiry was to adopt a discursive or commentary format. The opinion of experts, academics and clinicians were offered to explain why the perspective of the individual (patient) was crucial, albeit often missing, source of knowledge that had the potential to shape political and economic reforms and improve clinical, population and person-level outcomes (Wistow & Callaghan, 2008; Bruce et al., 2011).

The search strategy identified several theoretical and conceptual frameworks. The papers reviewed were more likely to describe how to engage with individuals, how to analyse, and how the process and outcomes of these approaches could contribute to change and reform in health service design and delivery, rather than presenting their findings from applying these approaches in the real-world (Kates et al., 2012; Rayner et al., 2018). Focusing in on how words and concepts were framed within the studies, revealed an unexpected shift overtime in the language used and how researchers were framing their findings. (Table 3.6) For example, papers published 2008–2011 tended to put an objective emphasis on why the patient's perspective was important. They described people as benefitting in being informed (told/monologue), that data collection was a technical skill that could produce quantifiable measures that could be easily generalised and would provide clear direction and efficiency benefits for the health system (see Table 3.6).

The emphasis placed on the papers published from 2012–2015 was less objective and less certain. I noticed that the interplay between the views of individuals (patients) and the relationships with their health care providers and services had shifted from being linear to a more messy or complex exchange. How engagement with individuals (patients) was described also shifted from being a technical skill that could be taught, to requiring behavioural change and a different mindset to be adopted. There was an increased reference in the papers' discussions to the vulnerabilities that existed, with organisations and providers being identified as novices in forming partnerships and collaborating with each other, let alone their capacity to reframe their relationship with individuals (their patients). The benefits for the service and the provider in seeking feedback from individuals (their patients) beyond general satisfaction measures, and the immediate cost and clinical impact of engaging individuals in care planning were beginning to be more frequently noted in the study discussions (see Table 3.6).

Finally, the papers published between 2016–2018 shifted from being uncertain to being more curious. I noticed that there was more ease in not being able to predict what was happening or going to happen. Phrases such as "care as envisioned" were used, as was exploring what an ideal future could look like from an appreciative perspective for the individual in the context of their circumstances and multiple roles. The studies were less focused on immediate service benefits, broadening from managing disease and illness towards enabling well-being, and adopting proactive and preventative health and social behaviours. Study discussions were increasingly aligned with the view that it would be unlikely to be able to measure impact at 12 months, there was less certainty about who would benefit and why, and what to measure. General support for an extended evaluation period, three to five years post intervention, was proposed as a mechanism for capturing any changes in mental models, social norms, professional and organisational cultures (see Table 3.6).

The shifts in how authors reported thinking about and describing engagement with individuals and their expectations over time was unexpected. Although there wasn't direct reference to political or economic philosophies and practices driving health reforms, the literature review provided important insights into the emerging contexts and the shift in roles, discourse and relationships of health providers, individuals (patients) who accessed health services, and the general community or citizens. There was also an increased recognition that there was unlikely to be a dominant model or "typical" experience for the individual when engaging with an integrated health service or provider. Delving deeply into understanding how people conceptualised their health experiences and what were the political and societal influences at play, is an area of interest for future research.

Table 3.6: Research trends observed in the literature 2008–2018.

Year Published	Focus of paper & language used	Example Studies
2008–2011	Describing/defining concepts and processes – organisational and policy drivers/definitions/formal pathways	(Miller et al., 2008), (Johnson, 2009) (Vanhaecht et al., 2009)
2012–2015	Values and attitudes of staff towards, more important than org design/mechanisms on effectiveness. Relationship between cost and quality and staff and patient Participatory – partnership – improvement – incorporate in design and evaluation – clinical and economic imperative. Health care professionals having mindset for collaboration is the most important indicator.	(Hardwick, 2013) (Morrow et al., 2013) (Delos et al., 2013) (Caine, 2014) (Grady & Gough, 2014) (Edgren & Barnard, 2015)
2016–2018	Person as a unique variable – their engagement is personal. Multidimensional understanding of the person. Importance of the patient's voice and understanding how this impacts on them from their perspective/what they deem to be necessary. Health is personal/connected – system – relationship between health and well-being – importance social – link from general well-being to population health. A health care customer is a resource integrator, applying a unique set of skills and resources to improve their well-being. Exploring care as envisaged, patient determines evaluation measures. Relationship-based care. Five years recommended as minimum period to detect changes in services or in user experiences and outcomes or measuring impact.	(Ewert, 2016) (Bartlett & Ahmed, 2017) (Beacham, 2017) (McColl-Kennedy et al., 2017) (Erens et al., 2017) (Rayner et al., 2018) (Tonges et al., 2018)

3.5.1.2 Definitional Clarity of Key Words is Critical.

The initial screening review of the 194 papers that met the inclusion criteria revealed varied and liberal use of words such as integrated care, patient perspective, patient participation, and patient-centred care in the title or key words. The papers mostly referred to individuals in reference to their role as a "patient" receiving health services, even when interviewed outside of the clinical setting. The review identified limited agreement across studies when defining an integrated health service, a range of interpretations as to what determined participation, and a tendency to use patient perspectives as a generalised term for seeking the views or feedback from individuals (patients).

To maintain integrity and transparency in the screening of the papers, after the first reading, I identified keywords and concept definitions that had originated from within the papers reviewed and adopted them as a guide for the next round of review (Table 3.7). Definitional clarity resulted in a further 121 papers being excluded. The remaining 73 papers were screened again, and sometimes again.

Table 3.7: Operational definitions of key words and concepts

Phenomena of interest **Key words and concepts**	In the absence of an agreed definition being identified in the literature, the following definitions were adopted in order to provide transparency and rigour in the literature review process.
Integrated health service	"Patient care that is coordinated across professionals, facilities, and support systems; continuous over time and between visits; tailored to the patients" needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health." (Singer et al., 2011, p.113) Must include more than one provider of care – primary & secondary or specialist or other. (Singer et al., 2011)
Individual level (person) perspective	"how" and "why" an individual understands their experience of integration; the value and/or benefit that they perceive from their experience. (Barnet & Shaw, 2013)
Individual level analysis – focused on understanding what was important to people	Impact [integrated care] may have on the outcome and issues important to people at the personal – level. "how an individual patient experiences care, rather than an attribute of a provider or an institution." (Barnet & Shaw, 2013, p.2638)

To preserve the integrity and transparency of my research, I ensured that concepts were clearly defined, and keywords were used consistently. This practice also enhances the potential usability of any research findings within policy or practice development.

3.5.1.3 Adopting Mechanism for Surfacing Everyday Practices and Social Patterns

What surprised me from the literature was how often the views and priorities of others, specifically the people who were referred to as patients, were discussed in the research papers without evidence of direct contact with these individuals or opportunity for the individual to affirm or provide an alternate perspective. I observed that people were being objectified, they were collected and reduced to one persona, and that this was taken to be acceptable, as it was a repeated pattern across the papers. I reflected on my biography and the self-discovery that this heuristic may likely be a personal rule that I instinctively practiced. Guided by Swedberg's (2014) theorising exercises, I was aware that I needed to observe how language was being used and what people were trying to achieve through the words they were using and how they organised their words. I began by observing my own mental short cuts and use of language, I looked for social patterns in my everyday practices and became more curious about the meaning that others were expressing and the sense I was making of it. I used my professional clinical and academic supervision to surface my tacit knowledge, to share discoveries, and to challenge new understandings to emerge.

I was conscious that the CASP (2018) Qualitative Checklist used to appraise the quality of the five qualitative studies included in the review, showed that none of the studies had demonstrated a level of certainty that the researchers had critically examined their own role or influence as an iterative process from commencement to completion of their study (see Appendix D: CASP Checklist). One paper provided explicit details about the researcher's role in the data analysis (Burridge et al., 2016); however, it did not describe how the researcher had continuously and critically examined their own role throughout the course of the study. Methodological quality was not an inclusion criterion for this literature review. However, it may be used in other reviews where these studies may have been excluded, which would further limit the opportunity that their research offered in raising the individuals' perspectives of their integrated care experiences for debate and deeper consideration.

Practices that I adopted when reviewing the literature were: systematically questioning the papers; screening for evidence that the methods described had taken place, and that it was the person's voice being represented; examining to what extent their voice could have been influenced by the environment, data collection tools, or processes; and determining that the research remained focused on understanding how the individual (patient) made sense of their experiences and priorities across their life course. With the absence of certainty regarding whether or how the researchers had appreciated their potential influence in the included studies, I was disciplined in adopting a reflective approach when reviewing the literature. I found adopting a mantra whereby I continuously asked myself, “Whose voice is it that I am hearing and for whose benefit is it that this question is being asked?” to be effective.

Journalling, reflecting, and discussing within my peer learning set enabled me to be mindful and to acknowledge the presence of my learned mental models and the resulting inferences that could have resulted in unconsciously interpreting or missing important cues within the research papers. At this point of the study, I made the conscious commitment to avoid using the word “patient” in reference to my intended research subjects, and adopted the words individual, citizen, person, and research participant. I believed this to be a rational way of situating their identity as individuals living independently in the community who had expressed interest in sharing their integrated care experiences for research purposes.

3.5.1.4 Exploring Social Power, Roles and the Social Environment

The studies included in the literature review described individuals’ roles and relationships with their health as evolving. Similar to the three roles proposed by researcher Judith H Hibbard (2003), each held the potential to improve the quality of care. It was Hibbard’s (2003) view that when individuals take on roles such as the informed choice role, the co-producer of care role, and the evaluator role, that this would improve their direct care and also position them well for bringing about change within health services. She proposed a conceptual framework in which each of these roles are mutually reinforcing, with the evaluator role having the greatest probability of bringing about the change required in health services and providers, which would see the potential of the other two roles realised (Hibbard 2003). Hibbard (2003) continued to research ways in which individuals could express more control over their health care and how to measure active engagement as a way of improving health outcomes and advancing health reforms similar to Berwick’s (2016) Triple Aim mentioned earlier (Greene et al., 2015).

In the context of the feminist perspective of my research, understanding the role or position held by the individual (patient) was important, as it provided insights into the assumed basis of their social power, such as being active and initiating actions in relation to their everyday health needs and goals. The literature review provided insights and surfaced tensions in the names and roles given to people who received or accessed integrated health services. It was common in the literature for the individuals accessing the services to be identified as patients, yet at the same time they were described as taking on roles, such as Hibbard's (2003) co-producer role, within their integrated care experiences. In addition, I found it difficult to determine from the studies whether individuals identified themselves as being in the patient role, or if they would have preferred to be identified differently. I was also unclear about whether they believed they had taken on new or changed roles in the course of their integrated care experiences. I could not say with certainty whether individuals perceived that they had increased their basis of social power within the context of their integrated care experiences, or whether researchers were adopting a new way of describing individuals' roles on their behalf and had perhaps unintentionally created the illusion of shifts in the power bases.

A number of examples were found in the research where individuals' (patients) perspectives were represented by survey responses that provided no opportunity for free text comment or focused solely on predefined elements of the service and how the service could be improved. These examples suggested that researchers had pre-determined what was important to learn from the individual, rather than allowing them to express their own viewpoint. Research methods such as empirical surveys serve to provide the researcher with a static version of reality that reduce the data to objects that can be controlled and measured (Neuman, 2000). Use of this method has been cautioned within the context of qualitative social research, as it limits discovery when seeking to understand personal meaning and has been described as having a dehumanising effect on the data (Reinharz, 1997). Studies such as these were excluded from the review. The five studies included in the literature review all used research methods that indicated that they were interested in the individual's unique perspectives, examples included using in-depth semi structured, face-to-face interview in a familiar environment, inviting participants co-produced questions, or to contribute any additional information that they thought to be important.

The importance of the social environment, both within the individuals integrated care experiences and within their everyday lives, was a finding from the meta-aggregation and synthesis of the literature review findings. The synthesis of the findings revealed that an individual's sense of free-will in making choices, prioritising, or taking actions related to what was important to them could emerge as a desire, an everyday reality, or a sense of loss. It was personal to the individual and their circumstances. I was mindful that the concept of a person's sense of agency is a complex phenomenon, rather than simply a characteristic or something that could be given to an individual or taken by another. In the context of my study's conceptual framework, freedom and choice were influential concepts within interpretive phenomenology.

Lopez and Willis (2004) described the concept of situated freedom as, “an existential phenomenological concept that means that individuals are free to make choices, but their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives” (p. 729). Limiting the discussion to the five studies included in the literature review, it was evident that all had made attempts to offer choice within the context of their personal circumstances as a means of supporting the individual in their engagement in the research.

In adopting the perspective of a social researcher interested in surfacing and understanding the deeper layers of individual meaning as to how this shaped their lived experiences and influenced their choices or actions, the literature gave me a greater appreciation of my choice of research method. In addition, aligned with feminism perspective, in the role of researcher, I needed to be aware that power was ever present and be prepared to practice moral agency in acting with respect and integrity, accepting accountability for creating the social environment where the participant felt safe and enabled to share their experiences, perspectives, and what mattered to them.

Guided by Swedberg (2014), I appreciated that I could not create meaning for the participants; however, I could attend to the social conditions and practice continuous self-observation. Swedberg (2014) recognised the sociologist Max Weber’s (1864–1920) influence within how researchers practice the processes of emotional empathy as a way of understanding how another person was making meaning of a social situation. He also emphasised the importance of exploring memory and what people remembered, Swedberg (2014) wrote, “we are all linked to the past through invisible threads. History connects what individuals do now to what they did in the past” (p. 49). Listening with an open mind, with empathy, positive regard and suspending judgement are also principles attributed to the humanistic psychologist Carl Roger’s (1902–1987) conditions for creating a social environment of acceptance, valuing the person and the worthiness of their story.

3.5.1.5 The Qualitative Researcher as a Bricoleur

To provide the reader with the opportunity to appreciate the entanglement of the participant and the researcher’s role and influence, I have paid attention to being transparent in whose perspective is being presented, how this view was collected, and being explicit about my ways of knowing, assumptions, and philosophical stance. In Denzin and Lincoln (2011) they refer to the qualitative researcher as being a “bricoleur” (p.4), which I took to mean as being resourceful, creatively using what was available and responding to what was presented before me; bringing the parts together in novel ways rather than following a pre-determined plan. The interpretative bricoleur is said to be able to represent a complex situation through adopting ‘pragmatic, strategic and self-reflexive” practices (Denzin &Lincoln, 2011, p.4). In this research I adopted the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) qualitative research checklist to communicate to the reader the progressive focusing of the research and how this contributed to the overall quality of my research (Tong et al., 2007). In Chapter 6, I provide the reader with a summary of how I brought the pieces of the study, including the method of data collection, data analysis and reporting of the research findings together (Tong et al., 2007). The checklist also gave me a sense of assurance that I am offering the reader quality and rigour, increasing the potential for my research to inform future research, policy, and practice development.

3.6 CONCLUSION

In this chapter, I presented the findings from the systematic review of empirical research published between 2008 and 2018. The review focused on studies that had investigated the perspectives of adults living in the community with recent experience of an integrated health service. From the 745 papers identified in the literature search, five papers were determined eligible and included in the review. The included studies were critically examined as a means of understanding the pragmatics of how to introduce participatory approaches that can meaningfully capture the voice of the individual and to ensure my research stayed focused on better understanding what mattered most to that individual. This review provided examples of what person-level outcomes could look like and how they could shape the delivery of integrated health services.

The literature review was an invaluable process in appreciating how the literature has evolved in understanding the current thinking, and for recognising that change was constant. These insights supported the iterative approach to research design and gradual focusing of my implementation strategies as mechanisms for working with, rather than trying to manage the uncertainties that were identified and discussed in this chapter.

Most importantly, the literature review shone a light on the significant influence the research design plays in optimising the research participants’ engagement and allowing for their voices to be valued and heard.

The next chapter outlines the research methodology used for this study.

Chapter 4: Methodology

4.1 INTRODUCTION

The focus of this chapter is to introduce the research methodology, including detailing the methods and quality strategies applied to achieve the research goal while addressing the inherent issues of ethics and rigour. In the previous chapters, I gradually introduced the theoretical premises that underpinned this qualitative, interpretative research. In Chapter 1, I introduced Maxwell's (2013) interactive research model, and produced a tentative map of the overall research design (see Figure 1.1 Research on a Page – A Tentative Plan). I identified qualitative health research as an appropriate form of inquiry, with case study design appraised as suitable for undertaking research in the health services context. In Chapter 2, I provided insights into my biography, and what I brought to this research as a person and a professional. This was important because as the researcher, I am situated and interacted with all the components of the research design, in particular the methods and quality components.

Chapter 3's systematic review of the literature identified and interrogated the five eligible research papers. My intention was to gain insights from how others had approached research that aimed to explore and understand individuals' perceptions of their healthcare and how other researchers had framed the perceived benefits or value in a way that stayed true to the individuals' voices. I found that the five studies had applied qualitative research methodologies, with each study adapting a method to align with their study design and answer their research questions. Chapter 3, Table 3.5. presents each of the five included studies mapped to the literature reviews objectives.

What emerged was that the pragmatism and feminism perspectives I had adopted were complemented by Swedberg's (2014) theorising practices. Combined with the findings from the literature review, I now had a clearer line of sight about the focus of my inquiry, and I appreciated that it was important that new or different meanings continued to emerge, rather than forcing my approach to comply with the rules of a particular methodology or method. I had a better understanding of Maxwell's (2013) insistence that qualitative research is real, not an abstract plan; hence, the research design would need flexibility to work with any tensions, new insights, or unexpected changes as they arose.

4.2 LITERATURE INFORMED RESEARCH REFINEMENTS

At the commencement of this research, I had taken guidance from Maxwell (2013) and Swedberg's (2014) thought exercises to awaken my curiosity about understanding the social world around me and to deepen my self-awareness. Moving from looking inwards, I then turned to looking outwards. I systematically searched the literature published between 2008–2018 for empirical evidence related to my study's phenomenon, being the experience of integrated care from the perspective of individuals living independently in the community who had recently had direct access to the health service within the context of their life's course.

The literature review reinforced that there were limited research publications available to learn from. It also surfaced important insights that I needed to consider in order to achieve my goal of delivering quality, robust research evidence capable of advancing how integrated health services are understood and can deliver on their promises of health and social reform. In the following section, I explain the refinements I made to the research design based on the findings from the literature.

4.2.1 Creating clarity and maintaining focus

Both a finding and a limitation of the literature review was the absence of consistency in the definitions used for key terms. The liberal use of phrases such as "integrated care" and "patient perspective" reflects the variation in how these concepts have been taken up within the health services. For example, patient participation and perspective were generalised terms and used interchangeably. Patient feedback was reported to be collected through varied means, ranging from a closed structured questionnaire to an open-ended interview. One way of making sense of the variation was that the definitional inconsistency in the literature was consistent with the WHO's (2016 a) guidance that the features and ways of monitoring the implementation of the *Framework for Integrated People-Centred Health Services* should reflect local conditions and needs. Although a good intention, a consequence of the WHO's (2016 a) guidance may be that health services will find it difficult to learn directly from each other.

To reduce the impact of definitional ambiguity for future researchers, in Chapter 3, I deliberately established working definitions for three key words and concepts that I had adopted from the literature review (see Table 3.7: Operational definitions of key words and concepts). The words I identified as integral for framing my research were integrated health services, individual level (personal) perspective, and individual level analysis. With the benefit of this clarity, it was evident that I needed to narrow the participant inclusion criteria to only individuals who had recently experienced a specific integrated health service being eligible. In response to the lack of clarity as to whose perspectives and meaning informed the research findings and whether the findings reflected what was significant to the individual's experience or were only of interest to the health service, I made the decision that the individual level (personal) perspective would be the only privileged voice. This directed my research's focus on the phenomenon of lived experience and meaning of integrated care from the perspective of the individual.

The literature review showed that the empirical evidence supported that individuals could describe and were engaged in evaluating their experiences of healthcare. Each of the eligible papers provided examples of people describing what was most important to them in the context of their current health and social needs, and in relation to their future life goals in their own words. What the individuals described as being important was also shown to be of relevance to the design of integrated health services. Hence, exploring how the participants in my study saw, experienced, and named their involvement in their integrated care offers an important contribution to the field.

My role as the researcher was positioned as integral in creating the conditions that would enable individuals to describe their experiences and meaning in their own authentic voice. It was my responsibility to ensure I was prepared before entering the research field, that I had quietened my mind so I could actively listen, was self-aware, and was ready to actively collaborate and interact with the study participants as they shared personal accounts of their everyday lives (Stake, 2010). The literature highlighted the difference it made for research participants when they were in familiar social environments and had a sense of personal freedom or choice in regard to their participation within the research. This was a critical consideration for my research design. Neuman (2000) used the metaphor of "an evolving relationship or living organism (e.g. plant) that naturally matures" (p. 170) to describe the interactions between the qualitative researcher and their study participants. On reflection, this surfaced for me the importance of gradually nurturing my relationship with the study participants, rather than trying to control the process or the outcome of the interview processes.

4.2.2 The researcher's relationship with the research.

In qualitative research, the researcher's relationship with the research has been described as "a real phenomenon" in itself (Maxwell, 2012, p. 71). The researcher influences and is influenced by the research. I was surprised that the qualitative researchers of the five eligible studies had not mentioned “critical subjectivity”, meaning awareness of how they had influenced the research process (Maxwell, 2013, p.255) or “intersubjective reflexivity” which Peat and colleagues (2019) described as dynamics existing within the researcher-participant relationship (p. 8). The quality appraisal of these five studies using the CASP (2018) qualitative checklist was unable to provide assurance that the researchers were aware of their influence on their research, or in what way they could have distorted the participants accounts of their experiences. Overall, the researcher’s stance or how they impacted on the research was found to be poorly described or absent.

Embedding researcher reflexivity throughout the course of the study was deemed crucial for achieving my research goal, in that I was respecting the authenticity of the persons lived experiences, The steps I took to ensure the research represented a “fair, honest and balanced account” (Neuman, 2000, p. 171) of what actually took place rather than what was predicted to happen, were monitored using the Consolidated Criteria for Reporting Qualitative Research (COREQ) qualitative research checklist (Tong et al., 2007). This was built into the research design as a means for continuously monitoring the quality of my research.

4.2.3 Looking to impact on how we think

Completing Maxwell’s (2013) researcher’s identity memo (see Appendix A: Researcher’s Memo), helped to articulate my pragmatic and feminist stance, in that I was intrinsically motivated by the opportunity to reveal and challenge power through elevating individuals’ perspectives as a way of enabling different ways of thinking and talking that may lead to different behaviours. Engaging in in-depth qualitative phenomenological inquiry has been credited with producing insightful interpretative accounts of experiences that have been effective in shining a light on and advancing ways of thinking about others experiences of healthcare and health services (Neubauer et al., 2019; Peat et al., 2019). The literature review served to increase my resolve that designing a study that enabled the privilege of listening to and seeking to understand individuals’ perspectives and what mattered most to them would deliver valuable insights, and potentially incite social action.

4.3 UPDATING THE RESEARCH DESIGN

Maxwell (2013) described his interactive research design as integrating the theoretical and operational components; in other words, the thinking and doing of research. In his model, when the research goals, questions, and the conceptual framework are aligned, then your thinking is aligned; while alignment of the methods and quality strategies mean that the research approach will serve to answer the research question with integrity. All of the design components are then connected and interconnected (Maxwell, 2013). In Chapter 1, Figure 1.1 Research on a Page – A Tentative Plan represented how I was thinking about conducting the research prior to reviewing the literature. With consideration of the insights and discoveries that the literature review now offered me, and in accordance with Maxwell's (2013) interactive research design principles, it was appropriate and necessary to critically reflect on my initial thinking, update the research design where necessary, and then focus on detailing the research approach, method, and quality.

4.3.1 Updated Research Goal

The research goal was modified to ensure that it was explicit that the overall goal for the research was to respect and privilege the voices and perspectives of the research participants, adults living in the community. To do this, a slight but significant update was made to the initial research goal's opening statement so that it read, *"The goal of this research is to respect the person and privilege their voice and perspectives in order to:"*

4.3.2 Progressive Refining of the Research Question

In Chapter 1, I shared my initial impressions of the background and context within which the research was situated. In adopting both Stake (2010) and Swedberg's (2014) advice, I held back from explaining the issue or stating the problem, providing time and an open mind to allow the focus of the research to emerge. Rather than committing in advance, and being blindsided, Stake (1995) recommended the approach of making a flexible list of questions to guide the research and that could be progressively refined as the research evolved. The theory was that as my thinking evolved, the research would progressively focus, with the questions gradually becoming clearer or more defined (Stake, 2010). Maxwell (2013) made the point that "well-constructed, focused questions" are an outcome, rather than a starting point when designing your research (p. 78). He also claimed that "qualitative researchers often don't develop their final research questions until they have done a significant amount of data collection and analysis" (Maxwell, 2013, p. 78).

Similar to the research goal, the research question was refined to ensure that the research participants' individual level (personal) perspectives were clearly at the heart of the research. I decided to take a tight-loose approach, crafting an overarching framing question and then focusing questions that would guide my explorations. As demonstrated below in Table 4.1, the updated questions remain aligned with the research's qualitative, interpretative theoretical influences, with the modified questions designed to ensure the integrity of each participant's perspectives were protected. Framing the research question in this way emphasised the interactive relationships between the research question and the methods and quality components.

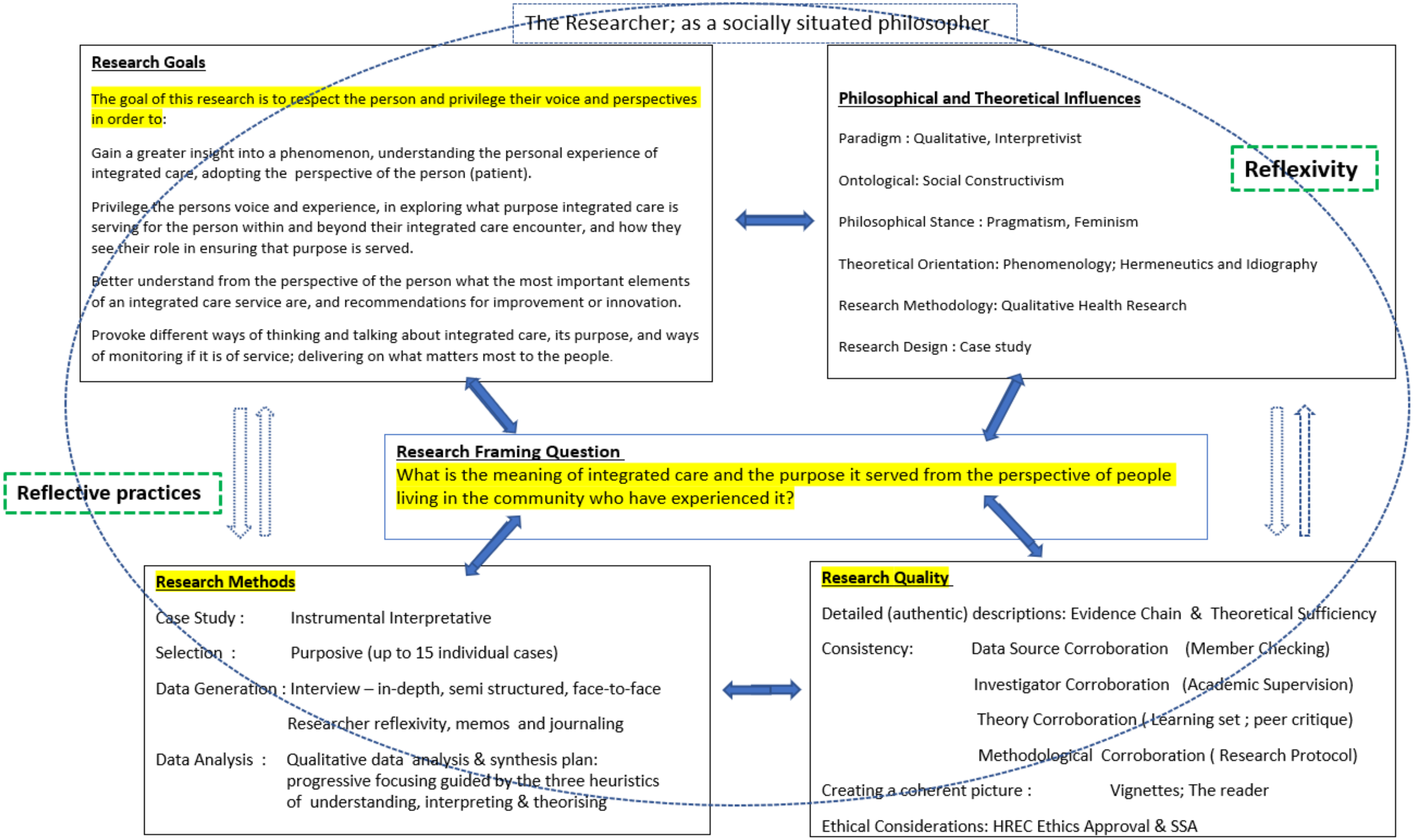
Table 4.1: Progressively refined research questions

Initial Research Question	**Refined Research Questions** **(Framing and Focusing Questions)**
How do individuals living in the community who engage with an integrated care health service make sense of this experience as part of their everyday health needs and goals?	Framing Question *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* Focusing Questions *(Chapter which focuses on this question)* i) How do people make meaning of their integrated care experience? *(Chapter 5)* ii) In what ways do people perceive their experiences of integrated care were of use to them? *(Chapter 5)* *iii)* How do people evaluate their experiences of integrated care and why? *(Chapter 5)* *iv)* Are there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe? *(Chapter 6)* *v)* In what ways are this research's findings similar to or different from what has been published in the literature? *(Chapter 7)* vi) What does this research add to understanding of how individuals experience integrated care? *(Chapter 7)*

4.3.3 Updated Research on a Page

Applying Maxwell's (2013) approach for designing a map of the overall research on a page, Figure 4.1, provides an updated version of the Research on a Page – Tentative Map from Chapter 1 (Figure 1.1 Research on a Page – A Tentative Plan). This map ensured that I maintained coherence as I interacted between the thinking and doing components of the research. To guide the reader, the updates to the research goals, research question, research method, and quality components are highlighted. The next section expands on the planned approach to conducting the research, focusing on the research method and quality.

Figure 4.1 Updated Research on a Page



Research Goals

The goal of this research is to respect the person and privilege their voice and perspectives in order to:

Gain a greater insight into a phenomenon, understanding the personal experience of integrated care, adopting the perspective of the person (patient).

Privilege the persons voice and experience, in exploring what purpose integrated care is serving for the person within and beyond their integrated care encounter, and how they see their role in ensuring that purpose is served.

Better understand from the perspective of the person what the most important elements of an integrated care service are, and recommendations for improvement or innovation.

Provoke different ways of thinking and talking about integrated care, its purpose, and ways of monitoring if it is of service; delivering on what matters most to the people.

Philosophical and Theoretical Influences

Paradigm : Qualitative, Interpretivist

Ontological: Social Constructivism

Philosophical Stance : Pragmatism, Feminism

Theoretical Orientation: Phenomenology; Hermeneutics and Idiography

Research Methodology: Qualitative Health Research

Research Design : Case study

Research Framing Question

What is the meaning of integrated care and the purpose it served from the perspective of people living in the community who have experienced it?

Research Methods

Case Study : Instrumental Interpretative

Selection : Purposive (up to 15 individual cases)

Data Generation : Interview – in-depth, semi structured, face-to-face

Researcher reflexivity, memos and journaling

Data Analysis : Qualitative data analysis & synthesis plan: progressive focusing guided by the three heuristics of understanding, interpreting & theorising

Research Quality

Detailed (authentic) descriptions: Evidence Chain & Theoretical Sufficiency

Consistency: Data Source Corroboration (Member Checking)

Investigator Corroboration (Academic Supervision)

Theory Corroboration (Learning set ; peer critique)

Methodological Corroboration (Research Protocol)

Creating a coherent picture : Vignettes; The reader

Ethical Considerations: HREC Ethics Approval & SSA

4.4 RESEARCH METHODS

The research method details the way in which the researcher chooses to interact within their research in order to uncover the data most pertinent and valuable for understanding the research phenomenon (Maxwell, 2012). To address the research goal and question, including maintaining consistency within the philosophical and theoretical perspectives and beliefs I held to be true, the systematic review of the literature reinforced the complexity of undertaking qualitative research in the context of health and social systems, and unanimously supported the application of social research methods as the most effective approach. As established in Chapter 1, a case study research design is well-suited for research within messy and dynamic environments of health services and where the intent of the research is to focus on particular situations that can be experienced (Greenhalgh et al., 2009; Rolfe et al., 2008; Stake, 2010).

4.4.1 Instrumental Case Study

The design of this research was influenced by Stake's (1995) position. He described case study research as drawing on the "naturalistic, holistic, ethnographic, phenomenological, and biographic research methods" (p. xi). In an instrumental case study, a case is selected because it facilitates the opportunity for the researcher to gain greater insights into an issue of interest, something embedded within the case and its context (Stake, 1995). With my research being both qualitative and interpretative, I had direct involvement in all aspects of the research, which aligned with my goal of a deeper understanding of the phenomenon of interest (Diaz Andrade, 2009).

In this research the case was instrumental to understanding the research issue. While there were a number of participants within the case, the case and the "case of" were singular. Adopting the case study line of inquiry, the case was "a case of", gaining a greater understanding of the experience of integrated care from the perspective of people living independently in the community who had recently had direct access to the health service within the context of their life's course.

The interpretative nature of case study method allows for exploring to understand the phenomenon, and how it exists and is constructed within the ordinary lifeworld of the people experiencing it (Ponelis, 2015). The concept of holding gently resonated, in knowing that I was researching a case of, which was a theoretical construct, I was able to let my understandings gradually take shape and my interpretations become known as the research progressed and be a by-product of the research (Ragin, 1999).

4.4.2 Selection

4.4.2.1 Case Setting

The case study setting was a real situation, it was specific and bounded by the literature, by geographical, and by bureaucratically defined boundaries (Luck, et al., 2006; Stake, 1995; Yin, 2014). This study was set within the boundaries of a specific New South Wales (NSW) Health funded and governed, Sydney metropolitan local health district, offering a range of acute and community services to the public at no cost, which included an integrated health service. This service provided a range of integrated care programs to local residents, targeting people living with chronic diseases or other vulnerabilities common to that particular community. Further details related to the particular integrated health service are provided in Section 4.6, Research Protocol . The study participants were all enrolled with and had recently attended this specific integrated health service. It is important to note that the intention of this study was to preserve the reality of each study participants understandings, not to judge or compare their perceptions with related public media or policy documents. The case setting was instrumental and facilitated the opportunity for me to better understand the study's phenomenon.

4.4.2.2 Selection of Cases

Curry and colleagues (2009) stated that in contrast to quantitative sampling techniques that rely on statistical probability theory, qualitative sampling is based on purposeful or theoretical sampling principles. The goal is to identify information-rich participants who hold certain characteristics, detailed knowledge, or direct experience relevant to the phenomenon of interest (Curry et al., 2009). The process of purposefully selecting the participants considered Stake's (1995) caution not to select study participants simply by attributes, rather to look for participants that are interesting and accessible, but with dissimilar characteristics (p.6). Staller (2021) summarises in saying, "purposive sampling is about selecting the best, information-rich, relevant, broad-ranging, and plentiful data available to gain insights and in-depth understanding by creatively solving puzzles with convincing evidence" (p.899)

In regard to "how many" do you need in the sample, the consensus is that "it depends" (Staller, 2021, p.900) The sample size depends on the breadth and complexity of the interpretative inquiry; however, it is accepted that the number of participants is generally smaller than those used in quantitative studies and the intensity will be greater. In accordance with the interpretative, hermeneutically aligned phenomenological orientation of this research, in-depth accounts of personal experience were collected that required detailed individual level, micro-analysis. The expected sample size for qualitative health research studies taking this approach is small, "typically less than 10" (Peat et al., 2019, p. 8). With the goal of studying 10 individual cases, a minimum of 15 cases was identified, this served to minimise the impact of participants not being able to participate for personal reasons or withdrawing from the study. The inclusion and exclusion criteria developed for the study are detailed below.

Inclusion Criteria

- Enrolled with the specific integrated care unit health services and has attended a minimum of three appointments, with the last appointment less than one month ago,
- Resides in the specific geographical catchment area.
- Lives in the community; specifically, is not living in an aged care facility or receiving 24 hour supervision.
- Able to speak English.
- Not restricted by gender.
- Eighteen years of age and over.
- Capable of understanding the general nature of the study and providing their consent to participate in an interview.

Exclusion Criteria

- Children and/or young people (i.e.<18 years).
- People highly dependent on medical care.

4.4.3 Data Generation: In-Depth Semi-Structured Interviews

The systematic review of the literature undertaken to inform this research supported that the method of choice for social researchers was the interview. Stake (1995) supported that interviews enable access to multiple realities from the viewpoint of those who have lived them. The data generation method chosen for this research was semi-structured, in-depth interviews. This method enabled structured and intuitive study of the participants meanings (Tichen & Higgs, 2007). Importantly, this method kept the participants' experiences, what was said and how they were making sense of their experience, as the focus of the inquiry (Smith, 2011). Supported by the combination of interacting closely with the study participants during the interview, their data and my reflexive practices, I anticipated that I would be better placed to engage with the participants' meanings, construct my own meaning, fuse our meanings to create interpretative meaning, and then translate this into a form that was digestible for reading within a research report (Diaz Andrade, 2009: Neuman, 2000).

4.4.3.1 Collecting Perspectives and Meaning

The interviews in this study facilitated discovery. They allowed the opportunity to sit with and listen to the participants' thoughts, feelings, and the meanings that they had made from their experiences. In my researcher role, this allowed me to experience the participants making connections from their past and present experiences, with their social world, and to future actions (Mears, 2009). Face-to face interviews enabled a social interaction, that allowed for rapport to be established to support the depth and honesty that I was looking for from participants' responses (Stake, 1995). Interviewing participants in person also provided insights into expressions, feelings, and body-language generated in response to the participants' interactions with the interviews and the questions.

Establishing an environment of safety and trust from the outset, and then throughout the research, helped to facilitate the openness critical to trying to stay as close to lived experience as possible (Laverty, 2003). As identified from the literature review, developing a partnership with participants that enabled mutual construction of meaning rather than being organised as a hierarchical procedure allowed for a more equal position of power, with the intent that the knowledge constructed and information generated through the interview were "both mutually negotiated and contextual" (Mills et al., 2006). A supportive presence during the data collection processes was also critical in establishing and reciprocating the openness that underpinned establishing trustworthiness and a sense of psychological safety. Allowing the participants to schedule the interview times, allowing the interview questions to flow rather than directing the conversation, allowing for openness to respond to questions the participant might pose during the interview, along with factoring in time for the researcher to prepare for the interview and to practice assuming a reflexive stance under different conditions were some of the critical, yet pragmatic considerations in the application of the research method.

4.4.3.2 The Researcher

The researcher is the primary tool for qualitative, interpretative research (Guba & Lincoln, 2005). As detailed in Chapter 2, I accepted that I was inseparable from the research, that I brought my values and how I perceived the world into my investigative work (Denzin and Lincoln, 2011). A feature of case study design is that the researcher is encouraged to take advantage of their own knowledge in relation to the case, and to consider coding systems or instruments that might be of use in advance (Stake, 2010). It was important that I considered and planned for the interview so that I was equally attuned to what was said, what was really being said, and what was not being said. I developed an interview guide (see Appendix G: Research Interview Guide) through development or amendment of existing aids that I found to be effective in supporting me to listen deeply during the interview process, and being focused, yet remaining open to discovery (Stake, 1995). Being attentive during the interview, I also took free hand field notes to capture my thoughts, reactions & musings. These notes were critical for when I moved to the first step of analysis, being reading the transcripts, as I could reference these notes as I engaged in "listening between the lines" (Laverty, 2003, p. 29).

I embedded reflexivity practices, which allowed me to immerse myself iteratively and systematically in the participants everyday reality whilst I also noticed and journalled my own reactions and experiences. This is important, as it allows the reader to join me in critiquing and informally auditing the research and my position as it evolves and matures overtime. As summarised by Stake (1995), "expertise comes largely through reflective practice" (p.50), and it is important that, "the reader can see the biases the researcher is trying to deal with" (2010 p.166). Routinely engaging in reflexivity through every phase of the research, my stance was both subjective and intersubjective. Taking the time to explain and make my reflexive practices explicit to the reader aligned with my commitment to providing an evidence trail that supported the research's commitment to authenticity.

4.4.3.3 Reflective Engagement and Play

Heidegger's (1927) hermeneutic movement, or circle, reflects the dynamic nature of everyday human life, it recognises how the past, present, and future "shape and inform our lives as we shape others" (Conroy, 2003). The application of the German philosopher Hans-Georg Gadamer's (1900–2002) hermeneutic thinking was what generated the movement through reflective engagement and play, which is a metaphor for experiencing the text through opening up with the possibilities of new understandings, letting go and suspending disbelief, and giving the time to go back and forth, thinking and reflecting (Regan, 2012). I adopted the principles of the hermeneutically aligned phenomenological approach as it enabled me to engage creatively and to focus in on situated human meaning, which aligned with my intention to "uncover and unfold meaning" as it had been lived (Suddick et al., 2020, p. 2). I found that adopting this approach complemented Swedberg's (2014) theorising practices and aligned with my ontological perspective of social constructivism, where realities are believed to be locally constructed, influenced by others, and can be altered by the knower. Holding these perspectives, I believed that knowledge was "the best understanding we have been able to produce thus far, not a statement of what is ultimately real" (Laverty, 2003, p. 26).

When choosing to engage or play with this approach, to begin with, I completed the preparatory phase of self-reflection to become aware of my background understandings, my history, heuristics, and assumptions. If I was adopting a phenomenological perspective alone, these reflections would have been bracketed and set aside to not interfere with the research; however, the hermeneutical influence enabled these reflections to be embedded and readily available for reflective engagement (Laverty, 2003). The researcher's identity memo and reflections in Section 2.2.2 provided an insight into my preparatory processes for engaging with this research. In addition to the formal memo, I found that keeping field note reflections and a reflective journal throughout the research was of personal benefit. Journalling my critical reflections allowed me to own my assumptions and interpretive processes.

4.4.4 Data Analysis

Referencing the updated research on a page (Figure 4.1 Updated Research on a Page presented earlier in this chapter, it was important that I situated my approach to data analysis within the context of interacting with the research goals, questions, and the underpinning research epistemology. By design, my thinking guided my doing (Maxwell, 2013). For example, in adopting a social constructionism perspective, I hold the belief that meaning, and experience are socially produced and reproduced, rather than inhering within the individual (Galbin, 2014). Therefore, any coding or thematic analysis conducted within this perspective cannot and does not seek to focus on motivation or individual psychologies, but instead seeks to theorise the individual's account of their social reality (Braun & Clarke, 2006, p.85).

Being an in-depth qualitative interpretative study of a small number of lived experiences, micro-analysis and micro-interpretation were recommended (Stake, 2010). Micro-research commonly features coding and classifying, which means sorting data sets by topic, theme, or issues important to the research. Within qualitative research, it can be said that "data are not coded…they're recoded" by the researcher in a progressive interpretation of meaning that is cyclical rather than a linear process (Saldana, 2016, p.68). To govern the procedures and mechanics of coding, I adopted the code definitions and coding practices sourced from Johnny Saldana's *The Coding Manual for Qualitative Researchers* (2016).

Saldana's (2016) advised that as each qualitative research is unique, there is no authroity that can claim which coding method is the "best", it depends "on the nature and goals of your study”. (p. 69). I adopted his suggestion of engaging in an initial coding of the data before advancing to reorganising and refining codes into categories that behold collective meaning or explanatory patterns (Saldana, 2016). Restricted by the length of manuscripts when reporting qualitative data analysis, the discussion on analytical methods in published research is typically kept brief, with only the most relevant or salient accounts reported, usually as chunks of dialogue, vignettes, or collages, with the intention of highlighting the headlines of the research and inviting the reader to observe deeper and make their own interpretations (Saldana, 2016). As my research method required a constant blending of the researcher’s viewpoint and the data collected in the field, there was the potential for many interpretations or alternatives to be revealed. My goal was to be able to descriptively, with integrity, compose and present my interpretations of the different meaning and experiences of the study’s participants and tell their stories (Stake, 2010).

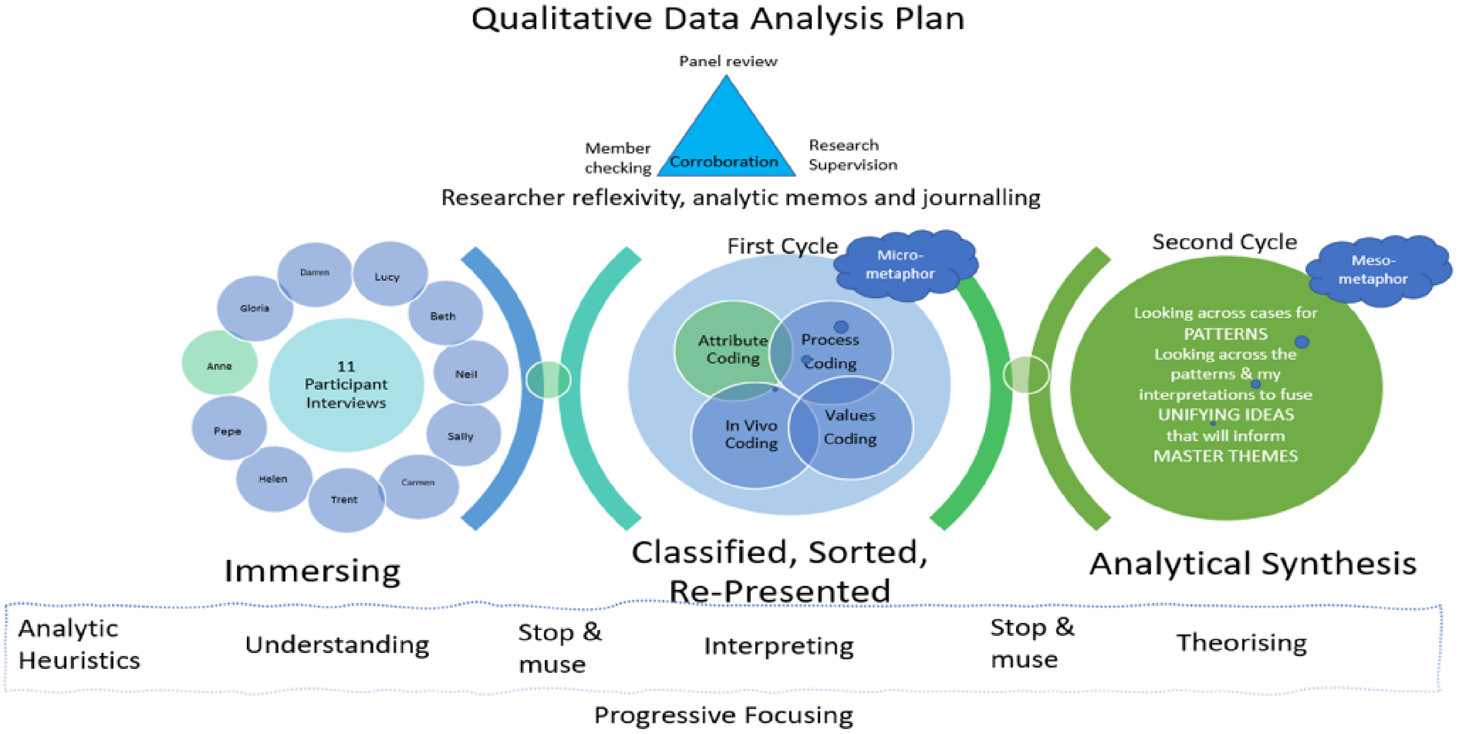
4.4.4.1 Qualitative Data Analysis Plan

Drawing from the three perspectives that resonated with my beliefs and personal theories, while also exciting me to be open to new ways of understand the world, (Saldana & Omasta, 2018: Stake, 2010; Swedberg, 2014), I designed a qualitative data analysis plan, that is somewhat unique, yet specific for my resesearch (Figure 4.2). Moving from left to right of the plan, I commenced with understanding by immersing myself in each participant’s data and revisting my field notes. Here, I established self-reflexivity practices that continued throughout the analysis. In the first cycle of analysis, each participant’s interview data were manually analysed systematically, case by case. Following the step-by-step approach commonly associated with interpretative phenomenological analysis, I did not progress to the next participant’s transcript until the prior case had been closely examined and coded (Peat et al., 2019).

Figure 4.2 Qualitative Data Analysis Plan

Research Framing Question

What is the meaning of integrated care and the purpose it served from the perspective of people living in the community who have experienced it?



Research Focus Questions

i) *How does the person make meaning of their integrated care experience?*

ii) *In what ways does the person perceive their experiences of integrated care were of use to them ?*

iii) *How does the person evaluate their experiences of integrated care and why?*

iv) Looking across the participants, were there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences?
If so, describe?

v) In what ways are this research's findings similar to or different from what has been published in the literature?

vi) So what does this research add to our understanding of how individuals experience integrated care

4.4.4.2 First Cycle Analysis

The coding methods I adopted in my first cycle of analysis were selected because they were found to be both pragmatic and effective in organising the data sets. Taking onboard Saldana’s (2016) advice, an exploratory approach was taken to testing out and combining different methods in order to reveal the essence of the phenomenon of interest. The first cycle analysis focused on the first three research focus questions. The approach included classifying, sorting, and re-representing data to create interpretative accounts and a micro-metaphor for each participant’s integrated care experience.

The first cycle of analysis commenced with attribute coding. This allowed for the unique descriptive characteristics of each participant to be classified and sorted, as illustrated in Table 4.1. The attribute codes were informed by Tong and colleagues (2007) criteria for reporting qualitative research checklist (COREQ) and were an effective way of summarising what I interpreted as unique about each participant and in providing the reader with a general understanding of the participants as people and their circumstances relevant to the phenomenon of interest, being their experiences of integrated care.

Table 4.2: Participant attribute codes

Participant (pseudonym)	Interview logistics	Age group (years)	Gender	Living arrangements	Work status	Interests	Integrated care referral	# Visits	Integrated care program(s)	Other health services

With the goal of seeking to understand each participant’s experience and the meaning I was making from the interview transcripts, the next method of analysis was to explore what stood out. Process coding classified and sorted the observable or conceptual actions or movement that a participant shared within their interview. The coding used was predominately “ing” words. This approach to coding is known to be effective in classifying the dynamic nature of everyday experiences (Saldana, 2016). Examples of process codes generated from the data included “gaining access”, “tipping point”, and “being educated”.

Complementary to process coding were in vivo or verbatim coding. This provided balance, as it ensured that the participants’ voices, their words, remained central and intimately connected within the codes and the analysis process. Keeping the participants’ voices alive as the data were being pulled apart and classified was an effective way of bridging my interpretations and the participants’ meanings. Examples of in vivo codes from the data included, “giving it a go”, “saving money”, and “just turn up”.

The values coding method was useful when interpreting and coding what I saw as being important to the participants and in unearthing beliefs or heuristics that I interpreted as potentially influencing how participants' were making meaning from their experiences, and what was giving it significance. Examples of values codes from the data included, "trusted advice", "being neighbourly", and "taking precautions".

To conclude the first cycle of analysis, I presented an interpretive summation that shared my interpretive understandings relative to the research's overall framing question, "*What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?"* Here, I summarised my interpretations of what each participant's integrated care experiences meant to them and what I believed to be the purpose or their utility. In essence, I was interpreting "a case of" for each participant.

Influenced by Swedberg's (2014) approaches to theorising, I challenged myself to produce a metaphor as another form of expressing what I understood to be happening. After acknowledging the influence of the philosopher Max Black, Swedberg (2014) encouraged the creative process of making an association between words when creating a metaphor (p. 90). This meant that the metaphor proposed words whose meanings interacted with each other, rather than substituting the meaning from one word to another. I related to this, as any metaphor I created would already be an interaction between the participants and my meaning. I do not profess that I am accomplished at creating metaphors, and although I found the process quite confronting, I also found that it was mentally stimulating. An example of a metaphor I created was "time is health" .

The first cycle analysis completed for each participant provided 11 distinct sets of classified and sorted data (see Appendix L: First Cycle Analysis - 11 x Coding Participant Interview). The findings from the application of the first cycle analysis for each participant are presented in Chapter 5. It is my belief that my novel interpretative approach to data analysis played an important role in protecting the integrity of each participant's data, ensuring the unique meaning of each person's experiences was stored, yet accessible.

4.4.4.3 Second Cycle Analysis

The qualitative data analysis plan (Figure 4.2 Qualitative Data Analysis Plan illustrated how the second cycle of analysis shifted focus from analysing each individual dataset separately to bringing their experiences and meaning together. In the second cycle, I again reviewed each individual data set, the interview transcripts, interpretative accounts, and codes.

However, this time, I was openly looking across the participants' integrated care experiences, staying open to any commonalities, differences, or surprises in how they made sense of what had happened and how their integrated care experiences had worked for them.

The analysis commenced with the manual search for patterns. Being a large phenomenological data set, a bifocal approach was taken. I adopted Stake's (2010) guidance of remaining sensitive to answering the research questions to gain a better understanding what this was a case of; while also remaining sensitive to the meaning and experiences the participants had shared to better understand their everyday lives. Stake (2010) forewarned the tension of staying true to both at the same time and the need to make room for convergence or divergence in what emerged. This meant that in looking for patterns, searching for understanding, or getting an impression of what was happening across the participants, the research was likely to get more complex rather than simpler.

In this study, second cycle analysis included looking for and explaining patterns of ideas from across the data sets, fusing the participants and researcher's meaning into unifying ideas, construction of master themes, a meso-metaphor and, where possible, interpretive claims to support challenge and develop theory. The application of the second cycle analysis and findings produced are discussed in Chapter 6 and for reference a detailed a table is presented in Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes.

4.5 RESEARCH QUALITY

Interpretative phenomenological research is inherently messy, with the processes of discovering personal meaning being more often ambiguous than explicit to the reader. Embedding measures that can assure the reader of the researcher and the research's trustworthiness within all phases of the research was the final segment of my interactive research map. Like all other research strategies, case study research has its faults and its risks. Stake (1995) claimed that the ethical risks are substantial, and it is critical that the researcher remains conscious of their intellectual shortcomings and that a respectable concern is held for the validation of the research methods and findings to minimise misrepresentation and misunderstanding. Diaz Andrade (2009) supported Stake (1995) by stating that if you chose case study design, you "have the extra burden of convincing their readers of the legitimacy of and drawing conceptual implications from their findings" (p. 45).

4.5.1 Establishing authenticity

Stake (1995) expressed strong views about the researcher’s ethical obligation to ensure the authenticity of their interpretations. As the researcher I am responsible for checking for consistency, in how I demonstrate integrity within my research processes and that any claims made reflect the research evidence and can be confirmed by a detailed evidence trail which includes quotes and verbatim descriptions (Neuman, 2000). To strengthen any research claims, Stake (1995) recommended applying different types of checks, including data source triangulation, investigator triangulation, theory triangulation, and methodological triangulation. For interpretive approaches to case study, Diaz Andrade (2009) maintains that the chain of evidence is the most likely to engender trust within the reader and that it is appropriate to replace the term “triangulation” with “corroboration”, which means strengthening your argument through additional evidence. Adopting these approaches to quality, allows for the reader to personally disagree with my interpretations of the data; however, the evidence or factual account I have provided will be indisputable. Diaz Andrade (2009) also proposed that interpretative case study research uses the term “theoretical sufficiency” rather than “saturation” (p, 44). He explains that both terms suggest that the research’s interpretative findings have been analysed; however, saturation implies the goal of “completion”, while in contrast the goal of interpretative case study design is to build a holistic understanding of a phenomenon that is continuously evolving (Diaz Andrade, 2009, p.44).

4.5.1.1 Corroboration: Member Checking

Member checking was found to be useful for checking data sources, meaning that the facts of an interview were checked to be accurate from the perspective of the study participant who had provided the information. I noted general comments from the literature review that study participants may have limited time available or interest in returning later to check the interview transcript. I took on the advice that I needed to determine what was the most important factual data to be checked, raising this with the participant before the interview commenced and completing the check as soon as possible (Stake, 2010). To do this, I established with each participant during the original data collection that we could pause at any time to check and confirm any ambiguity, and before completing the interview we would confirm any factual data provided, which was mostly reference to demographic attributes.

Data quality did not depend on the study participants checking or agreeing with my interpretations of the data. Although we may have held quite different interpretations, it was important to still recognise that both the researcher and participants had a stake in the research process. This aligned with my perspective that meaning was locally and socially constructed and, in particular, if there was a delay the participant may have moved on in their thinking from the time of data collection. In this research, trustworthiness was corroborated through member fact checking, maintaining the auditable evidence trail, and inviting "multiple eyes" to engage with my interpretations as they evolved (Stake, 2010, p. 127).

4.5.1.2 Corroboration: Multiple Eyes

To support the research's quality, I purposively corroborated with many and varied sets of eyes. Investigator corroboration involved engaging other researchers, theory corroboration involved panellists or reviewers from different theoretical viewpoints, and methodological corroboration involved detailing the progressive movement and interaction that occurred within my study in the research protocol (Figure 4.3: Research Protocol) (Diaz Andrade, 2009; Stake, 2010). The intent was not to resolve different views, but to hold them and muse, taking this time to think creatively and surface any tensions that may benefit in being further unpacked or discussed with peers (Swedberg, 2014). Stake (2010) reiterated the importance of a critical examination of the research methods by colleagues and mentors.

I intentionally looked for informal and formal opportunities to reflect on, confirm, and challenge my interpretations of meaning and any relationships that were developing within the study. I took the opportunity to present how I was constructing my thinking and the study findings through conference presentations, panels, and participating in workshops (see Appendix H: Conference Poster – Outcome Measures That Matter). Other forms of corroboration included engaging with peer learning and with a critical companion. Tichen and Manley (2007) describe critical companionship as being an intentional dyad that establishes a safe and trusting relationship, that facilitates critical dialogue, surfaces and challenges assumptions, and encourages testing of emerging ideas and new meanings. For this relationship I engaged across the course of the research with a patient advocate, experienced in living with and managing a chronic health condition at home. I found this corroboration to be valuable personally and as a developing social researcher. I was also able to expand my network of associations with community groups and different people who shared common interests.

I was accustomed to participating in supervision as a clinician and a researcher, and I maintained professional and academic mentor relationships. Every 2–4 weeks I met with my academic supervisors, who brought knowledge and expertise to the design, execution, data analysis, and reporting aspects of the research. My supervisors were both obliged and committed to ensuring the quality and the integrity of my research. Engaging in discussion, feedback, and input regularly throughout the research provided me with the opportunity to tap into, explore, and learn from how they responded to the data and my interpretations, it was a privilege and energising to have access to their meaning and impressions as they formed.

4.5.1.3 Theoretical Sufficiency: Social Phenomena Evolve Over Time

Aligned with the theoretical perspectives and beliefs that frame this research, my assumptions were that the social world was complex, that social reality was locally and specifically constructed and as an interpretative researcher my goal was to reveal an interpretation of the meaning that the study participants had constructed from their lived experiences, at one specific point in time. Malcolm Tight (2023) supports Diaz Andrade (2009) preference for applying the phrase "theoretical sufficiency" (p.2) as a more fitting reflection of when the interpretive researcher could demonstrate that they had comprehensively explored their data and had provided the evidence trail that supported a sufficiently well-developed understanding of the phenomenon of interest. In the iterative analysis of the study participants accounts of their lived experiences, I found it to be useful to initially focus on immersing myself, one at a time, within the first three participants accounts. Within this initial interpretative analysis I explored applying different approaches to classifying, sorting and re-presenting each participant's account. I developed a deep appreciation for each participant, guided by Swedberg's (2014) theorising practices I moved from lightly touching the data, to deep interrogation. I found that determining confidence that I had a good understanding was subjective, and that I could not predict when this point would be reached for each participant. Although I have taken a consistent or systematic approach to qualitative analysis throughout the study, my engagement with each participant's account and the meaning they shared, was personal and responsive to what emerged from their data. The practices of maintaining a comprehensive evidence trail and corroboration described earlier, were critical in determining a sense of confidence that I had reached a point of "conceptual depth" in my interpretative accounts, that reflected theoretical sufficiency (Tight, 2023, p.6).

4.5.2 Access to the interpretive processes

In interpretative case study design, the focus is on identifying relationships, how concepts relate to each other, posing and testing propositions about how things are connected within the social reality of the every day, rather than making generalisations made from the particularity of each individual's experience (Neuman, 2000). Stake (2010) described generalisation as “applying a statement to many or all cases” (p. 219). Stake (2010) argued that it would be rare that a researcher would generalise from small-scale qualitative research. He stated that there may be some small similarities across the cases; however, there remained risks and limits to what the researcher can specify (Stake, 2010). He does support naturalistic generalisations in that they support general sense making within the everyday social world, he described them “as conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well-constructed that the person feels as if it happened to themselves” (Stake, 1995, p. 85). By providing detailed accounts of the methods, analysis, and about myself as a researcher, I am inviting those outside of the case study access to observing, interacting with and evaluating my actions and assumptions. Through my processes of interpretations, my goal is to build a relationship with the reader, that translates to a sense of trust in the quality of the data, which then promotes the readers engagement with the research.

4.5.2.1 The Reader

The readers, both the academic and the everyday, play an important role in case study research. Stake (1995) described the reader as the “constructors of knowledge” (p.126). It is expected the reader will also experience reactions and draw relationships from the empirical data as they engage with the case study. Neuman (2000) explains that the reader, as a social being, will constantly be making sense of and interacting with the researchers’ interpretations of the study participants experiences, mostly drawing on what is familiar to them. Walsham (1995) cautioned about assuming that the reader would adopt a similar view to that of the researcher, when they were making their sense of the case study findings. This emphasises the ethical and moral considerations the researcher must attend to in how the study is designed, implemented, and the way findings are organised. It also accentuates the futility of attempting to manage the readers perceptions; that they will construct their experience their way. My goal was to invite the reader in and leave them to theorise and construct their own meaning. It is an ambition of this research that it serves in some way to empower thought and action in others.

4.5.2.2 Vignettes

Vignettes are widely referenced mechanisms for illustrating an aspect of an individual case, or to represent typical or atypical observations or interpretations across cases. Stake (1995) cautioned researchers regarding engaging in “narrative fraud”, through using a persuasive vignette that is “emotionally tinged and unrepresentative” or a “rare and vivid moment” (p. 130). In re-presenting my interpretations of the study participants experiences and meaning, in Chapter 5 the reader will find that I have used vignettes to pull out moments that I considered significant in both understanding the participant's unique meaning or experiences, while also being relevant to the overall research. Being mindful of the volume of findings in qualitative research, a vignette provides a short, interpretative illustration grounded in the participant's experience and voice. Vignettes have also been reported to be an effective strategy for keeping the reader engaged and provoking their curiosity (Saldana & Omasta, 2018).

4.5.3 Ethical considerations

Being qualitative interpretative research, my interpretations and reasoning not only reflected the phenomenon of interest, but shaped it; hence, I held responsibility for ensuring ethics were embedded within the research (Mortari, 2015). As detailed below, I provided the study participants with a level of protection through obtaining formal research ethics approval for my research. However, I retained responsibility to consider the ethics of every situation and to take the necessary steps. Reflective practices were embedded within the research design, and these practices were critical in bringing any ethical dilemmas or situations to my awareness so that I could address them in a timely, appropriate, and ethical way. I recognised the limits of depending on the researcher's reflectivity, in that it was a cognitive process and was situated within the complexity of being human in the lived world; consequently, blind spots were inevitable (Mortari, 2015). As discussed, to maintain the ethical integrity of the research, I also engaged with regular supervision and critical conversations as a way of seeking outsider observations that would surface any ethical concerns, ensuring appropriate and timely actions were taken.

4.5.3.1 Ethics Approval

Submissions for formal ethics approval were submitted in accordance with the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors Committee, 2007 [Updated May 2015]).

The research was submitted online via the National Ethic Application Form Version 2014-V2.2 for ethical and scientific review with the local health district's Human Research Ethics Committee (HREC). The committee agreed that the application met the requirements of the *2007 NHMRC National Statement on Ethical Conduct in Human Research Approval* and approval was granted on October 7th, 2016. As approval was granted by a recognised external ethics committee, a research ethics application was then submitted to the University of

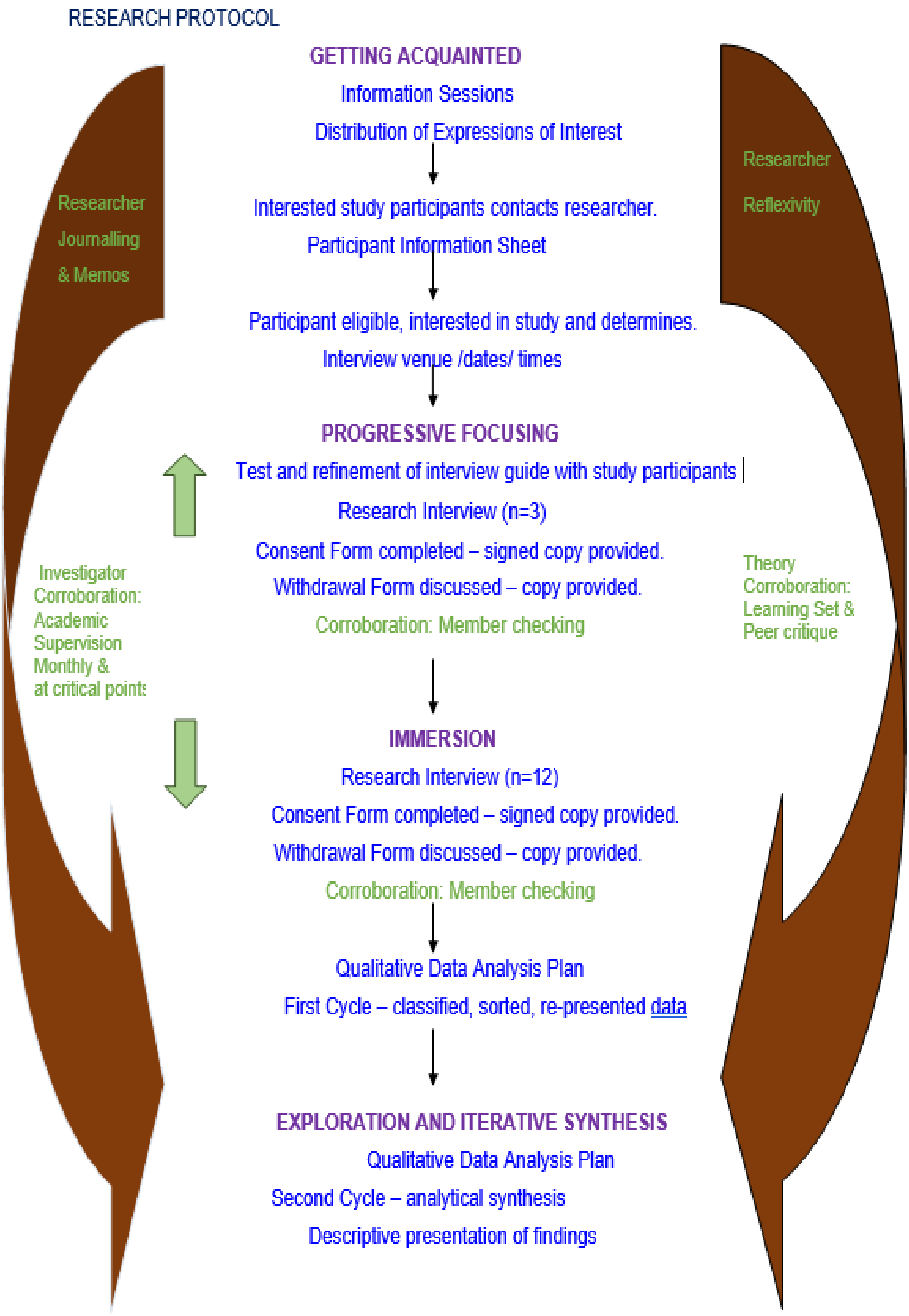
Technology Sydney (UTS) HREC Expedited Review Committee. Approval was granted 1 November 2016. Finally, a Site-Specific Application Form and Declaration were submitted for review by the local health district's Executive Delegates and Research Governance Office, with approval granted 18 November 2016.

On September 24th 2021, I submitted a request for extension of HREC approval, which was approved by the NSW local health district's HREC. The new HREC expiry date was 30 December 2022. Notification of the HREC approved extension was also submitted to the University of Technology Sydney (UTS) HREC. See Appendix I: HREC Ethics Approval Letters.

4.6 RESEARCH PROTOCOL

The following research protocol (Figure 4.3) was the detailed blueprint that I used in communicating with stakeholders, including the local Ethics Committee's HREC. It summarises how the research methods and quality strategies were applied in the implementation of the research. The implementation of the study followed the thinking that as I progressed, I would gradually discover and gain greater insights into "the case of", the investigated phenomena.

Figure 4.3 Research Protocol



4.6.1 Research Context

In this section, I introduce the particular integrated health service that served as the setting in which this research protocol was implemented. The descriptions and definitions I have provided were publicly available on the World Wide Web, published in information pamphlets, and within journal publications (Stewart et al., 2017). It is important to make this caveat obvious to the reader, as I am mindful of not building an expectation within the reader's imagination or unintentionally generating bias through my description of the integrated health service. I want to protect the novelty of this research, which is that it reflects the experiences understood and shared by the people living independently in the community enrolled with the particular integrated health service that I have privileged by listening to their voices and their meaning.

The integrated health service is geographically located within a coastal, urban area within the metropolitan boundaries of Sydney, New South Wales, Australia. In the public media, it is described as delivering innovative, integrated services that supports people with complex, chronic conditions to live well in the community. At the time of the study, integrated health services were defined by the *NSW Health Integrated Care Strategy 2014-2017* as:

> Integrated care involves the provision of seamless, effective, and efficient care that responds to all of a person's health needs across physical and mental health, in partnership with the individual, their carers and family. It means developing a system of care and support that is based around the needs of the individual, provides the right care in the right place at the right time, and makes sure dollars go to the most effective way of delivering health care for the people of NSW (NSW Health, 2014, p. 1).

This particular integrated health service is situated on the grounds of a 375 inpatient bed major metropolitan public teaching hospital, which offers a comprehensive range of inpatient and outpatient healthcare services to local residents. Housed in a purpose built, stand-alone facility, it is positioned adjacent to the existing community health services building, with direct pedestrian access from the street.

When promoting the opening of the service in August 2015, an article published in the community newspaper by the local health service reinforced that, although situated on the corner of the health campus, it was "not [a] hospital" (Trembath, 2015). The 300 square meter building was designed to "keep people with chronic illness and other complex long-term conditions out of hospital". It would do this through the concepts described as "anticipatory care" and "patient self-management, so people can learn how to look after their disease's themselves" (Trembath, 2015). This included preventative care and would complement the care provided by general practitioners. In 2016, the manager of the integrated care service was quoted as saying 400 patients had accessed integrated care programs with "outstanding health outcomes" being reported (Kolimar, 2016).

In 2017, a case study was published from the perspectives of the health managers leading the development and local implementation of the integrated care health service model (Stewart et al., 2017). To guide the adoption of a person-centred focussed design for the service, a range of community consultations were undertaken, "focussed on the local aboriginal community and local residents with long-term health conditions" (Stewart et al., 2017, p. 53). The authors reflected that they were in the early phases of implementation and evaluation, with a "long way to go" (Stewart et al., 2017, p. 58). No community or health consumer advisory group was established or planned at this phase.

Within the timeframes of my research data collection, March 2017–March 2019, examples of integrated health services available at this particular service, at no out-of-pocket cost to the service user, included a community diabetes program that provided practical information around healthy food choices, being active, and preventing complications; chronic wound management program that assessed and developed personalised plans to manage and treat wounds; a skin cancer check program; and an Aboriginal and Torres Strait Islander people healthy lifestyle support program and chronic disease care program. Community members could self-refer to some programs by contacting the integrated health service directly, while some required a general practitioner's referral. Health professionals were encouraged to refer members of the community who were living with or at risk of a chronic disease to the integrated health service. It was concluded that the integrated health service was achieving its aim of providing a high-quality service under one roof with minimal wait times with no referral, this was evidenced by increased activity, in that a growing number of community members were accessing the service (McGlynn et al., 2019).

4.6.2 Research Protocol: Four-phased Approach

To provide the reader with the quasi-experience of the implementation of the research protocol as it was explained to the Research Ethics Committee, expanding on the thinking behind the doing of the research method, I detail each of the four phases below. The qualitative data analysis was discussed in the method section of this chapter, and is explored in detail in the following chapters. In this section, I provide a brief summary of the relevant phases.

Modelling the emergence of understanding and meaning creation, I embedded the practices of progressive focusing within the research protocol, whereby I continuously inquired of the case, exploring and seeking to interpret, refine, and focus as the study progressed (Stake, 2010). Each of the phases identified in the research protocol (Figure 4.3 Research Protocol) are detailed below.

4.6.2.1 Phase 1: Getting Acquainted

This phase included introducing the researcher (myself) and the research to the case setting, a particular integrated health service. In completing the risk assessment for my ethics application, I identified that the redesign or restructure of the integrated health service may result in enhancements, closure, or discontinuing of the model of care as possibilities. This is an everyday reality of change and health services. To ensure study participants had accessed the integrated health service as currently defined as much as possible, the mitigation strategy was to commence recruitment and interviews as soon as the ethics approval was granted. In the "getting acquainted" phase, I engaged in activities outlined below.

Preparing

Time was dedicated for preparing to engage with the research field and any potential participants. It was critical that I was authentic in any engagement in the field and that I was respectful in all interactions. I kept a detailed account of ongoing processes, feelings, thoughts, emergent ideas, hunches, and questions. Reflexivity included acknowledging my own values, beliefs, and assumptions as being important for the ethical conduct of the study and for the auditability and trustworthiness of data analysis. With the intent of understanding "the case of" the participants' experiences, I arranged to walk through the integrated health service at a time and date determined by the health service. I only accessed areas available to the research participants and saw what would have been visible and publicly available as part of their care experience. Spontaneous and unstructured conversations occurred at this time.

Recruitment

Potential research participants were not approached directly; however, they could have been engaging with or visiting the service when I was on-site. Participant recruitment included the following activities:

- With the aim of preparing and supporting the integrated care staff responsible for delivering the different integrated care programs to be able to respond to general questions related to participation in the research, staff (clinical, non-clinical and administration) were invited to participate in information session(s). I responded to the staff preference for when, where and how we met. Some staff preferred to receive written information via email and others preferred to meet in person, individually or as a group.

- The research information flyer provided a general description of the research, including what made a participant eligible and what participation required of them. The flyer instructed interested individuals to express interest by contacting the researcher via phone or email. Research information flyers were displayed in the general reception and waiting room area of the integrated care unit.
- The integrated health services provided services to the community that were on-site, at nearby facilities, through telephone consultation, and home visits. Individuals enrolled with the integrated health service were advised about the research by receiving the routine general service update communication, or they were provided with a copy of the flyer directly or advised where the information was located and how to indicate their interest.
- I made myself available to be contacted by any member of the integrated health service to enable access to timely support in the event further information was required.

Participant Screening

All research participants self-responded to the expression of interest to participate in an interview focused on their experiences of the particular integrated health service. To be included in the research, all participants were required to self-identify as living at home unassisted while being enrolled with the service, having attended a minimum of three times, with the most recent visit being in the last month. Potential participants who expressed interest in the study were assessed for suitability as follows:

- Depending on the potential participant’s preference and circumstances, I followed up from their initial contact via phone, email, or in person, and offered to coordinate a further meeting to discuss the research.
- Referring to the inclusion criteria, potential participants were coached to self-audit their suitability to participate in the research.
- I responded to all potential participants who showed interest, respecting that each potential participant brought a unique perspective.

- The HREC approved Participant Information Sheet, Informed Consent Form and the Withdrawal Form are located in Appendix J: HREC Approved Supporting Documents. Once the participant indicated their suitability and interest to progress, a copy of the above documents was made available for them to review in preparation for the interview.
- Inability to recruit the projected number of eligible participants was recognised as a potential risk to the research. The mitigation strategy applied was to acknowledge all potential participants who expressed interest in enrolling in the study and invite them to provide their contact details. Potential participants were advised that they may be contacted, and that the researcher would notify them when the data collection phase had been completed and they were thanked for their interest. Their contact details would then be destroyed.
- Participants were not considered enrolled in the study until after the informed consent processes had been completed.

4.6.2.2 Phase 2: Progressive Focusing

Interested participants that met the inclusion criteria were advised that the interview could take up to 60 minutes, including orientation to the research and signing of the consent form. In this phase, I guided an initial sample of three participants through the interview process. This allowed me the opportunity to observe the participants engaging with the questions and to receive feedback and input from the participants regarding the questions and any improvements. The processes followed during this phase are described below.

Prior to the interview:

- The first three potential participants that had contacted me and self-assessed that they met the inclusion criteria were contacted and invited to identify a convenient date, time, and location for the interview.
- To minimise any inconvenience for the participants, I was flexible regarding timing. All participants preferred to be interviewed either before or after their next planned visit to the integrated care service.
- Venue options of a private consultation room on-site or a private room off-site within a short walk from the integrated health service were provided.

Interview setting:

- Most participants stated that it would be convenient for them to meet in the private consultation room I had secured on-site at the integrated health service.
- All participants were familiar with the venue, including required travel time, parking, and transport options.
- The consultation room that I secured was the first office down the corridor from reception. All rooms looked similar. The participants were familiar with the environment. The room had a thick frosted glass wall facing the corridor and a door that could be closed. You could hear muffled footsteps if people walked down the corridor, but nothing distinct. The room had natural light; however, fluorescent lights where required. There was a desk up against the wall and four chairs. The walls were mainly bare, with a couple of posters above the desk with information about the services offered by the unit and their contact numbers.
- The office-type chairs were able to be re-positioned to be semi facing each other, situated within reach of one corner of the desk to be able to lean on the desk to write if necessary.
- One participant requested to be interviewed in a different location, a treatment room, as she required a specific chair to be able to sit comfortably for the duration of the interview. The request to occupy a treatment room for the interview was accommodated by the integrated health service. This participant’s preferred chair was secured to the floor, so I positioned a free-standing chair close by for the interview.
- I arrived 30 minutes prior to the agreed interview time to ensure the room was available and prepared. At times, portable medical equipment was left in the consultation room, which I was able to move to another, or less obvious, location. The unit had a small open kitchen area, where staff and visitors self-served refreshments such as tea, coffee, or water. We were welcome to access refreshments and use the bathroom facilities.

At the time of the interview:

- I waited in the entrance area and met the participants on their arrival.
- All participants were invited to choose their preferred chair or were free to move their chair into their preferred position.
- The interview commenced with brief introductions, then a discussion guided by the Participant Information Sheet, Withdrawal Form, and the Consent Form. Participants chose of their own accord to consent or decline.
- The Participant Information Sheet advised that there should be no discomfort in taking part in this study. At the time of the interview, I reinforced that if the participants felt that some of the questions asked were upsetting or did not wish to answer a question, they were free to skip it and go to the next question, or they may request to stop the questions at any time. If the participant was observed as becoming upset or distressed, I stopped immediately and checked-in with them.
- An independent, qualified, health professional was readily available for participants, and access to appropriate follow-up support services was arranged. This was available free of charge.
- The participants could decide to take part and later change their mind, they were free to withdraw from the project at any stage. I explained that as the research progressed, it may not be possible to withdraw all of their data from the study results.
- Once the Consent Forms were signed, I provided a photocopy of the signed consent to the participant for their personal record keeping and kept the original in a secure location, as per the approved ethics protocol.
- After finalising consent, the participant was provided with a copy of the prompt interview questions that I had designed to guide the open-ended semi-structured interview. Appendix G: Research Interview Guide shows how each participant was guided through the same set of questions.
- Each participant was invited to choose a pseudonym that they were known by from that point forward and in relation to any data produced in the research. A study enrolment number (project code) was also documented in the participant's study record and on all study documents.

- All research files were password protected. Any hardcopy data were kept in locked filing cabinets and kept secure, as per the University of Technology's Ethics Procedures.
- Each interview was digitally recorded on two devices to minimise risk of human or technology error. I advised the participants that I would also be taking some rough notes throughout the interview. Additional paper and pen(s) were made available to assist the participant in capturing musings as they arose or for drawing images to support communicating their responses to the interview questions.
- At the completion of the interview, each participant was asked to confirm factual demographic data and whether, in light of their understanding of the research aims and objectives, there was anything else that they thought important that had not been included in the questions or revealed during the interview or could be improved, as part of member checking that I had committed to in my research plan.
- At the completion of the interview, I walked with the participants as they left the building.
- Immediately following each of the interviews, I established a routine of allocating time and thinking space to reflect and journal on the data/interviews.

In response to the initial three participants feedback that they found the processes of coordinating the interview logistics to be suitable, that they felt comfortable during the interview, and the questions flowed easily within the conversation, I discussed the feedback with my academic supervisors, and it was agreed that I should progress to the next phase.

4.6.2.3 Phase 3: Immersion

In this phase, I commenced the recruitment of up to 12 potential participants and coordinated a date, time, and location convenient for them to participate in the up to 60-minute interviews. Some potential study participants self-assessed that they were ineligible; for example, they identified that they were receiving inpatient hospital care or they were not the actual person receiving integrated care, they were the individual's carer. These individuals were thanked for their interest in the study. Another potential participant, after several attempts, was unable to coordinate a day/time that was convenient and eventually advised they were not interested in progressing to the interview phase. No data was collected related to these participants, nor was consent obtained.

Each of the eight additional participants that agreed to take part in the research interviews followed the same process. Replicating the approach taken for the initial three interviews.

Qualitative data analysis

The study's qualitative data analysis plan (Figure 4.2 Qualitative Data Analysis Plan) was detailed earlier in this chapter in the research methods. All interviews were transcribed by the same transcription service, which was confirmed for compliance with security and confidentiality requirements. Analysis commenced with several rounds of listening to each interview recording and reading of the transcript. I focused on one participant at a time and did not commence data analysis of the next participant until the prior analysis was complete. The systematic manual micro-analysis included initially getting a sense of the overall account, then focusing in on specific aspects, and then drawing outwards to explore how those specific aspects were situated in the whole account. This analytic process was then repeated. I engaged in theorising and journalled throughout the analysis.

Each participant's interview transcript went through the same micro-analysis and micro-immersion as detailed in the qualitative data analysis plan. I commenced the qualitative micro-analysis of the interview transcripts, applying a systematic manual process of applying the first cycle analysis coding methods, focusing on one participant at a time. With the intent of understanding each participant's perspective and their story, the coding commenced with close examination of the first case. I immersed myself in one case at a time, reading and re-reading the interview transcript and any related notes provided by the participant or that I had made at the time of the interview. Micro interpreting the data closely, initially noting observations, feelings, or questions in the margin, I took analytic memos to capture why a code was applied and any insights or relationships that were surfacing or reoccurring within the data themes. I engaged with reflexive practices throughout, including the hermeneutic circle detailed earlier in the chapter. The results of the first cycle analysis are presented in Chapter 5.

4.6.2.4 Phase 4: Exploration and Iterative Synthesis

Guided by the qualitative data analysis plan (Figure 4.2 Qualitative Data Analysis Plan), the second cycle analysis was implemented in the fourth and final phase. This included the cross-case synthesis analysis that enabled the researcher to theorise and search within and between the data sets. I explored across the case codes and themes for conceptual links, identifiable patterns, consistencies, or common meanings, while also noting any idiosyncratic differences. Some concepts were expanded, some revised, and some abandoned. The coding and categorising of the data ceased when I had a sense that I had sufficiently explored the data enough to stop the analysis. My assessment of "good enough" was corroborated by my supervisors and peers, and was supported by my detailed evidence trail (Tight, 2023).

Synthesised concepts and insights from the research data were observed for any convergence or divergence with the published literature. I also drew upon existing theory and concepts to further explore the emerging understandings. In playing with the use of metaphors, vignettes, and re-presenting the case data in different formats, my goal was to respect and preserve the diversity within the meaning and experiences of the participants, while also contributing to producing an insightful interpretative account of the fusion of the overall research findings. The results of the second cycle analysis are presented in Chapter 6, while discussion of the overall findings within the context of the literature and insights is provided in Chapter 7.

4.7 CONCLUSION

This chapter introduced important frameworks supported by the literature and personalised to this research. Three frameworks were provided; first, the updated research on a page; second, the qualitative data analysis plan; and third, the research protocol. They were designed to provide the structure required to give credibility to the research evidence trail, and the flexibility required for being responsive to emergence within the research while maintaining the research's quality. As a result of implementing these frameworks, the desired purposive sample of study participants who had direct experience relevant to the phenomenon of interest were recruited. To be included in the research, all participants had self-identified as living at home unassisted, were enrolled with the same integrated care service, had attended the service a minimum of three times, with the most recent visit being in the last month prior to the interview. The target was to recruit 10 participants. Eleven individuals met the participant selection criteria, attended their interview, and consented to participate in the research. No participants withdrew from the research after the interview process. The intentional approach to recruitment was effective in providing access to a variety of participants suitable for inclusion.

Guided by the qualitative data analysis plan, in staying close to the study participants' voices, I manually and systematically undertook the first cycle micro-analysis of each of the interview transcripts. I iteratively engaged with the data through being focused on the micro detail and then drawing outwards to comprehend the whole. I repeatedly engaged with each individual data set, before gradually progressing to the second cycle of analysis. Throughout these analytical processes, I engaged with reflexive practices, including Swedberg's (2014) theorising and journalling. In the analysis phase, critical review and challenge were sought from the panel of academic supervisors in the processes of coding and identifying emerging themes. The supervisors also contributed to the dependability or reliability of the research by requesting evidence that the research procedures were being followed. The informal peer learning set enabled my reflection and exposed me to other's perspectives and realities. This process and my critical companion conversations heightened my awareness of any personal heuristic rules that might have been playing out during the analysis.

The following chapter exposes the reader to the findings interpreted from the first cycle of analysis, and the insights these offered to the framing question through responding to the first three focus questions.

Chapter 5: Interpretative Findings – First Cycle: The Participants' Experiences

5.1 INTRODUCTION

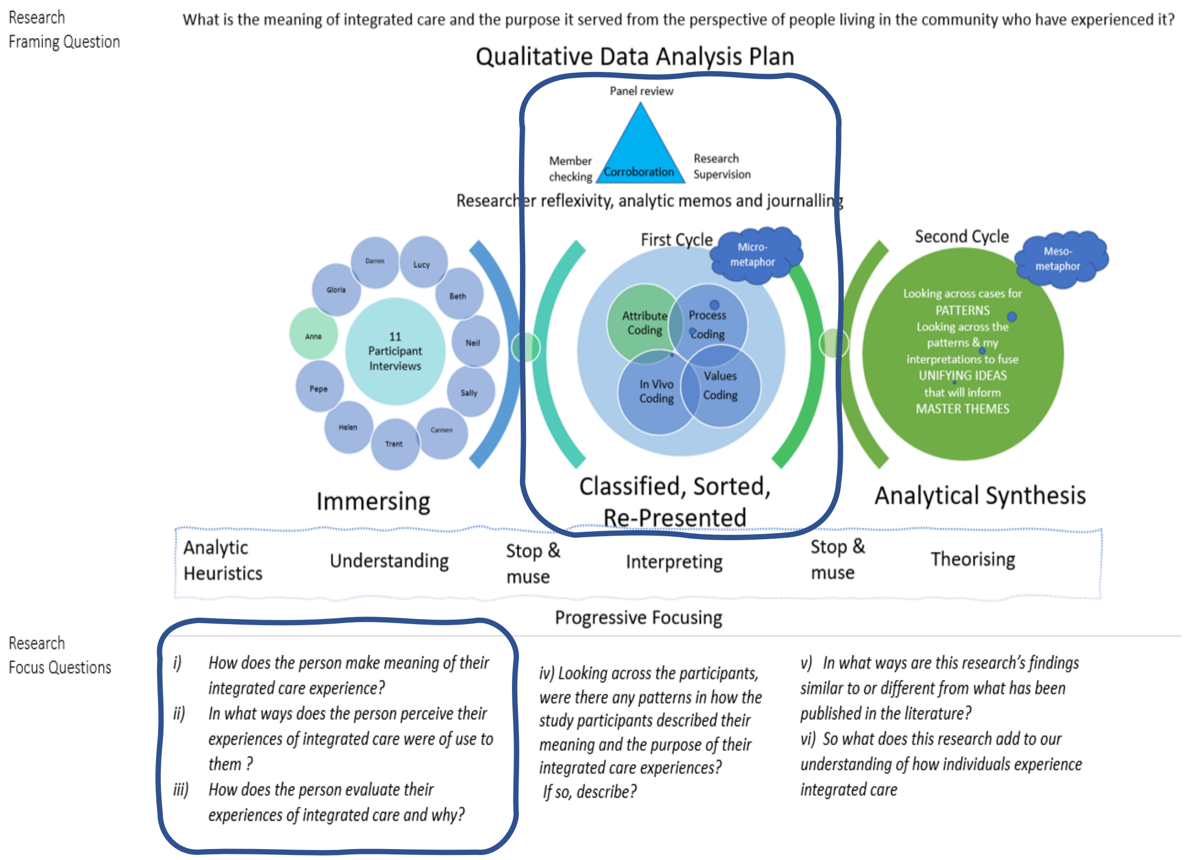
This chapter presents the findings in relation to the research framing question; *"What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?"*. The findings feature the progressive merger of the research participants' interview data, which recounted their experiences and the meaning they held for them, with my interview field note reflections and my reflexive journal thoughts and musings that I had formed as I immersed myself in reading each transcript. The approaches taken for data analysis and synthesis were interpretative, personal, and iterative. It is accepted that the findings will remain elusively unfinished, they represent "the story that seems most meaningful" from my standpoint (Stake, 2010, p. 131). It is also recognised that the findings continue to evolve as the next reader makes their own meaning. Nevertheless, the findings are presented with a commitment to establishing trustworthiness with the reader, through ensuring any interpretive claims are traceable to the data source and include evidence of being robustly challenged through multiple eyes.

The analytic synthesis of the research findings was approached with deliberate gradualness, recognised as an ideal approach when the intent is to engage in thinking differently, developing new theories or challenging beliefs (Turan, 2017). The interpretative findings have been purposively re-presented to gradually immerse the reader in getting acquainted with my impressions of each participant and then the first analysis of their interview transcript, before progressing to considering the collective experiences of the group. The qualitative data analysis plan introduced in Chapter 4 (see Figure 4.2 Qualitative Data Analysis Plan), illustrated how I interacted and progressively sought to understand and made sense of the research data. The plan illustrated the many moving parts and considered responsiveness I took to understand, interpret, and theorise, always acknowledging the participant as the expert of their experiences. Gradually, the research data, my personal insights, and interpretations were fused to reveal and construct interpretive summations.

5.2 STRUCTURE FOR RE-PRESENTING EACH PARTICIPANT'S MEANING AND EXPERIENCES.

Repeating the same approach, each participant's interview transcript was studied carefully one at a time. A gradual process, sometimes taking weeks, I observe the data alongside my interview field note reflections that captured my reactions and musings. I start to form impressions as to what I understood to be going on for each participant, constructing meaning from their experiences and how I saw them making sense of it. Facilitated by analytic processes, and acts of interpretation, I gave meaning to these first impressions, in slowly reconstructing the participants story and re-presenting their account, which was now a fusion of their words and my meanings.

Figure 5.1 First Cycle Analysis: Re-presenting participants' interpretative accounts



What is the meaning of integrated care and the purpose it served from the perspective of people living in the community who have experienced it?

i) How does the person make meaning of their integrated care experience?

ii) In what ways does the person perceive their experiences of integrated care were of use to them ?

iii) How does the person evaluate their experiences of integrated care and why?

iv) Looking across the participants, were there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe?

v) In what ways are this research's findings similar to or different from what has been published in the literature?

vi) So what does this research add to our understanding of how individuals experience integrated care

This interpretative account is accompanied by excerpts of each participant's own words. Following the qualitative data analysis plan illustrated in Figure 5.1, I move from left to right. The first cycle analysis interpretations were drawn from the analytic synthesis of each participant's data set with my interview field note reflections and reflexive journal thoughts and musings. The first cycle coding enabled the initial classifying and sorting of the data, followed by an iterative process of progressively focusing using the structure of the first three research focus questions. This organising structure is replicated for each participant.

5.2.1 First Cycle Analysis: Signposting for the Reader

The research's interpretive phenomenological design generated a considerable amount of in-depth data for each participant, that I intimately and iteratively examined, classified, and sorted. The structure taken for re-presenting the data was influenced by Stake's (2010) encouragement that I tell "the story that seems most meaningful", while staying in focus with the research framing and focus questions (p. 131). To guide the reader in finding their way, I will refer to my interpretations of Anne's experience of integrated care to signpost how I have told her story. A visual representation of my approach can be found in Appendix K: First Cycle Analysis: Guide for the Reader - Coding Anne's Interview Transcript. Here the reader can examine how I have iteratively engaged in the analytic processes, including noting what surprised me (my assumptions), what intrigued me (my positionality) and what disturbed me (surface tensions within my value, attitude, and belief systems) as I sought to understand what Anne's experiences meant to her and the purpose they served. My interpretations are then summarised in Appendix L (see Table L1: Anne's Experience of Integrated Care) alongside Anne's transcript and her first cycle codes.

The re-presentation of Anne's data begins with a general introduction to her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. The introduction is a fusion of Anne's words and my meanings. Attribute coding allowed me to identify and organise what I saw to be Anne's unique descriptive characteristics, as illustrated in Table 5.1. The aim is for the reader to feel acquainted with my interpretation of Anne, and to have the opportunity to relate to her as the unique person that she is.

Table 5.1: First cycle interpretative findings: Anne's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Anne (A)	Date: March 2017 Location: Integrated Care Unit Transport: own car Interview Length: 54 mins	75–80	Female	Own home, with Husband	Carer	Gardening Regular Exercise Being "a detective'	Dermatologist referral (specialist)	~ 8 visits Since Dec 2016 attended every few weeks over 4-month period	Wound Clinic	General Practitioner Community Nurse Chemist Plastic Surgeon

Next, I respond to the first research focus question, "*How did Anne make meaning of her integrated care experience?*". In my response I summarise what I interpret as being the significant elements of Anne's meaning making processes. This forms part of the first-cycle coding of Anne's interview transcript. To capture the dynamic nature of her everyday experiences, I manually engaged with Saldana's (2016) process coding. To do this I re-read, classified and sorted what stood out from Anne's transcript as being actions or movement. I also used Saldana's (2016) values coding method to surface what I saw as being important to Anne and that could potentially be influencing how she was making meaning from her experiences. An example of a values code for Anne is "being neighbourly". In vivo or verbatim coding ensured that Anne's voice remains central and intimately connected to her codes and the analysis process. In re-presenting Anne's meaning, the reader will note that Anne's codes (e.g., "abiding by rules") are a fusion of Anne's words with my interpretations. To respond to the second research focus question*, "In what ways did Anne perceive her experiences of integrated care were of use to her?* I again draw from Anne's codes (e.g., "keeping informed") and provide the reader with my insights as to why I interpreted that Anne perceived her experiences to be of use to her.

With the third research focus question, "*How did Anne evaluate her experiences of integrated care and why?* A table was created to re-present what I interpreted, drawing on what she had expressed throughout the interview as being what mattered the most to her and why. The reader will note in the interview guide (see Appendix G), I inquired as to what most important to each participant regularly throughout the interview. I accompanied this interpretation with examples of how I believed Anne to be engaged in the processes of evaluation, and what I interpreted she was using to assess her experiences. Below is an extract from Appendix L Table L1: Anne's Experience of Integrated Care, displaying how I interpreted Anne to be continuously monitoring and measuring her experiences of integrated care.

Table 5.2: Excerpt from Appendix L Table L1: Anne's evaluations of her integrated care experiences

What Matters and Why	**Measures**
"I now know … what to look for and what actions to take". **Why?** I have the understanding and information I need to make choices and take actions.	**Self-assessment** Sense of confidence – self efficacy in my ability to self-manage – predict and prevent. I have a plan of action with points of reference and options. I have people's names and contact details.

To conclude the first cycle of analytic synthesis, I respond to the research's overall framing question, "*What is the meaning of integrated care and what purpose does it serve from* *the perspective of people living in the community who have experienced it?*". Here I provide the reader with a summary of the meaning I have made from my experience of interviewing Anne, immersing myself in her transcript and having engaged in reflexive practices throughout. The interpretive summation is my ultimate viewpoint of what each participant's integrated care experiences meant to them, and what I believed to be the purpose or their utility. In essence, I am interpreting what this was a case of, for Anne.

Influenced by Swedberg's (2014) approaches to theorising, I chose to adopt a novel approach, and I challenge myself to produce a metaphor, as a meaningful, succinct, yet provocative way of expressing my speculations as to what I understood to be occurring for Anne. I would not be surprised if the reader questions this approach or its value, considering the volume of in-depth data I have already re-presented. However, my ambition in producing a metaphor was to find words that reflected the complexity yet grounded simplicity of what I had interpreted. The metaphor I produced for the story I had told about Anne was "time is health". I found the reflective and cognitive processes of creating a metaphor from Anne's data to be personal, pragmatic, and powerful, in that it created a lasting impression that easily brought me back to Anne and what she shared about her experiences and meaning of integrated care. I encourage the reader to engage in producing a metaphor that simply expresses how they have come to understand Anne in the context of this research.

The re-presentation of each participant's first cycle analysis mostly followed the same structure. A point of difference is the use of vignette within Helen and Lucy's findings. Offering the reader a short, interpretative illustration grounded in the participant's experience and voice, the vignette serves to engage the reader with moments that I consider significant in both understanding their unique meaning and experiences, while also being relevant to the overall research. An additional table is also included in Carmen's findings as a way of re-presenting her unique contribution in how she had expressed the depth of thinking she had dedicated to the considerations of opportunities for improvement for the integrated health service.

5.3 FIRST CYLCE ANALYSIS FINDINGS.

Following the format described in the qualitative data analysis plan, this section re-presents the first cycle analysis interpretative account for each of the 11 research participants. Starting with Anne and concluding with Neil, the findings begin with acquainting the reader with each participant in the context of my interpretations and concludes with my speculation about what was occurring. The reader is encouraged to adopt a disciplined approach to applying Swedberg's (2014) theorising practices, in that you pause and muse over what has been re-presented before progressing to the next participant's findings. The reader will know when its time to pause when they see this blue line at the completion of each participants first cycle analysis findings ▬ . This approach also aligns with the research goals, to respect the person and privilege their voice and perspectives, this pause provides time for reflection and to appreciate each participant's experiences and meaning.

5.3.1 Anne's Meaning and Experiences of Integrated Care: An Interpretative Account

Re-presented below is an account of my interpretations of Anne's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Anne's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. As detailed earlier, Anne's attribute coding, Table 5.1, provides a general descriptive introduction to Anne and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Anne's first cycle coding is included in Appendix L (see Table L1: Anne's Experience of Integrated Care).

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Anne's words with my observations and sense making. The exert below from my research journal (Figure 5.2) gives insights into how I was gradually making sense of Anne within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.2 Researcher's Journal Excerpt: Getting to know Anne.

> *Anne's physical presence during the interview had left an impression on me. I had noted that Anne was small in stature, a slightly framed woman next to the researcher, who is 173cm tall. Anne had a small scab wound on her nose, a slight scar on her ear and a shallow dip on her lower leg that looked like she had had something removed and was healing. Anne spoke in a soft voice that was a little raspy at times, requiring her to clear her throat often. She was relaxed and quick-witted, reminding me, "and no swearing (laughter)", when the digital recorder was turned on. Anne always referred to me by my name. She listened quietly and then asked pointed questions or sought clarification. After completing the consent form, Anne checked with me as to whether it was completed accurately. Annes explained that she took pride in following instructions, and she treated people how she would like to be treated.*
>
> *Anne described herself to me as being in her late seventies, she continued to live with her husband in their first home, the same one that they had moved into as newlyweds in 1961. Anne's husband was 10 years older than her; he had had a few falls. Anne said that she was "officially his*

carer". Anne recalled vivid memories of her husband's injuries from falling and shared her fear of tripping over herself. Anne had taken actions to fall-proof her home and made personal adjustments, "I take little steps because I feel you've got more connection with the ground". Anne liked to keep to her routine. Anne enjoyed feeling like "a bit of a detective". She liked keeping a look out for her neighbours and was always open to new information.

I came to realise early in the first cycle of analysis that it would take me time to appreciate and make sense of the memories, emotions and aspirations Anne had shared with me during her interview. I found myself intrigued by what appeared to be an incongruence between her appearance, the words she used, and the behaviours she described. Anne gave the impression of being genuine in describing herself as "unassuming" and "someone who proudly followed instructions". Yet at the same time, when Anne shared why she adopted this demeanour, she revealed that she was actively influencing, and willing to makes changes to her circumstances, as she deemed necessary to achieve her objectives. I found the words strategic, intentional, and adaptive coming to mind when I was reflecting on my interview with Anne.

In recounting her every day and health related experiences during the interview, Anne revealed that over the past seventy plus years, she had experienced, or was aware of, patriarchal social power relations that can exist between doctor-patient and male-female interactions. Furthermore, she shared how she had established a way of being within this social structure that worked for her. She shared that on the surface she "goes along" and does what she is told, as she believes this would be expected of her. While under the surface she enjoys actively investigating options, or as Anne said, "doing things". Anne was full of surprises, and she helped me appreciate the importance of practicing reflexivity as a qualitative researcher.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Anne and her story.

5.3.1.1 Research Focus Question 1: How did Anne make meaning of her integrated care experience?

Anne described her experience of integrated care as a "free", "friendly" service that would help her to progress the healing of her wounds. I interpreted from Anne's interview that she held the belief that if everyone played their role as they should, the integrated care service would be a good use of her time. From the first cycle analysis, two codes stood out. They were:

Abiding by rules

Anne described her experience of integrated care as “pretty much like going to the doctor”. In the context of Anne’s interview, this suggested to me that she felt that the experience, including the existence of social power dynamics, were known to her. Anne expressed the view that for health providers, integrated care, “it’s a job for them”; however, Anne also voiced that she felt, “that they’re caring, they want to help you”.

Knowing my place

It was important to Anne that the healthcare providers brought their “experience and professional knowledge” to overseeing the healing of her wounds and were “thinking about what else [Anne] should be doing” and “making changes” if not progressing as expected. In return Anne would “provide the wound”, “social conversation”, and be “available when they were available”.

I interpreted this as Anne drawing on her previous experiences and being strategic. From one standpoint, it could be interpreted that Anne was compliant, freely giving her time and trust away, “I don’t complain, I don’t make suggestions or suggest changes”. She knowingly took on the role of a courier of information rather than being a source, “She [doctor] wrote a letter back to the referral doctor [and said] ‘Next time you go, just hand him this’”. However, from another standpoint, when describing her experiences, Anne gave a sense that she knew what was in her locus of control and that she was actively invested in “doing things” towards achieving her goals, that her “problem was fixed and better”.

5.3.1.2 Research Focus Question 2: “In what ways did Anne perceive her experiences of integrated care were of use to her?

Annes experiences of integrated care were interpreted to be directly relevant to what information she said she needed to know and the actions she believed needed to be taken for her wound healing to progress and for her to secure her general health so she could fulfil her responsibilities, now and into the future. The following themes from the first cycle analysis best reflect what I interpreted Anne had found to be useful.

Keeping informed

Anne explained, “the wounds I’ve had were never painful. And they filled me in on the progress, which was good”. I interpreted that the integrated care service gave Anne a point of reference and helped her to learn about wound healing in a way that she could apply at home. This was useful as she now knew what to look for, “it’s starting to granulate now, and that’s good”.

Time was something that I sensed Anne valued and protected. Her integrated care experiences were useful in giving her a new appreciation that progress could take time, and importantly that this was ok, “making time to let heal”. It stood out to me that Anne considered being informed as being useful for avoiding any future threats to her health, it was important to Anne to be prepared, “informed of all the things that I’m eligible to have”.

Being given choices and permission to act

Anne described in her interview how her integrated care experiences had been useful in informing her as to what actions she needed to take to progress healing, of what to look for that would be cause for suspicion, and when and how to act if concerned. Anne described that having the option to call if needed, “I’ve got a phone number they gave me to ring if needed on anything”, was important to her. Anne shared that she had not had reason to contact the integrated health service between visits or with concerns.

Being proactive and able to initiate preventative actions stood out in the interview as being important to Anne. She provided an example of preparing to avoid falls in the home for herself and her husband. I interpreted that fear had been a driver for Anne’s actions. Anne often referred to her home as her “comfort zone” and believed that she would be able to best fulfil her carer role if they could “stay in their own home”. I noted that Anne’s integrated care experience offered her options that would be useful in the future.

I formed the view that Anne was innately curious and open to testing out different ways and responded positively to being given choices. Anne recalled, “I needed to keep the leg dry, they never said what I couldn’t do. I was really a bit doubtful at first. I was saying ‘Will this work’? And do you know what, it [has] never leaked once in two years”. I interpreted that Anne was expressing defiance and confidence when she pledged, “This won’t beat me”.

Positive experience

I formed the impression that Anne’s description of the service as being “friendly” had influenced how useful she had found her experiences. Anne raised several times that she believed it was important to be “neighbourly” and “look out” for each other. She liked that people were “interested” in others and reflected that being “known” by the integrated care team and “knowing them” would be helpful in the future if she had to call on them again. I noticed a relationship between how Anne felt about a social interaction and then her assessment as to whether it was a good place to invest her time or would motivate her. Anne expressed that she was aware that things were eventually going to get “harder and harder”.

5.3.1.3 Research Focus Question 3: How Anne Evaluated her Experiences of Integrated Care and Why?

Throughout Anne's interview she provided examples of the significance of, and her commitment to, continuously monitoring her progress. Anne described how she managed her time, integrated the care of her wounds into her daily routine, and how she motivated herself, recognising that she had a choice in how she approached her health. To Anne, "health is everything". Table 5.3 below presents what I interpreted as being important to Anne from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.3: How Anne evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
"I now know … what to look for and what actions to take". **Why?** I have the understanding and information I need to make choices and take actions	**Self-assessment** Sense of confidence – self efficacy in my ability to self-manage – predict and prevent. I have a plan of action, with points of reference and options. I have people's names and contact details.
"Good use of my time" **Why?** Not wasting my time	**Reliability** People do what they say they will do. Attendance as per agreed schedule/diary. People are knowledgeable and have expertise in the field. People are friendly and open to being known. People will help me learn/explain to me.
"Good value" **Why?** It's "free" and "convenient"	**Self-assessment** Comparison to previous experience Access to parking Phone contact

5.3.1.4 What is This a Case of: Interpreting the Implications from Anne's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From Anne's interview transcript, I interpreted that utilising the integrated care service was about taking planned action that resulted in access to reliable expertise and knowledge that could inform and contribute to progress, which was beneficial to Anne's overall health. It stood out to me that Anne's integrated care experiences served the purpose of keeping her informed, which meant she felt she could make choices, and then she could "do things". It gave Anne confidence that she knew she could reach out to experts, if and when, she needed to. The metaphor that came to me, when thinking deeply about what was the essence of the story that Anne had shared with me in the context of this research, was "time is health".

5.3.2 Helen's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the format used to present Anne's findings, re-presented below is an interpretive account of Helen's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Helen's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Helen's attribute coding, Table 5.4, provides a general descriptive introduction to Helen and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Helen's first cycle coding is included in Appendix L (see Table L2: Helen's Experience of Integrated Care).

Table 5.4: First cycle interpretative findings: Helen's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Helen (H))	Date: April 2017 Location: Integrated Care Unit Transport: two buses and walked Interview length: 78 mins	75–80	Female	Own home, alone	Retired	Studied biology, social activities, learning skills and languages, two children	Self-referral via GP	~ three visits over 4-month period and initially attended senior week	Wound Clinic	GP practice with seven doctors, chemist

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Helen's words with my observations and sense making. The exert below from my research journal (Figure 5.3) gives insights into how I was gradually making sense of Helen within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.3 Researcher's Journal Excerpt: Getting to know Helen.

Helen introduced herself in the interview as a busy woman. Helen shared that she had recently turned 75. She lived alone, not far from her daughter. She had been a bush walker for 50 years, which she loved, but had to give up recently due to her legs. Helen said, "I couldn't do it [bush walking] and, so, I dropped out of that". I noted that I had found it easy to empathise with Helen's pragmatic dismissal of stopping something she enjoyed, as she reminded me of a relative who was also a retired bushwalker, and had explained to me that if you cannot be independent, you are a burden. I was left wondering if this either/or thinking was how Helen had made sense of her circumstances.

Helen said she wore hearing aids most of the time, and was wearing them today. I noticed that Helen talked very quickly and provided detailed responses that jumped from the past to the present, making connections between different observations and experiences. Helen shared that she had studied biology and described herself as an analytical thinker who likes to know the "why". Helen preferred to investigate her hypothesis, to seek out other opinions and gather more data, so she could then compare and take action. She did not rate what she calls the "fishing expedition approach" or "defensive medicine", which she explained as when you collect a lot of data first and then try and work out the question.

Helen said she had a son and daughter. Her daughter did her PhD and now provides supervision for overseas PhD students. Helen was currently estranged from her son, who had been living on and off in the care of mental health services. Helen laughed when saying "I've got problems you wouldn't believe". Helen reflected that she was beginning to realise that stress affected her and that she considered herself "vulnerable".

When getting acquainted with Helen during the interview, she explained to me that she had studied biology and that she had a process of analytical reasoning that she applied to most aspects of her life. She described that she liked to discover, observe, collect data, investigate, experiment, analyse, and then replicate the experiment under different conditions. The opportunity to collect data, for example, a "free blood test" during senior's week was what initially brought her to the integrated health service. This was when she discovered the integrated care wound clinic, and although already receiving treatment for her leg wounds from her GP, she self-initiated a referral to the clinic. I interpreted that securing the appointment was testament to Helen's personal agency, whereby she had calculated the risks and then balanced doing what she had to do with doing what she chose to do, and she took responsibility for any consequences. It stood out to me that for Helen, thinking before acting was important.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Helen and her story.

5.3.2.1 Research Focus Question 1: How did Helen make meaning of her integrated care experience?

Integrated care for Helen was about following her process of analytical reasoning. I am still unsure if it was opportunistic or carefully planned, however Helen described her integrated care experiences as providing her with what she calculated to be low risk access to clinical knowledge and expertise that would provide further data or answers to questions relevant to her personal circumstances, and her need to treat her wounds. It was important to Helen that her wounds were treated effectively, as this would mean she would be able to maintain her mobility, which she described as being integral for her well-being and social lifestyle activities. Taking into consideration Helen's studies in biology, I interpreted Helen had developed a heuristic rule overtime that organised her thinking into a connected web, reflecting an ecosystem. I have selected four codes from the first cycle coding, that reflect the unique yet connected meaning that I had interpreted from Helen's interview data.

Giving that a go

Over "umpteen years" Helen explained that she had invested considerable thinking and time into how to best progress healing and protecting her skin, she was, "experienced in being allergic, sensitive to various things". Helen had been receiving treatment from her local GP "for over 12 months". Helen disclosed to me that neither the GP nor the integrated care team knew that she was attending both of the services for treatment of the same issue. I got the sense that she was utilising the experience as part of her own healing experiment. I interpreted Helen's motivation as not ruling anything out, "give that a go", and letting the diagnostic processes determine "the right treatment".

Explaining why

Helen felt that "the GP treatment is the same, it's no different from what the (integrated care) clinic was doing"; however, what was different was that "it (integrated care) feels very individual, not standard treatment". Helen noted that her experience of integrated care had included her being asked questions, and them responding to her questions and explaining why, "they gave me the reason why I could not use canola oil instead of olive oil". Helen liked that the integrated care service was thinking before doing, "the fact that they thought of different options. What I couldn't use and what I could… To know the rationale behind [not just treating surface symptoms]". Helen made comparisons with her GP experience where she had to ask, "What was that for?". What stood out for me was that Helen's experiences were about gaining personalised data that she could then analyse and decide whether to act on. In Helen's words, "I want to know why, particularly if it's not working, I've got to do something, you know".

Directing it myself

Helen viewed integrated care as helpful; however, "I've actually been directing it myself, but all the help and advice and what to do and everything (from integrated care)". I noticed that Helen consistently described herself as making the decisions about her integrated care, including "I arranged my clinic appointment", "thought I would wait and see", and "I rang and I said to them, how to contact the nurse, what the problem was, what I was going to do". Helen shared how she preferred to plan ahead, and had a framework for weighing up risks, benefits, and consequences; ultimately, determining what was "safer" for her. Helen felt any progress in treatment was, "because of my common sense of what I've chosen to do, rather than what they (integrated care) said to do".

Not Knowing

In re-reading Helen's interview, there was a theme in that for Helen to effectively direct her health care, she needed to know how. I interpreted that the basics for Helen were information, a systematic approach, and following a process. Within Helen's experience of integrated care, she shared that there were times when she did not know information, "I didn't have a number to ring"; when she was unclear what the next step was, "I got mixed up. Couldn't remember"; when she noticed information was missing, "I had to ask them to put the PBS number on it, because otherwise if it's not there, [it] costs you a fortune"; and when processes had been changed, "They had to phone up – the results had gone to the GP – I didn't know. They don't give you the thing anymore – the report in an envelope – which was useful because you knew you had them". I noticed that Helen expressed some frustration, although seemed to be accepting. I interpreted that the experiences of "not knowing" may have contributed to her feeling that she was the one directing her care. I sensed that it was in her nature to step up and create a sense of order, where she could feel safe. Helen said, "I think being independent is a lot to do with me".

5.3.2.2 Research Focus Question 2: "In what ways did Helen perceive her experiences of integrated care were of use to her?

I interpreted that Helen's experiences of integrated care were useful overall, as she was able to translate the information provided and use this to customise her activities. This approach was aligned with her analytical reasoning processes, which contributed to her feeling safe and hence able to direct her care. The following codes from the first cycle analysis best reflect what I interpreted Helen had found to be useful.

Feeling safe

It stood out to me from Helen's interview, that when she felt like she knew what she was doing, she then felt safe. For Helen, it was useful that the integrated care service provided her with samples of cream, and she was "able to test them to see if [I am] allergic". Avoiding wasting money in purchasing, "products that you may be sensitive to" and "having a treatment plan with instructions written on it", were useful to Helen and contributed to her sense of safety.

Having a diagnosis

I noticed that Helen found it useful to have point of reference, a focus point for her planning. Helen shared that having access to accurate and historical information was useful when deciding on options or which treatment to purchase, which was why she had maintained a relationship with the local chemist "for decades". Helen disliked what she called the fishing exhibition approach. She explained that she liked that the integrated care team went through a step-by-step process of deduction, they followed their line of inquiry, investigated, which resulted in a diagnosis, "poor blood flow". Knowing the facts was useful for Helen, in that, "the fact that they thought I might have poor blood flow… and that was thinking … that was good". Helen also found it useful knowing that she could access an ongoing source of information, "I know the clinic is here, I know I have bad circulation, they have provided suggestions".

Thinking ahead

Helen shared her personal health and well-being plan, which included engaging in intentional and mindful activities. She had noticed a difference between people who engaged in these activities and those who had not, "it seems to work". Helen had enrolled in activities, "directed at health, physical health, like exercise classes or brain type things. Not just wishy-washy things. Things that you've got to think and remember, learn, like dancing, complicated coordination activities". Helen shared that her independence, which was once a strength of hers, may now be contributing to her vulnerability. She recently discovered that she liked the company of people as much as the activities and had begun building a social network. Helen was willing to take action and make changes, "[it] has made me think a bit. Think around what plans to put in place, making changes, what is safe". Her diagnosis from the integrated care team had been useful in motivating her to think to the future, "mobility definitely, especially now I know what the problem is with the legs. I think that I will gradually become less mobile".

5.3.2.3 Vignette

It is important for me to note that Helen also shared experiences that were not useful. I interpreted these experiences as undermining Helen's sense of safety and left her feeling vulnerable. In Figure 5.4 Vignette: "Helpful if I'd known", I expand on an experience shared by Helen, and my interpretations of the consequences for Helen and the impact it had on me and the questions it raised for me.

Figure 5.4 Vignette: "Helpful if I'd known".

As part of the interview, participants were asked to think about when they were self-managing at home, and what they found to be useful when something unexpected happened or if they were worried about their health (related to integrated care treatment).

In response to this prompt, Helen shared her experiences from when she was at home and felt uncertain in what to do about her integrated care treatment and was looking for reassurance from the service. Helen explained that following her first appointment, "I got this allergy problem with this stuff, what should I do?". Completing her own risk assessment, she decided "it's not important" and waited till the next integrated care appointment in two weeks.

Following her second appointment, she went to the chemist to fill the prescription provided by the integrated care staff, the chemist was unable to provide the prescribed cream and recommended an alternative. Helen's next appointment was in five weeks' time. Helen, who now had a contact number for the integrated care unit, rang to advise them, "I'm not using what you think I am using". Helen explained to me,

> *"They (reception) just took my details and where they could contact me if I wasn't home. I provided my daughter's details because she is home all day. It would have been helpful if I'd known that they (integrated care staff) knew. '[We] got your message, you're doing the right thing'. I haven't heard back. They were either satisfied with what I said. The fact [is] I don't know. I don't know if they got the message. My skin was improving, I thought 'What could I do'?".*

Helen expressed frustration that the integrated care processes had left her not knowing, and her own plan of providing her daughters contact details had also not worked. She said she just wanted to know they knew; she was happy to self-direct her treatment.

With humour, Helen went on to share that the integrated care unit did contact her for feedback on the senior's week event she attended, wanting to know if it was useful. Helen expressed surprise that they did not know that she had been attending the clinic. Helen responded to them, "Yes, I've gone to the clinic. I thought, 'I've already been twice already'. I said it was useful and all this kind of thing. I told them [about not getting the call back], they said 'Oh that's useful feedback'".

At the time of our interview, Helen had still not received a call back, yet she had noted that the integrated care clinic now displayed posters which had a direct number to the integrated care clinic on them, which she saw as an improvement. However, in the interview, Helen continued to question her own thinking and actions, wondering where she could have improved her own processes. Helen said,

> *"It would have been reassuring to know that they knew what I was doing and it was OK to do what I was doing, because it was all like what I decided to do? 'Maybe I should have?... but the fact the skin is improving ... I thought 'well there's nothing more I can do. Its working fine. Its fine'".*

Helen then described how her thinking expanded, she had somewhat accepted that she was fine, that she was safe, she was now wondering and worrying about others who were not as experienced with allergies as her. What would they do in these circumstances?

Helen also started to consider some of the risks and consequences of the approach she had taken to concealing her visits to the integrated care clinic from her local doctor,

> *"…other people who haven't been used to these things [being sensitive]. It would have been a bit disconcerting 'What do I do?' Go to the GP and the GP would have thought 'Well it's not my treatment.' [So] what do I do?'".*

I chose this as a vignette, as I found Helen's story to be thought provoking. Helen was generous in sharing what she was thinking and feeling during her experiences of uncertainty. In my earlier conversation with Helen, she had shared how she had refined her reasoning skills over time and was confident in self-directing her integrated care treatment at home. In knowing what she was doing, she felt safe.

Yet the unplanned events, and unmet expectations Helen described had challenged her processes and threatened her confidence. I interpreted that Helen's decision-making model depended on access to trustworthy, reliable information. One mechanism of ensuring reliability was seeking input or feedback relevant to her personal circumstances from an expert or trusted source that her reasoning and actions where reasonable – a feedback loop. Without access to this, Helen could not test her thinking, which put her at risk of error or waste of resources.

This surfaced emotions for me. I could imagine Helen, at home alone, thinking about her dilemma. Confident in her assessment, yet aware of her possible bias and that there may be some additional data she was not aware of. Considering the consequences, "I will be fine" she tells herself, while at the same time asking herself, "Will you be fine?" What arose for me, was that in the absence or failure of communication systems, it is amazing how quickly a confident person can be destabilised. Helen was trying to compensate for the failure, going through loops processing her thinking, actions, and possible consequences for herself, her GP, and for others.

I had the impression that if Helen had not been setup to expect she could contact the integrated care service, she would have established her own mechanism of testing out her thinking and actions. There was a sequence of errors, not getting the call back about something important to her, when she had increased the probability in giving her daughters number, then the irony of receiving a follow-up call asking Helen to provide the service with feedback about something that was important to the health service's planning.

Through the lens of patient safety, this scenario had potential for harm for Helen and could be considered a patient safety system error. Helen's sense of safety was compromised, as she did not know what to do, and future confidence or trust in the service could also be compromised.

I then also reflected on the integrated people-centred health service's framework, questioning whether the person should be at the centre, or should it be a web of reciprocal independence? I appreciated the concept of shifting the power dynamics, but questioned whether for power to be *legitimate, does it have to be exclusively held by one group or another? Whose needs matter most, take priority, when each stakeholder was leading in their own domain, the individual living at home, the integrated care service, the GP, or even the family? If Helen had given up some of her power or control in sharing with the GP and integrated care that she was seeking treatment from both, I imagine her experience would have been different, maybe not necessarily better. I was left musing; "How can it be made safe for everyone to put their power aside?"*

5.3.2.4 Research Focus Question 3: How Helen Evaluated her Experiences of Integrated Care and Why?

A unique characteristic I noted of Helen was her awareness and openness to sharing her processes of analytical reasoning. Evaluation was embedded within this thinking model, it influenced her thoughts and actions. The Table 5.5 below presents what I interpreted as being important to Helen from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.5: How Helen evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
My thinking and actions will result in benefits for me. **Why?** I am analytical. I like to calculate, I like data/evidence. I am being responsible. I am not wasting my money or time.	**Self-assessment** Test/compare against personal theory. Compare against data observed from others – reliability/replicability. Feeling responsible – I have avoided possible consequences. I have kept safe
I have received a "good" diagnosis. **Why?** Decisions are more robust if they have followed a structured scientific approach. I need facts and data that is able to be stored and drawn on later.	**Self-assessment** I can see evidence of a systematic approach. Data in storage – accessible/benchmark Self-assessment I feel confident. I have a level of certainty.
I know what I have to do for me going forward. **Why?** My circumstances are unique. I can do this myself.	**Self-assessment** Relevance – My plan and options are personalised to me. I can do this myself

5.3.2.5 What is This a Case of: Interpreting the Implications from Helen's Account of her Experiences

The research's overall framing question was *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have* *experienced it?* From immersing and reflecting on Helen's interview transcript, I interpreted the meaning of integrated care was at its essence, a calculated risk and investment, it was very personal. I felt that it was significant for Helen that she was at the centre of her experiences, she was the investor, designer, driver, and implementer. I sensed that for Helen, this was about the actions she needed to take now to set her up for the future she was predicting. I interpreted that the most important purpose her integrated care experiences served was to give her confidence that a rigorous and scientific approach had been taken, that she had access to reliable data for planning now and in the future, and she had a contact for when required in the future. The metaphor that came to me, when thinking deeply about what was the essence of the story that Helen had shared with me in the context of this research, was "process is reliability".

5.3.3 Gloria's Meaning and Experiences of Integrated Care: An Interpretative Account

Replicating the format used to present the previous participants findings, re-presented below is an interpretive account of Gloria's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Gloria's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Gloria's attribute coding, Table 5.6, provides a general descriptive introduction to Gloria and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Gloria's first cycle coding is included in Appendix L (see Table L3: Gloria's Experience of Integrated Care).

Table 5.6: First cycle interpretative findings: Gloria's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Gloria (G)	Date: May 2017 Location: Diabetic Clinic Transport: own car Interview length: 57 mins	70–75	Female	Own home, alone with dog	Retired registered nurse	Art (painting), visiting friend in aged care facility, attending art exhibitions	Orthopaedic (specialist). Inpatient referral extended to outpatient	Approximately four months as an outpatient	Wound Clinic	GP, rheumatologist, orthopaedic

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Gloria's words with my observations and sense making. The exert below from my research journal (Figure 5.5) gives insights into how I was gradually making sense of Gloria within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.5 Researcher's Journal Excerpt: Getting to know Gloria.

While listening to Gloria talk, I noticed her to be of medium height, a large-framed woman. She described herself as having significant mobility issues; that she used two walking aides. Gloria apologised many times about being late for our interview and talked about the challenges of getting from her home to the car, and then to the clinic. Gloria explained to me that the multistorey staff and visitor car park was not suitable for her, as she was not able to manage the incline up the driveway or the pedestrian ramp. Gloria seemed grateful that the integrated care staff had negotiated for her visits to be held in the Diabetic Clinic, which was where we were sitting. Gloria liked that the clinic had a signposted disabled car park directly outside the building that could be reserved with hospital security for her visits. The Diabetic Clinic also had a wide and secure chair with armrests that Gloria could use to aid her in getting up from the chair.

During the interview, Gloria described herself as being in her early seventies. She talked proudly about her many years working as a nurse in the emergency department of a large teaching hospital. Gloria now lived alone with her dog. She said her circumstances were complicated. She bought her friend's house so that she could afford to move into a nursing home. Gloria sold her home and farm to buy the house. On what she thought to be a positive note, she now had money to buy a 4WD car that would be easier for her to get in and out of. She has also purchased an electronic scooter, which is still in the box at home. Gloria said that she visits her friend regularly at the nursing home. She also liked to paint and had an art studio at the back of her home; however, she rarely went there now.

In reflecting on Gloria's interview transcript, what stood out to me was that she seemed to have this unique ability to assess a situation, the people, and resources she had available, and then put a plan into action to achieve her desired results. In the context of her integrated care experiences, the story that I heard Gloria tell featured intentionality. Gloria recounted how she had tapped into the integrated care wound clinic expertise as a way of progressing the healing of her leg ulcer, so she could then have hip surgery. I could imagine Gloria, as she had described to me, running a busy hospital emergency department. What was unexpected in getting acquainted with Gloria was how vulnerable she felt. Her sense of vulnerability drove her to be more creative, and made having a sense of control and a plan in place, all the more important for her.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Gloria and her story.

5.3.3.1 Research Focus Question 1: How did Gloria make meaning of her integrated care experience?

Gloria described her integrated care experiences as being a critical link in a system of connected consequences. I came to appreciate that for Gloria to engage in the everyday living activities she enjoyed, she needed to reduce the pain she experienced from her hip, which meant having hip surgery, which she was not eligible for until her leg ulcer healed. Gloria shared that when she was introduced to the expertise of the integrated care wound clinic when she was an inpatient, she quickly recognised that this was what she needed, and directed all her attention and creativity to making sure she would gain the greatest benefit from the expertise available to her. From the first cycle data analysis, the following two codes stood out.

We have a thing

In describing her integrated care experiences Gloria was clear that she had "thought it through", deciding that the knowledge and expertise of a particular person within the integrated care service was what she needed access to, and she went about "setting things up". What was important to Gloria, what she was protective of, was that she shared a "thing" with the nurse. I interpreted this as mutual respect, that Gloria was responding to the way the nurse, "describes to me, explains, he asks me, I have a say". She was a co-contributor in her care, "When making changes he'd say, 'how did that feel?'. He'd ask, 'Was that alright last time'". Gloria reciprocated respect through not allowing anyone else to touch her dressing, "You're not touching it, I'll go home".

I know what's going on

I interpreted that her integrated care experiences provided Gloria with access to a trusted, knowledgeable expert who explained her wound care and provided updates on progress, which then enabled her to confidently plan ahead in what she should avoid and where she should invest and prioritise her time and effort. She explained that her experiences of integrated care meant that she was not going ahead "blindly", rather Gloria felt, "you know what you're saying yes to". Gloria felt she needed to be accountable for her actions, "I won't take anything or do anything unless I know what's going on". Gloria appeared to have confidence that her health care professionals "knew" information, even though she was not aware of them talking to each other, "They (GP and clinic) haven't talked, but they know". What stood out to me from her interview was a growing sense of uncertainty as to whether Gloria's need to know what was going on was as she had said, for planning her care needs. Or was it for monitoring the care she was receiving, or perhaps even for mitigating risks and compensating for the gaps in communication between health professionals that she was likely aware of as a previous healthcare professional. What was clear, was that for Gloria, her experience of integrated care was aligned with her philosophy, “I manage to do things”, this was her workaround to achieve her health goals, “if you think things out you can usually get around it”.

5.3.3.2 Research Focus Question 2: “In what ways did Gloria perceive her experiences of integrated care were of use to her?

I interpreted Gloria’s experiences of integrated care to be of use, as they contributed to her methodically planned strategy to achieve her timeline for hip surgery. Although Gloria was deliberate and projected practical confidence and self-belief in her thinking and actions, she also projected an awareness that she could not achieve her health or life goals alone. What I interpreted to be of most benefit to her, was to have access to a trusted network of people who she could rely on when needed. The following codes from the first cycle analysis best reflect what I interpreted Gloria had found to be useful.

Finding comfort from pain

I would describe Gloria as essentially pragmatic, she knew and accepted that she would experience pain during the healing process. What was useful from her integrated care experience was an explanation as to what she should tolerate and when she should act when at home. “When the dressing is done well – Does it hurt? Of course, you can feel it – sometimes the treatment can sting for 24 hours. I know when the integrated care nurse puts it on, that it will settle and its comfortable”. Gloria shared how the pain she experiences from her wound and her hip impacted adversely on all aspects of her life, including her sleep, diet, daily living, and social activities, “I[‘ve] got to get this hip done because the pain is horrendous. I yelled with pain”. Finding comfort from pain, even for a short period, was a practical need for Gloria.

Setting things up

Being able to have her say in her integrated care was of use to Gloria, as she needed to ensure that any plans that were set up, so she could, “do it myself”. For Gloria, what stood out to me was that independence was a reality not a choice, “It’s not about being independent. I have to be independent because I haven’t got anybody”. Gloria knew that “if needed, I would ring the integrated care clinic. I have their numbers”. This plan was also useful, as it was practical and similar to other fail-safe systems that Gloria had established and had confidence in, for example “my neighbour puts out and brings in my garbage. If he hasn’t seen me, he comes in. If the back door is open, he knows I’ve got[ten] up and I’m ok. If [it’s] not open, he will come looking for me. If I fell, I may have to lie [there] for a couple of hours, but I know someone is going to come".

Knowing them

Gloria was very aware that, "I don't have a family that are going to help me". I interpreted that she countered this, by making it her business to, "know them [clinical staff] all". She shared how she intentionally and strategically used these relationships, an example she gave was, "When I was in hospital last time, I asked, 'At discharge what do I do?' The doctor replied, 'If you would like, you can come to my clinic'. [I said] 'Yes, I will'. [It] gives you a leg in, I don't hope to go there, but you have to be practical". Gloria's experiences of integrated care were deemed useful, as she perceived the people and the processes were practical, reliable, and safe. I interpreted that this gave her confidence that if she called on them, they would respond.

5.3.3.3 Research Focus Question 3: How Gloria Evaluated her Experiences of Integrated Care and Why

From the experiences and meaning that Gloria shared, I interpreted that evaluating was part of her everyday living, it was part of her way of being and thinking. Table 5.7 below presents what I interpreted as being important to Gloria from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.7: How Gloria evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
I've everything set up – I'm OK. **Why?** I can do it myself.	**Self-assessment** I can implement my plan effectively. I am confidence/feel peace of mind. I can call on trusted people when needed. I have strategies in place that have or will prevent or avoid complications or inefficiencies. I am on track – progressing towards my timelines and goals. My pain is tolerable/level of comfort.
I know what's going on. **Why?** I have access to knowledgeable explanations and reliable information that I can use to monitor my progress and adjust.	**Self-assessment** I have a say – I feel included. Proven reliability of information sources I feel a level of certainty that I understand what I need to do (knowledge transferred from the expert to Gloria) The data is useful for my timeline/plans. My level of pain/comfort experienced.

I have access to what I need. **Why?** I have to be independent. I am not a burden to others – put extra stress on others. I haven't got a lot. I've got a few dollars.	**Self-assessment** Comparison to previous health experiences and experiences in healthcare Access to parking Able to access people/information. I have invested wisely. I can visit my friend and engage with social interests. Level of pain/comfort experienced

5.3.3.4 What is This a Case Of: Interpreting the Implications from Gloria's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Gloria's interview transcript, I interpreted that the meaning of integrated care was personal, it was about what she needed to access or protect in order to manage her health and everyday living needs, while also seeing it as an important relationship for her future independence. I interpreted that the purpose her integrated care experiences served for Gloria were assurance and hope. She expressed confidence in that she was doing everything possible to achieve her timeline, and that her approach was effective. Gloria's hope was that she would be able to integrate the service into her professional network so that she could call on them in the future. The metaphor that came to me, when thinking deeply about what was the essence of the story that Gloria had shared with me in the context of this research, was "vulnerability is fuel".

5.3.4 Lucy's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Lucy's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Lucy's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Lucy's attribute coding, Table 5.8, provides a general descriptive introduction to Lucy and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Lucy's first cycle coding is included in Appendix L (see Table L4: Lucy's Experience of Integrated Care).

Table 5.8: First cycle interpretative findings: Lucy's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Lucy (L)	Date: Oct 2017 Location: Integrated Care Unit Transport: own car Interview length: 69 mins	60+	Female	Own home, with husband	Retired librarian	Reading, regular exercise, social activities, volunteering, two daughters	Self-referral (recommended by family)	Visited three times over a 4-month period	Skin Cancer Clinic	GP had retired –now did not have a regular GP

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Lucy's words with my observations and sense making. The exert below from my research journal (Figure 5.6) gives insights into how I was gradually making sense of Lucy within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.6 Researcher's Journal Excerpt: Getting to know Lucy.

From the beginning, I noticed that Lucy appeared relaxed and familiar within the interview environment. She described herself as an active 60-plus-year-old woman. Lucy explained that she had lived in the area with her husband, and two adult children who had now left home, for many years. She still met regularly with friends that they had in their 20's.

Lucy described herself as a thinker. During the interview she recalled fondly her long career as a librarian. Reading was still a large part of her life. Having "always been an avid reader", Lucy happily browsed through books, taking away information that interested her. Lucy was confident in her ability to discern the "authenticity" of what she read, and whether "it is academic". Lucy shared that at times she could be cynical, that she was happy to discard or dismiss "what she thinks is rubbish". Lucy shared as an example that she, "may visit a doctor with what I think may be a problem, and then decide not to go through with the advice". Lucy had not had any significant health problems, she described herself as relaxed towards her health, "maybe even a bit lazy". She felt she accepted "what is thrown at her", with a tendency to wait until things happened and then "react and panic". She was currently paying attention to keeping physically active, motivated by her 93-year-old mother who had limited mobility. Lucy believed her mother's lack of regular exercise contributed to her immobility and wanted to avoid the same fate.

In meeting Lucy for the first time, what stood out to me during the interview was the way in which she introduced herself and how she created an impression of being a relaxed and assured woman. Lucy shared with me that she had gradually lost confidence in her usual health provider's quick assessments during her regular skin cancer screening, so she had sought out the integrated care service on recommendation from relatives and friends who were health professionals. When describing her thoughts and experiences, I noticed Lucy would refer to her past experiences, and then use these to situate what it was like for her now. I would describe this as an active process of reflective reasoning, whereby Lucy was coming to realisations or connections in the moment. I also noticed that this meant her responses seemed tentative, rather than being absolute. Lucy shared that she was a retired librarian. Throughout the interview, I noticed Lucy had adopted critical thinking skills into her everyday life. On first impressions Lucy presented as both self and emotionally aware. Lucy described herself as a self-confessed cynic.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Lucy and her story.

5.3.4.1 Research Focus Question 1: How did Lucy make meaning of her integrated care experience?

Lucy described that she had noticed, that for her, her sense making processes tended to start from a place of "cynicism". She had found that she would then process her experiences through a series of mental deductions and observations where she did not rule anything out until she had thoroughly examined it, discarding irrelevant information (or in Lucy's words "rubbish') along the way. Lucy said that a legacy of being a librarian for many years and now retired, was that in one way she felt confident in her ability to assess whether information was "authentic"; in another way, she was cautious of being biased and would critically question her own judgement. These thought processes showed up when Lucy appraised her experience of integrated care and then challenged her own assessment, "but has that [confidence] come because they actually found something. They did take the time. They did find something. Or is that co-incidental?". Lucy identified that she had family and friends who were health professionals and she expressed trust in their knowledge in saying, "they know best". Lucy somewhat light-heartedly referred to herself as "a bit crazy", which I interpreted as Lucy expressing less confidence in her own judgements. Lucy shared that she had found that her head would say trust the doctor, while her "sixth sense" instinct was to question or not follow the Doctor's advice immediately, but "dwell" before acting. From the data analysis, the following two codes stood out from the first cycle analysis.

Making decisions

Following the recommendations of people she trusted, Lucy self-referred her initial visit with the integrated care skin cancer clinic. Lucy was given the “all clear”; however, in-between visits, “someone said ‘what’s that?’. At home I looked and thought ‘There is something there’”. Lucy said that her next appointment was six months away, and so she began to worry, “I’m feeling that I’m being over cautious, worrying about being silly about it”. However, she also remembered that at her last visit they had said to her, “We don’t expect to see you, but you’re welcome”. Remembering this gave Lucy the confidence that the integrated care service would welcome her to self-initiate contact. Lucy said it was this statement that had informed her decision to make an appointment.

Lucy also described in her interview the ways in which she guided and negotiated her treatment, she said, “There were a few areas I thought were problematic. I asked if they might be able to check and remove [them]. In the end we negotiated a bit, and they did take it away”. I noticed that this experience was significant for Lucy, it aligned with how she wanted to be seen by others, “I don’t want to be seen as one of those worriers who turn up on the doorstep everyday… It comes from how you want to be seen. I know they probably don’t remember you from a bar of soap”.

Reassuring

Lucy described in her interview how she likes to learn through observing other people’s behaviours, she said, “I watch people, try and take on board – I can do that”. Lucy expressed the view that other people “anticipate” and are “active” regarding their health, while she is “fairly relaxed”. Lucy explained that she likely takes this approach because her, “health problems have been insignificant”, therefore she could afford to be “laid back” and “go with the flow”. In contrast, Lucy had noticed that if a health problem is identified, her first reaction was to “panic”. In reflecting on her experiences of integrated care, it was important to Lucy to feel that her, “doctors, for whatever you’ve been there for, that they have done their job thoroughly”. To Lucy this meant, “you are probably safer”. It was also reassuring to Lucy that the integrated care staff explained, “Look, we’ve really had a good look. There’s nothing there”. I interpreted that this was reassuring for Lucy, as rather than worrying and playing it over in her head, “that there’s much worse than it really is”, she more likely able to, “relax and forget about it”. I also had the impression that in Lucy knowing she could “come back”, this also bolstered her confidence.

5.3.4.2 Research Focus Question 2: “In what ways did Lucy perceive her experiences of integrated care were of use to her?

Lucy described her experiences of integrated care as having a profound impact on the way she was making decisions and behaving. The following codes from the first cycle analysis best reflect what I interpreted Lucy had found to be most useful.

Being Proactive – protecting skin (self)

The message that Lucy recalled as taking away from her integrated care experiences was, “the very important need to protect my skin”, which was supported by “the fact that they could see that I’ve got plenty of sun damage”. I interpreted that this information was useful for disrupting Lucy’s usual pattern of thinking and behaving, “I’ve always been aware, but I’ve been lazy. So it’s taken away that laziness feeling and that – it’s not a kind of ‘it won’t happen to me’ thing, but maybe it’s probably just you can’t go flat chat and don’t bother [laughter]. So I need to be much more careful”. Lucy reflected that she did not “know why” this experience had “brought” it home for her. Lucy described how she has changed her behaviours, in that before she goes out for the day, she “applies sunscreen” and was “also wearing a marvellous little hat”.

Taking preventative action – protecting family (others)

Lucy described how her experiences of integrated care had helped her to “feel OK” about acting on her worries. Lucy said, “I now anticipate that it could be something – [I] go and do something about it. I’ve actually learned that it’s OK”. Lucy said she had also found herself advising others to take preventative action, she said “that’s new”. For example, Lucy said “I’m also yelling at my husband, who rows”, that, “before I didn’t care. That was his business, but now I’m saying ‘You[‘ve] got to do it. You’ve got to’”.

They know who you are

It is my view that Lucy’s experiences of integrated were useful because she knew she could “go back if needed”. I had the impression that she believed that if she came back, she would not be labelled a worrier. Lucy had shared how she felt it was important to have, “some sort of continuity with your history, so that they have some sort of background of who you are and why you are”. Lucy said that she no longer had a regular general practitioner; her usual doctor was the same age as her and had recently retired. She shared that she was not good at building relationships, which I interpreted as meaning that she did not feel confident about finding the right person for her. Lucy said, “you’ve got to click with someone. I still don’t. If someone said, ‘Who’s your doctor?’ I would not have an answer”. Lucy worried that in the future she would have “a whole range of issues” like her 93-year-old mother, which she wanted to avoid. Lucy predicted that avoiding spending hours “visiting doctor surgeries” and “keeping away from mental health services or knee operations” to be the most important in regard to her future health. I interpreted that feeling it was ok, “that you can go back”, was a positive and anticipatory framing of her desire to avoid health services in the future.

5.3.4.3 Vignette

During Lucy’s interview I was impressed by the observations and provocative insights she shared with me about health, health services and society in general. In Figure 5.7 Vignette – Times are changing; Are health services? I attempt to summarise what Lucy raised as opportunities and challenges during our interview, including my interpretations, the impact it had on me and the questions it raised for me, in the context of integrated care.

Figure 5.7 Vignette – Times are changing; Are health services?

Lucy was fairly adamant that she approaches most situations from a cynical viewpoint; while I interpreted that she took a critical viewpoint. Lucy’s preference was to think, which she sometimes called worry, before doing. Lucy also tended to use comparisons to describe her experiences. With this in mind, Lucy raised some insightful and challenging questions when sharing what she had noticed was a problem or opportunity for improvement.

For example, Lucy was curious as to whether the health system was fit for purpose for her generation, who she had noticed to be healthier, in contrast to her mother’s ill-health needs. She was worried that “change takes time” and what would be required to “prompt change” so health services would be more relevant for her circle of fit and healthy friends. Lucy felt her generation and her children’s needs from a health service were “totally different” to how they were set up now. Lucy had observed that her friends were “not using the health system” and was wondering if in not putting demands on the health system for change, there would be less motivation for change.

Lucy had also observed health and social inequities, acknowledging the privilege of her own social and demographic circumstances, that in essence she was “protected”. While she had noticed when visiting other suburbs, who “don’t have the accessibility” to healthy lifestyle options as she had, and she shared concern for their increased vulnerability for experiencing “obesity and diabetes”.

From what Lucy shared with me during the interview, I believed that Lucy would dwell on these insights; however, she was also ready to act if invited. Lucy would be a valuable asset to any community group looking to improve local health services. She said that she was not aware of any opportunity to engage in service redesign or improvement discussions with the integrated care service; however, she was involved in her community as a volunteer helping mothers and babies in crisis, which she said was “much more exciting than she ever dreamed of”.

I found Lucy’s observations and thoughtful consideration to be provocative, in that everyday people were noticing that the current system appeared to be based on addressing ill-health, rather than the promotion and protection of health. This raised for me that most health service *improvements were based on feedback from patients and carers who had used the service, rather than from people who were not, or may in the future. This likely biased what people raised and reinforced the status quo, rather than promoting change. Lucy's observation and concern about the health inequities defined by a person's post code were poignant and left me with a feeling of hopelessness in how to disrupt this cycle of failure in protecting the health of our more vulnerable groups. Yet, I was also inspired by Lucy's thoughtful and considered observations and questions and was left wondering how to help Lucy's voice to be heard.*

5.3.4.4 Research Focus Question 3: How Lucy Evaluated her Experiences of Integrated Care and Why

The Table 5.9 below presents what I interpreted as being important to Lucy from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.9: How Lucy evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
I am taking action. **Why?** I realise it's important to anticipate and protect my health. I am actively avoiding further, or future, ill-health that requires medical care.	**Self-assessment** I am doing what I see others are doing. I am having regular checks, rather than waiting. I am initiating preventative action for self and others. I am not seen as a worrier who turns up on the doorstep every day. I know I can choose to go back if there is a problem or a need. I feel they know me.
I am making decisions. **Why?** I have what I need to make considered decisions/choices about my health.	**Self-assessment** I feel confident in their (health professionals) assessment – "good hearing". I feel like I am involved, I have determined or influenced decisions about my health care. I have assessed (using librarian skills) quality of information (or if I think it is rubbish). I'm not being over cautious, worrying about being silly.

5.3.4.5 What is This a Case of: Interpreting the Implications from Lucy's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Lucy's interview transcript, I interpreted that her experiences of integrated care disrupted her thought patterns in how she was making sense of her “worries” and taking a “lazy” approach to health. Hence the meaning of integrated care for Lucy was that it allowed her to reframe her thinking, which lead to her taking action rather than worrying that she was “being silly” or that she would be seen as a “worrier” by others. It is my view that Lucy’s integrated care experiences served to shift her towards adopting a more proactive and preventative mindset and behaviours that protected her and her family’s health. It was significant for Lucy, that she felt ok about how others would see her, and that she could see that accessing the integrated health service was a way of achieving her vision of avoiding health services in the future.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Lucy had shared with me in the context of this research, was “anticipating is avoiding”.

5.3.5 Darren’s Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Darren’s meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Darren’s interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Darren’s attribute coding, Table 5.10, provides a general descriptive introduction to Darren and his everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Darren’s first cycle coding is included in Appendix L (see Table L5: Darren’s Experience of Integrated Care)

Table 5.10: First cycle interpretative findings: Darren’s attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Darren	Date: Feb 2018 Location: integrated care unit Transport: own car (travelled 120km) Interview length: 49 mins	35–40	Male	Lived with father in family home	Part-time, university qualified	Visited mother in aged care	Plastic surgeon referral (specialist)	Attending for six months	Wound Clinic	GP, pharmacist, specialist gastroenterology

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Darren’s words with my observations and sense making. The exert below from my research journal (Figure 5.8) gives insights into how I was gradually making sense of Darren within the wider lifeworld he was describing to me, and how I tried to re-construct and connect the pieces to his integrated care experiences, as the interview progressed.

Figure 5.8 Researcher's Journal Excerpt: Getting to know Darren.

In starting off his interview Darren shared that he was in his late thirties, and he appeared proud in stating that this was the hospital where he was born. He shared his observations that there had been recent changes made to the hospital campus, and his concerns about groups with different agendas who he believed were not really thinking about what was best for the safety of the community or whether they could afford the car parking fees. He shared some of his thoughts as to how to improve pedestrian safety, such as installing a speed camera or establishing a "health precinct" 40 KM zone similar to the school zones.

Darren explained that he was living with a chronic disease, being diagnosed in 2000. He was familiar and confident with accessing treatment and support services, such as community nursing, and in accessing products and supplies online. He said that he had been giving thought as to how to ensure the integrated care service was both efficient and effective. Darren reflected on how important a "really open, communicative relationship" was for his treatment and psychological needs. Darren believed that "the mind needs the body to work, and the body needs the mind to work".

Darren was emotional when explaining how his medical conditions had impacted on his financial situation. Darren said he had studied at university and was now working part-time, as he required days off work to attend to his medical needs. He had to leave the local area and was now living in a regional area with his parents. Darren explained that he had travelled 120km that morning.

Darren had tears in his eyes as he shared that his mother was now living in an aged care facility, since experiencing a head injury following a car accident a couple of years ago, and he felt pleased that he could be close by to support his father. Darren still visited his local family general practice, commenting that his usual doctor was preparing for retirement, and that he had begun forming relationships with other doctors in the practice. He had also created a profile on the myGov website and given permission for his medical records to be placed there. Darren explained this would mean that his medical records were "easily and immediately" available.

From my initial acquaintance with Darren, I had a sense of a calculated logic in how he approached his everyday life. Darren was open to sharing the thinking behind his thinking. I did not feel like Darren was attempting to control the interview or be deceptive; however, I did get the impression that Darren was influencing our situation to ensure it would best serve his needs and was within his capabilities. The journey to being enrolled with the integrated care wound clinic that Darren shared, also came across as being carefully considered and goal driven, with facilitating the healing process and ensuring the effectiveness of the treatment being the objective. Darren demonstrated his awareness of the risks and his confidence to ensure the right conditions are in place to achieve his goals. He said he had taken pre-emptive actions in self-initiating contact with his “gastroenterologist about the [wound clinic] treatment, and they [gastroenterologist] suspended his treatment [the medication he was taking] so that it can be sort of weaned out of the systems, and hopefully, in that respect, it [his wounds] would start to heal a little bit quicker, which for all intents and purposes, it has. I find that my wound now is healing up quite well”.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Darren and his story.

5.3.5.1 Research Focus Question 1: How did Darren make meaning of his integrated care experience?

Within the interview, Darren described his approach to meaning making as “methodical”. I noticed that Darren tended to order and prioritise his thoughts, expressing his greatest need and then others in sequence. He gave many examples of how, in different aspects of his life, where he researched and critically considered the information available and then calculated the risk, followed by taking planned action. Which he would “follow to the “T”. This approach did not mean that Darren was close-minded to new information or learning new skills. He said that he was very prepared to be taught and coached with the goal of improvement, which he took to mean the healing of his wound was progressing. Several times Darren referred to “information as key”, and he described how he was strategic in building relationships with his healthcare providers. He referred to each of his healthcare providers by name. He described these relationships as being key to securing access to the “experts” knowledge. From the data analysis, the following codes stood out from the first cycle analysis.

Being prepared

I interpreted that Darren accepted that it was his responsibility to be prepared to “ask questions”. From Darren’s perspective, “it’s pretty much all you can do because when someone has been diagnosed or having something, they would want to know as much information as they can”. I understood that this meant for Darren, that he did his homework, research related information, and framed his questions in advance of his visit to the wound clinic. Darren talked about being “100% committed” to taking responsibility for organising his availability and time, “to get to where you need to go”. Darren repeated that he was prepared to “play his role”, and he was open to being “educated and coached”.

Darren critiqued the wound clinic administration processes as being, “pretty straight-forward. It’s very easy to understand. There was no ambiguity about it at all”. This gave him confidence that the clinic was prepared, which would minimise the likelihood of delays or mishaps. He also noted that the clinic had provided him “with supplies and everything else that I needed” so that he was prepared to self-manage when at home.

I interpreted that Darren held the expectation that the integrated care staff were “highly qualified” in their field, in that they were prepared and able “to answer all and any of the questions” that he may have, when he needed them to.

Balancing support and service

Darren used his step-by-step approach to break down and share with me how he made sense of his experiences of integrated care. He said that at his first visit he saw the nurse who “looked” at the wound and “suggested” what to do, “so that when I come back here for my second visit and see the doctor, they’ll be able to do a little bit more of a thorough examination and see what type of treatment that we continue on with”. Darren said he then “came back about a month later to see the doctor”. He appraised his second visit in saying, it “took me about 45 minutes, which was a reasonable amount of time just to feel comfortable in the area, which I did feel overwhelmed with so much information, but at the same time, I felt like that I had received this much support and service about treating the wound and speaking to someone about it. So the balance there I thought was quite good”.

Being aware

Darren would reference his feelings and the emotions he had experienced, from sadness to laughter, during the interview. He shared that he did feel anxious on his first visit, that he had “a lot of thoughts going through his mind”. However, he was able to find peace of mind in knowing he had access to a professional “who knows the job inside out, upside down, back to front” and who could provide the information in a way that he felt he knew “what was going on”. I interpreted Darren as being self and emotionally aware. In describing what he called the crucial element of his experience as being, “knowing that someone is there to help … and they know what they’re talking about”, I understood this to be Darren sharing his awareness of his vulnerability in being dependent on others, and I also interpreted this as underpinning his efforts to control his circumstances.

Being disappointed

“To get the end result, making sure that I’m healed” was Darren’s “ultimate goal”. He stated the belief that the most “efficient” way of getting there was if everyone played their role.

To Darren this meant being thorough and disciplined, it was not “a matter of magic, or luck, or anything like that”. Darren had assessed who needed to be responsible for what, in his view, “the healthcare professionals need to give me the correct information, so that I can undertake the correct methods of treating and managing my wound, so that the best possible outcome is achieved. So, 50% is on the clinic. The rest of it’s on me”. I understood this along the lines of a social contract. I am not sure how explicit Darren was in sharing the philosophy he described with the integrated health service.

Darren shared his experience of being “quite disappointed to be honest” by the integrated health service. Darren had discussed pain management on his second visit and was given a recommendation for medication on a letter head which he took his pharmacist. At this point he “found out that it was a narcotic, I needed a prescription. The pharmacist said, ‘I am not going to give you this’”. Darren then went to his local GP who “was not impressed”. The GP informed Darren that “the doctor prescribing should prescribe. That it was potentially highly addictive and risk of subsequent problems”. I interpreted that for Darren, this experience meant the qualified professionals had disappointed him, their process was found to be unreliable. I had the impression that he felt exposed and placed at risk. I imagined that his trust in the integrated care team would be likely threatened and that this may cause him to feel less confident or question the “correctness” of other aspects of his care. Darren stated he had not yet provided feedback to the integrated care team but was intending to at his appointment later in the day. This suggested to me that Darren felt safe to do so, or as Darren expanded on later in the interview that he was working on adopting a mindset of acceptance. This related to self-awareness, where he accepted his imperfections and practiced mindfulness. However, I am not certain that he was accepting imperfection from his health professionals.

5.3.5.2 Research Focus Question 2: “In what ways did Darren perceive his experiences of integrated care were of use to him?

In context of Darren sharing his disappointment during the interview, with his experience of the incorrect prescribing process, he maintained a strong belief that the information existed that would assist his wound in healing, that he just needed to diligently follow the instructions provided by the experts. That he had to accept his circumstances and stay focused on doing what he believed to be best. This was seen as useful as it would ensure he was “on track” and would guide his calculations of his progress and any risks. The following codes from the first cycle analysis best reflect what I interpreted Darren had found to be most useful.

Having instructions

Darren expressed a certainty that there was a “correct” way to care for his wound and that he could be “trained” to do it. The instruction guide provided by the integrated care clinic “was probably the most useful” for Darren. I interpreted that it gave him the assurance that he could check and make sure he hadn’t “skipped a step”.

Having what I need

Having ready access to supplies and information were useful to Darren, as he was confident from his previous positive experience in caring for his colostomy and stoma that he could self-manage and be resourceful. He expressed a strong self-belief that he could be educated in wound care, and if he had the correct search terms or knew which sources were reliable, he could do his own research competently.

Keeping health manageable

Darren described himself as holding a “holistic perspective” and believed that his life and health were in “symbiotic relationship”. As the interview progressed, I developed an increasing appreciation of the precision and control I had noticed when Darren and I were first getting acquainted. I now respected that he had critically analysed what he could not tolerate, for example “I can’t afford to get sick; I can’t afford to have little mishaps like this happen on a frequent bases”, and that in response he carefully “managed” his lifestyle to optimise his health. He also personally managed and protected his health information and managed any relationships with health professionals. I interpreted that he was cognisant that he was dependent on timely access to their knowledge and expertise.

5.3.5.3 Research Focus Question 3): How Darren Evaluated his Experiences of Integrated Care and Why

I found myself experiencing a range of emotions as I walked with Darren through his experiences of the integrated health service and how he had made sense of them. Darren made constant reference to his previous medical treatment and support services received for colostomy and stoma care, which he perceived as positive and had been adopted as his benchmark. The benefit of his repetition of his thoughts and actions during the interview, I could gradually conceptualise what I called Darren’s personal health belief model:

- I can be educated/ instructed/coached.
- I can add to/complement from other sources.
- I can access the medication/ supplies/support I need.
- I am able to make choices/ accept consequences – self-manage my time

- I can access information/ expertise required to get results.
- I cannot afford to get sick or have mishaps. This is not good use of my time or resources.
- Technology can enable information transfer – reduce risk/ inefficiency – over/under/ wrong treatment.

The Table 5.11 below presents what I interpreted as being important to Darren from his experiences of integrated care and the measures he actively used to assess and monitor his experiences.

Table 5.11: How Darren evaluated and monitored his experiences of integrated care

What Matters and Why	Measures
I have access to what I need. **Why?** Ready access to information and supplies enables me to manage my healthcare efficiently and effectively	**Self-assessment** Comparison to previous medical treatment and support services received. Did I have access to everything I need – information/ supplies/ support. Are the instructions clear, is the provider qualified. Can I access/ ask questions when I need to. My wounds are healing.
I can personally manage my health. **Why?** In my health belief model, everything is connected I need to proactively manage the risks to my health	**Self- assessment** I understand what I need to do to be healed and on track forward. I feel confident that information is correct, trusted and can be taught to me. I can methodically work through what needs to be done. I can use this to learn and prevent or minimise future complications – down the track. I am living a productive & comfortable life. I am feeling self-motivated and that I am using my time well'

5.3.5.4 What is This a Case of: Interpreting the Implications from Darren's Account of his Experiences

The research's overall framing question was, *"What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?"*. From immersing and reflecting on Darren's interview transcript, I interpreted that his experiences of integrated care meant that he was proactively managing his future health. He appeared firm in his belief that having access to expertise and instructions would progress the healing of his wound. Taking on this perspective, Darren could not afford to not use the integrated health service. I interpreted the purpose his integrated care experience served was to reinforce his commitment to protecting and managing his health, and that the greatest risk was being dependent on others who do not play their part and contribute unreliable information. The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Darren had shared with me in the context of this research, was "unreliable information is a virus".

5.3.6 Pepe's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Pepe's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Pepe's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Pepe's attribute coding, Table 5.12, provides a general descriptive introduction to Pepe and his everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Pepe's first cycle coding is included in Appendix L (see Table L6: Pepe's Experience of Integrated Care Table L6: Pepe's Experience of Integrated Care Table L6: Pepe's Experience of Integrated Care).

Table 5.12: First cycle interpretative findings: Pepe's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Pepe (P)	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 18 mins	45–50	Male	Own home, with family	Full-time, own, architect business.	Researching, exercise aids	GP referral	A couple of years ago and been ongoing. Initially visited weekly, then moved to alternate visits with the community nurse	Wound Clinic	GPs, community nurse, specialist (vascular surgeon)

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Pepe's words with my observations and sense making. The exert below from my research journal (Figure 5.9) gives insights into how I was gradually making sense of Pepe within the wider lifeworld he was describing to me, and how I tried to re-construct and connect the pieces to his integrated care experiences, as the interview progressed.

Figure 5.9 Researcher's Journal Excerpt: Getting to know Pepe.

Pepe described himself as being in his late forties and living with his family in a residential area within 20 minutes from the integrated care clinic. Pepe was self-employed and ran his architecture business from his home. He worked long hours and said that he needed to be protective of his time. Pepe explained that he always allowed one hour for travel to his appointments at the clinic. Sometimes he caught a cab, as the traffic and parking could be unpredictable. He preferred the first appointment of the day. As the interview progressed, I was mindful to be respectful of his time.

Pepe was a similar height to me, around 170 cm, with a larger frame. He confessed that he had always loved his food and had adopted some "bad habits" with working from home and with little time for activity. He was on a diet and had lost some weight, with "substantially more to go". He said that he was always looking out for new inventions that could help him to be more active while he was working. As a rule, Pepe only went to see the local medical centre when he was really sick, or if he saw something that was not right. He had previously had an infection that had "landed him in hospital for nine days" on intravenous antibiotics. This was Pepe's "biggest fear" and greatest motivation for vigilance in his wound care.

In getting acquainted with Pepe, I heard how he first came to be involved with the integrated health service and now a couple of years on, he continues to receive treatment for his leg ulcers. Pepe was matter of fact in his description. I had a sense that his description of his health treatment was influenced by his architectural design skills and that he was re-creating for me a visual blueprint that he stored in his mind of how all the structures came together and supported each other. For Pepe, it stood out that reliability and efficiency were the most important. When this was in place, then he would have effectively progressed the healing of his wound and have advanced his professional and personal goals.

What arose for me in listening to and reading Pepe's interview was the personal work or burden associated with self-managing the routine treatment of chronic wounds. The work was pervasive, which meant to me that it invaded your whole life, every moment, it was always there. It was a big investment; yet, I got the impression from Pepe that it was his life's work, rather than a burden.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Pepe and his story.

5.3.6.1 Research Focus Question 1: How did Pepe make meaning of his integrated care experience?

I found that Pepe tended to make sense of his integrated care experiences based on comparisons with his experiences at his local medical practice, where he felt that they "don't really know me". He believed that the personal approach taken by the integrated care staff had made an important contribution to improving and progressing his wound healing. For Pepe, this meant that it was a good investment of his time and that the integrated care service was a "value-add to what he's [Pepe] doing", providing a good return on his investment. From the data analysis, the following codes stood out from the first cycle analysis.

Good use of time

Pepe described that his initial experiences of the integrated health service included weekly visits. It then shifted to him receiving wound care from the community nurses at home. Pepe said that being "able to have treatment at home [weekly] and come to the clinic every 2–3 months. [It] suits me – it's convenient". He qualified this by saying that this avoided wasting time, having "to come in and sit around". I interpreted that Pepe meant he could put his time to better use.

In the experience of self-managing his wound dressings at home, Pepe would "observe and copy… [I] follow what they've done". He saw the efficiency of committing to a regime, "You don't have to reinvent the wheel, or whatever, you just do what they're doing". I interpreted that this also allowed him to "organise his day" and manage his time, "it's about 15 minutes out of my day to do the proper job", and therefore minimise disruption.

Pepe acknowledged that he was reliant on the healthcare staff to assess the progress of his wounds. I sensed that it was reassuring for Pepe that he observed "the nurse and clinic communicate; they report back and forth". I interpreted that Pepe saw a correlation between consistency in his care and improved reliability. Pepe shared that he did experience being visited by a number of different community nurses, who he then had to "brief" and "explain" the wound dressing to. He raised that he had concerns that inconsistency could prolong his healing, and he suggested improvements to make the process more efficient.

Feels personal

Pepe openly described the personal impact, in that healing his wounds was an investment towards improving his overall health, and he was willing to work with the integrated care team to do "whatever we can explore to speed up" the process. For this to happen, Pepe held the belief that he needed to have access to healthcare providers who were "knowledgeable" and "experienced" in healing ulcers, and who saw him as "part of the process". He needed "someone to value-add to what I'm doing". I concluded that Pepe's experiences of integrated care had left him feeling that they were invested in him, "they've [integrated health service] got an interest in my health and welfare. They want to see that I do get better".

5.3.6.2 Research Focus Question 2: "In what ways did Pepe perceive his experiences of integrated care were of use to him?

As an architect by profession, Pepe shared how he dedicated long hours to sitting at his desk completing design projects and that he was aware of his lifestyle, and perhaps hereditary factors, that were likely contributing to his ulcers. Pepe demonstrated an awareness of his low activity and poor eating habits, which meant he needed to be disciplined in his diet and vigilant in monitoring, knowing that any improvements or backwards steps could have a systemic impact. Pepe described how he had researched and invested in mechanical aids that would enhance his circulation and mobility. Pepe was aware that he needed his ulcers to heal so he could then increase his activity and improve his overall health. The following codes from the first cycle analysis best reflect what I interpreted Pepe had found to be most useful.

Reliable methodology

Pepe was the architect of his health and showed willingness to take the lead and responsibility for assessing his wounds for infection, and for treating and applying the wound dressings using "the same pattern". What he found to be of greatest use was "the methodology; it is a certain way – just knowing that, that gives you confidence, it is the same pattern that they do".

Early intervention plan – option to come in

Pepe had previous experience of a wound infection that had adversely impacted on him personally and his business, as it required extended hospitalisation. This was Pepe's greatest fear. Pepe said he knew "the signs" of infection and was "assessing and monitoring all the time". What he described as being of greatest use was that the integrated health service provided him the option and permission to take immediate action, "if there is a situation, just come in and see us [integrated care clinic]". Pepe shared that while at home his "warning bell" did go off and he noticed "somethings not quite right". Without hesitation Pepe, "came in and saw them". He said, "the option [to come in] is always there, which is good".

Helping healing

Rather than just diagnosing the problem, Pepe felt that the integrated health service had served to give him a solution. He said, "I saw the vascular surgeon, who told me the problem but did not really gave me a solution. The [integrated care] clinic here gave me a solution". This was useful, as the methodology provided for healing the ulcers was "helping". I concluded that once healed, Pepe would be more likely to increase his mobility, which would help in shedding weight. This would set his health up for the future, it was all interdependent.

5.3.6.3 Research Focus Question 3: How Pepe Evaluated his Experiences of Integrated Care and Why

Pepe described in his interview how he had experienced the integrated health service regularly over an extended period. This allowed Pepe to progressively integrate the wound clinic knowledge and methodology into his personal health regimen. He said several times that he felt part of the process, which suggested that his approach to evaluation would have a personal focus. Table 5.13 below presents what I interpreted as being important to Pepe from his experiences of integrated care and the measures he actively used to assess and monitor his experiences.

Table 5.13: How Pepe evaluated and monitored his experiences of integrated care

What Matters and Why	Measures
My care is customised and promotes healing. **Why?** When treatment and progress are accurately assessed and adjusted to his personal circumstances – it would be more efficient and reliable	**Self-assessment** Customised – I am part of the process. Convenience – I have options, good use of time. Consistent – minimal number of care providers, good communication Observation – colour, pain Measuring – time, weight, mobility Progress – less bandages, then I can use other devices.
I can attend to my care needs and initiate early intervention. **Why?** Pepe consistently indicated his belief that – "If I am disciplined, do the same thing (observe and copy), using the same supplies, it will ensure results (progress healing)".	**Self-assessment** Able to follow regimen – methodology. Have access to supplies – exactly the same materials. Able to contact for expert advice – immediacy – gives sense of permission – builds confidence/trust. Avoided or noticed early warning signs of cellulitis sequel/hospitalisation – reduces fear/anxiety.

5.3.6.4 What is This a Case of: Interpreting the Implications from Pepe's Account of his Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Pepe's interview transcript, I interpreted that for Pepe, the meaning of integrated care was that it had provided him with a solution that he had confidence in his ability to instigate, that would progress his healing, and that he had people with expertise who knew and were interested in him and who he could access when he needed them and would add value to his efforts. I interpret the purpose integrated care served for Pepe was that he felt like he had designed a personal, reliable, and efficient system, he was networked, and he had hope for his future health and welfare.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Pepe had shared with me in the context of this research, was "progress is hope".

5.3.7 Sally's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Sally's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Sally's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Sally's attribute coding, Table 5.14, provides a general descriptive introduction to Sally and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Sally's first cycle coding is included in Appendix L (see Table L7: Sally's Experience of Integrated Care).

Table 5.14: First cycle interpretative findings: Sally's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Sally (s)	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 24 mins	50–55	Female	Own home, with husband	Full-time, own retail business	Alternative health, spiritual healing	Self-initiated GP referral (recommended by a friend)	Third visit	Wound Clinic	Integrative GP Acupuncturist and Herbalist Oncologist

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Sally's words with my observations and sense making. The exert below from my research journal (Figure 5.10) gives insights into how I was gradually making sense of Sally within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.10 Researcher's Journal Excerpt: Getting to know Sally.

Within the interview, Sally presented as a slight, quietly spoken woman. Sally described herself as in her early fifties and that she had "always been into alternative ways of looking after myself, my family, everyone". Sally explained that she had skin lesions that she had been trying all different "alternative" medicines to treat. She said she was afraid of the toxins in medicines.

Sally described herself as stubborn, she said she tended to give things a go for a few months and then try something different. Sally's usual doctor was an integrative GP, he did not look at her wounds, but she felt he was helpful in other ways. She had also been going to an acupuncturist and herbalist for a few months. He had said that he had good results with others, but she had not noticed changes. Sally had also been referred to an oncologist who was a bit alternative. Sally stated, "It's very expensive".

Sally became teary when explaining the impact, the skin lesions were having on her life. She described dressing her lesions as being a full-time job, they take a long time to dress when getting ready, which she had to try and schedule into her day. This was on top of her commitments in running her own business. Since taking on the business, she had to let go of things that she said brought more into her life, like her American-Indian cards. She described that the cards helped her to connect with her spirit and her healing, just as the voice sessions she attended helped healing of emotions through vocalising sounds.

To begin our interview, Sally explained how she came to be enrolled with the integrated care clinic. Sally said her friend had received "really helpful advice and service" from the clinic, and out of "concern" for Sally's "suffering", recommended she should contact the clinic. Sally decided to ask her GP to write a referral, which he did. Sally said the whole process was unusual for her, as she was usually the one who made "the choices of how I look after myself and my skin". Sally said that she had "always been into alternative ways"; however, "now I am suddenly so sick" and the integrated health service was "specialised in the field, whereas my GP, he backs away because it's not his field".

Sally said that she "instinctively, intuitively" approached life's decisions with a preference to do "her own thing", which she referred to as being "a bit stubborn". I had the impression that even though there was much that was unknown, Sally still felt she was in control, in giving the "integrated care clinic a try".

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Sally and her story.

5.3.7.1 Research Focus Question 1: How did Lucy make meaning of her integrated care experience?

Aligned with what Sally called her intuitive approach to life, she tended to describe her experiences by referencing how things made her feel, for example, “makes me feel confident” or “I’m scared”. Sally also expressed emotions such as laughter and tears during the interview. I interpreted that it was important for Sally to feel like she was making the choices about how she looked after herself. I felt that she did not make choices lightly. Sally described how she had invested her limited time and money in seeking professional advice and treatment in order to heal her skin lesions, with limited success. Sally gave me the impression that the respect she felt for and the professional support and advice she received from the integrated health service was an unusual experience for her. I interpreted that this contributed to Sally “leaning towards” the service and giving the treatment her “best go”. From the first cycle analysis, the following codes stood out about how Sally made meaning of her integrated care experiences.

Getting professional advice

In describing her integrated care experiences, Sally commented, “‘I really like that it is somebody who’s experienced in that field, that can look at my skin and give me a proper opinion”. Sally explained that to be able to plan her life, including caring for her skin lesions, she needed professional advice from people who were specialised in the field. Sally knew this, as her current GP could not provide it and she had found that other specialist from related fields were also not helpful.

Sally said, “they tell me that, ‘they’re actually looking fine’ or, ‘I think you need to do something’, which I haven’t had to do so far. But that’s good to get that professional advice”. Sally was aware that her skin lesions were “a rare thing”, so getting professional advice meant that Sally could plan her treatment.

Feeling understood and respected (acceptance)

Sally shared a preference for basing her treatment on natural products, including essential oils, which she called “alternative” approaches. Sally shared her fear of “toxins” found in some medicines and took pride in looking after herself, family, and friends through “alternative ways”. Sally explained that she felt “respected” and “supported” by the integrated health service, in how they knew “how I want to do it – that’s good”. Sally noted that when she described her alternative approach that they did not respond with “Oh, no you shouldn’t do that”. Sally also received validation of her approach “[integrated care clinic] actually said, ‘Well, they do look okay, so keep doing what you’re doing’, and that was good to hear”. I had an impression this was a rare experience for Sally. Sally explained, “They really understand me. They know what I don’t like. I really like that they respect that about me – nobody else has”.

Asking questions

I formed the impression that once gauging the integrated health services acceptance of her and her alternative ways, Sally felt comfortable asking questions. She said, “I can check things I have researched or heard from others, I can just say, ‘Is this right?’ Like, ‘Someone’s told me this’”. In being able to “find out about” treatment options specific for her wounds, Sally was able to plan, calculate her time and investment. This felt “really good” to Sally.

5.3.7.2 Research Focus Question 2: “In what ways did Sally perceive her experiences of integrated care were of use to her?

What stood out to me as being of most use to Sally from her experiences of integrated care was that she felt it helped her make choices. In all aspects of her life, Sally demonstrated commitment to “doing what I think is right in how I look after myself”. The following codes from the first cycle analysis best reflect what I interpreted Sally had found to be most useful.

New approaches to healing

Healing her skin lesions was Sally’s goal. Sally described her approach to health promotion as being about “trying different things”. When self-managing at home, Sally had previously noted how long it took her to bandage her lesions each day, with minimal progress in healing. What was useful from her integrated care experiences was, “probably, the introduction to different bandaging. Yeah, that was really good”.

Choosing how to invest time and money

Sally made reference to treating her skin lesions as being a “full-time job”, that it was all she “thinks about”. As a small business owner, Sally showed that she was fiscally aware, and that she was willing to invest if she felt the return or impact was justified. What was useful to Sally was, “coming here [integrated care clinic], they actually gave me some products. And then when they ran out, I knew what to look for and to order. And that’s been really helpful. I mean, it does cost a lot of money. The bandaging costs a lot of money”.

Gives me confidence

Sally's experiences of feeling like "they really understand me", and that "they respect" her and even though the integrated care providers knew she was "alternative", "they still have time to give me the advice and to have a look at the actual wounds whereas nobody else has" made Sally "feel confident". Sally shared that she had "started to reconnect with some friends" and was "doing what I really love".

5.3.7.3 Research Focus Question 3: How Sally Evaluated her Experiences of Integrated Care and Why

Sally's approach to life initially sounded simple, she said "I like to do things my way". Sally described her approach as intuitive, which suggested to me that her decisions were based on visceral feelings. Yet, in my view, I would say Sally's approach was quite sophisticated, in that she was discerning in seeking out advice, she would scan any advice received using her "alternative" lens, before considering the investment required by her, weighing up the pros and cons and then taking planned action. Table 5.15 below presents what I interpreted as being important to Sally from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.15: How Sally evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
Knowing that what I am doing is good, Its promoting healing **Why?** My skin lesions are all I think about, it drains my time, money, and spiritual energy	**Self-assessment** I have considered alternative options and the pros and cons of the proposed approach. My providers understand and respect me – they appreciate my unique condition and alternative ways. I have access to professional advice. I can clarify and answer questions. I am investing my time and resources wisely. My lesions are healing.
I can live my life my way. **Why?** This my life philosophy, health belief model	**Self-assessment** I feel independent. I am curious – I can test/experiment with different options. I can access professional advice. I am aware of what else I need to consider. I feel connected spiritually to my energy source. Not feeling as exhausted.

5.3.7.4 What is This a Case of: Interpreting the Implications from Sally's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Sally's interview transcript, I interpreted the meaning of integrated care for Sally was about accessing professional advice that was both respectful and supportive of her preferences and life-choices, which then fostered confidence to ask questions and check meaning, where she had previously felt judged and stayed silent. The purpose served for Sally in regard to her wound care was that she believed she was doing the right thing and doing it her way, and in regard to her sense of self and purpose. I felt a connection to the spiritual joy expressed.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Sally had shared with me in the context of this research, was "respect is a healer".

5.3.8 Beth's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Beth's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Beth's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Beth's attribute coding, Table 5.16, provides a general descriptive introduction to Beth and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Beth's first cycle coding is included in Appendix L (see Table L8: Beth's Experience of Integrated Care).

Table 5.16: First cycle interpretative findings: Beth's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Beth (B)	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 32 mins	80–85	Female	Own home, lived alone (widow)	Retired (was left well provided for by husband)	Gardening, Pilates, shopping, researching, volunteering, has six children and has grandchildren	Inpatient referral then self-referral as an outpatient –	Had been attending on and off over a couple of years	Wound Clinic	Same GP for more than 20 years, Community Nurse, Specialists, (lungs/osteoporosis/ colorectal)

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Beth's words with my observations and sense making. The exert below from my research journal (Figure 5.11) gives insights into how I was gradually making sense of Beth within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.11 Researcher's Journal Excerpt: Getting to know Beth.

I noticed Beth to be a slight framed woman, who was neatly dressed with her hair pulled back into a bun and wearing light makeup. Early in the interview she shared that she was in her early eighties, a widow with six children, who was content living alone in the family home. Beth described the property as having a large garden and that she was fortunate to be able to employ people to do maintenance. Beth said her husband had left her well provided for, and that she recognised that she was in a fortunate position compared to others. Beth goes to Pilates twice a week, and goes out every other day, driving to the local shopping centre and pottering around the shops, browsing for Christmas gifts for her grandchildren.

During the interview, Beth spoke quickly and animatedly, often pausing to laugh at her own words. Beth has had the same GP for over 20 years. When explaining the medical specialists and hospitals that she had been in contact with over time, Beth was able to name each of them and provide a brief assessment as to whether she was "particularly impressed" or not. Beth provided an example of when she made a complaint about the suitability of the facilities in a private hospital, they moved her and apologised, which made her "quite cranky", as she was concerned for the other "poor people" that had not said anything. Beth said, "I would never go back there again. Ever, ever".

Beth described herself as responsible and stubborn, she liked to look after herself. Beth was a "great researcher", she was very proficient in looking things up on the internet using her mobile phone. She explained, "if someone says you can't do that, I tend to work out a way that I can, just looking up different things. I love being told I can't, then being able to. It keeps me occupied". Beth also liked to volunteer, she said, "nothing to do with being good. I absolutely adore it". Beth provided family support, as members of the family had "bad mental health", so she tried to be around.

In reflecting on the impressions that Beth had left me with at the end of our interview, the words self-assured, self-aware, and perhaps a little mischievous in how she approached her experiences of integrated care and influenced them so that they were "perfect" for her, came to mind. Beth recognised that she had to be careful, "not to go at things like a bull at a gate", that she liked to be in control and could be stubborn. Beth shared that she enrolled herself in the wound program after first meeting the nurse while a patient in the hospital. Beth playfully explained, "Well, I just thought I was in – so I just rang up [integrated care clinic] and they gave me an appointment". However, through the interview it became apparent that rather than being a misunderstanding, Beth had been quite intentional in recognising that she wanted the clinic's expertise as part of her healthcare team, "I've got to keep myself healthy [laughter]". Beth said, "I love being told I can't, then being able to". I sensed that Beth was not going to leave anything to chance.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Beth and her story.

5.3.8.1 Research Focus Question 1: How did Beth make meaning of her integrated care experience?

Beth was an 82-year-old widow with six adult children, living alone in the family home. How Beth described her personal circumstances provided me with insights into her sense making, for example,

> I suppose it's a bit of a control thing. I like to look after myself. I don't like other people getting involved. And you know, I think you should look after yourself as long as you can, obviously. And I still live in my house, and I've still got my garden. It's quite a large house, and I'm hoping to be carried out of their feet-first. Whereas, if my husband had been alive, we certainly would have got something much smaller.

I got the sense that Beth may not previously have been in control of decisions in her life. She recognised her "fortunate position" of being left "well provided for", nonetheless Beth also realised that she was "responsible" now and it was her decisions and actions that would keep her safe and healthy going into the future. Her experiences of the integrated health service meant she was "looking" after herself. From the first cycle analysis, the following codes stood out about how Beth made meaning of her integrated care experiences.

I'm in good hands

When describing her experience of integrated care, Beth used words like, "very professional" and that she had "complete faith in what they [integrated care clinic] tell me". Beth felt that she was "in very good hands because [integrated care clinic are] always looking for something new". Beth said that looking for something new meant that they were "interested", looking for "things that are going on" or about "learning what's new", which was beneficial for her health care. Beth described her experience as "absolutely marvellous". After visiting many doctors, she believed the integrated care providers had "cured it".

Feeling trusted

Beth noted, “He’s even given me his mobile number, which I find I would never use, it’s something that I’ve got a real thing about. I would never use it, my own doctor has given me hers, I have the mobile number – which I would never use”. Beth expressed pride in her independence and what I called her (moral) code that she lived by. I formed the belief that she would not abuse any privilege, such as having a mobile number. However, what having that number meant to her was that she was trusted, and their professional opinion was available if she decided to call. I interpreted that knowing this gave her confidence to make decisions about accessing health care.

Appealing design

It may be a generational concept; however, I had a sense that presentation meant a lot to Beth, “[integrated care clinic] presentation, it’s easy to get to; everything is nice and bright and appealing”. Beth thought it was important that there was a “pleasant atmosphere – which I think can make people feel better anyway”.

5.3.8.2 Research Focus Question 2: “In what ways did Beth perceive her experiences of integrated care were of use to her?

I interpreted that Beth’s experiences of integrated care were useful as she could now place them on her “list of people that I can go to if I have problems”. Beth valued that she could use the knowledge and techniques the integrated care clinic provided to maintain her independence, her lifestyle, and protect her health. With concern for others who may not be aware of the service, Beth suggested that it may be useful for the integrated health service to raise their profile, rather than leaving it to the individual to research and find the service. The following codes from the first cycle analysis best reflect what I interpreted Beth had found to be most useful.

Knowing backup was close by

I interpreted that Beth found it useful and reassuring knowing that she could contact the integrated health service, “the fact I know he’s here, and if I feel something is getting out of hand, I can just ring up and get an appointment with him, I find that very reassuring”. Proximity was also important, as Beth felt assured she could get herself there if need be, “very close back up, very close, it’s not far for me to come”.

Keeping myself healthy

Beth described the personal healthy lifestyle routine she had adopted, which in essence covered the determinants of health. I was unsure whether she had researched this beforehand, but I imagined so. I interpreted that she was aware of and accepted her responsibility, knowing that "I've got to keep myself healthy", which was underpinned by her belief that "you should look after yourself as long as you can".

5.3.8.3 Research Focus Question 3: How Beth Evaluated her Experiences of Integrated Care and Why

In re-reading the interview transcript I noticed some patterns in Beth's thinking, which like Darren earlier in this chapter, I interpreted as her personal health belief model. It included:

- I can look after myself.
- I can tell if somethings not quite right.
- "New" things are improvements on the existing.
- If people are aware, they will use the service/take action.
- I place faith in professional (specialist) opinions – it was what "cured" me.

I noticed Beth to be constantly evaluating and that she was clear about what and why the integrated health service was good or "perfect for her". Table 5.17 below presents what I interpreted as being important to Beth from her experiences of integrated care and the measures she actively used to assess and monitor her experiences.

Table 5.17: How Beth evaluated and monitored her experiences of integrated care

What Matters and Why	**Measures**
I feel I'm in good hands. **Why?** I need their professional opinion so I can be healthy (be cured), manage and lead my health at home. I know I've got things in place if I need them.	**Self-Assessment** I can see their enthusiasm. I can see they are researching, willing to try out new things and learn (just like me) I have things in place that are perfect for me. I can contact the clinic if I need to They are close by; I have the number. I am cured – in comparison to other health provider experiences.
I'm keeping myself healthy. **Why?** It's up to me. My goal is, when the time comes, to leave my home feet-first.	**Self-Assessment** I can maintain the level of independence; I have control of my life. I have a balanced lifestyle. I can look after myself. I am living in my house I can research and learn new information or ways. I can contact the clinic if I need to

5.3.8.4 What is This a Case of: Interpreting the Implications from Beth's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Beth's interview transcript, I interpreted that for Beth, the meaning of integrated care was about keeping herself healthy through intentionally accessing a health service that she believed to be perfect for her immediate health needs and a reliable service to contact in the future. The purpose served was that her wounds were "cured", and Beth felt confident and reassured.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Beth had shared with me in the context of this research, was "perfect is Picasso".

5.3.9 Trent's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Trent's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Trent's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Trent's attribute coding, Table 5.12, provides a general descriptive introduction to Trent and his everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Trent's first cycle coding is included in Appendix L (see Table L9: Trent's Experience of Integrated Care).

Table 5.18: First cycle interpretative findings: Trent's attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Trent (T)	Date: July 2018 Location: Integrated care unit Transport: got a lift Interview Length: 37 mins	40–45	Male	Lived with mother in family home	Unemployed tradesman	Walking group, social activities	Hospital referral as an outpatient attending hand clinic	Approx. 18 months	Bulbuwil healthy lifestyle program	GP, specialists, endocrine/gastro/ neurosurgeon, pharmacy

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Trent's words with my observations and sense making. The exert below from my research journal (Figure 5.12) gives insights into how I was gradually making sense of Trent within the wider lifeworld he was describing to me, and how I tried to re-construct and connect the pieces to his integrated care experiences, as the interview progressed.

Figure 5.12 Researcher's Journal Excerpt: Getting to know Trent.

My notes from the interview described Trent to be of medium height and a slight build. I noticed him to be quick to smile. Trent described himself as in his early forties and he lived at home with his mum. He said he used to be popular, with a successful trade business with government contracts. One day he tested positive for a prohibited substance when on-site, then no one wanted anything to do with him. He said he went from having "no time and lots of money" to "now I['ve] got all the time in the world and no money". Trent said that at that time, he found himself becoming depressed, and he had attempted to overdose and take his life.

Trent explained that he had had lots of problems with his bones, which meant he needed regular injections, which he got from his endocrinologist. Trent also had anger issues that he said got him in trouble. One day Trent broke his hand, and when receiving treatment at a specialist hand hospital, he heard about the Bulbuwil program; a healthy lifestyle program for any person of Aboriginal and Torres Strait Islander descent who had a chronic disease or was at risk of a chronic disease, and their families and carers. To access the service, he needed to identify as Aboriginal. Trent said they asked him, "How I got to be aboriginally blonde-haired and blue-eyed". He replied to them, "Yeah, I was adopted. And I know my birth family is from xx". Trent said that from there on, he was enrolled in multiple programs, he was also helped to apply for financial support for his medications and they had spoken to his general practitioner about putting him on a mental health plan.

I found Trent to be relaxed and eager to share his experiences of the integrated care programs he had accessed with me. Trent described it as being "life changing" for him. When Trent recalled to me his story of his life before he enrolled in the integrated care programs, it felt to me like he had had so many things happen in his life that had put him at a disadvantage, through inheritance, his own hand, or others. Trent, in a matter of fact manner, described to me how he had been adopted and separated from his Aboriginal birth family. He had a history of Chron's Disease and steroid induced osteoarthritis. He shared he had used illicit drugs, he had experienced loss of social status, and he had eventually attempted to take his life. He felt judged by others, that he was a burden to his mum, and that he had nothing to live for. Yet what surprised me was that the stories he shared about his experiences of integrated care, were in juxtaposition to his life story. I interpreted his words and sentiment to be genuine and sincere.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Trent and his story.

5.3.9.1 Research Focus Question 1: How did Trent make meaning of his integrated care experience?

I found that Trent had a unique way of describing what his integrated care experiences meant to him, through sharing how they made him feel. The experiences he shared, were grounded in his feelings of being welcomed, accepted, and cared for by the integrated care programs and all the staff.

At the time of the interview, Trent said he had been enrolled with the integrated care clinic for around 18 months. Trent described it as being like family. I was curious whether the process of having to identify his aboriginality to access the service was influential on this feeling. Trent felt that for the first time he had found people who could see him as a person and who were interested in him and in each other, as everyone was equal. Trent commented about being watched, but in an unobtrusive way, watched out of interest and care, rather than from a surveillance or looking for what is wrong. I had the impression that he was experiencing a sense of cultural safety, though Trent did not use these words. However, Trent did say that his experiences where different from his previous interactions with health providers, which he described as being treated like “a piece of poo”. From the first cycle analysis, the following codes stood out about how Trent made meaning of his integrated care experiences.

Feeling welcomed

Trent commented “I’ve never come to a place where you feel so welcomed, never, not even playing football, you know?”, he went on to say, “They will walk through fire for you, [they are] so welcoming”. Trent described how this feeling came from every interaction. To Trent feeling welcomed meant, “you can just turn up, grab a coffee, have a chat” at any time, “you don’t even have to have an appointment”. For Trent, feeling welcomed also meant “nobody’s better than anyone else” and most importantly, that you want to keep coming back. Compared to his previous health experiences, Trent said “everybody knows my name. It makes you want to keep going”, rather than walking out and never returning.

Feeling like I matter

In reflecting on his life and health experiences, to Trent, integrated care meant that he felt “like a human”, that he was “a person not just an object’. I interpreted that if you were an object, you would have no say, no feelings, no family, things could be done to you or you may be ignored. Trent’s experiences of integrated care meant he felt cared for. He felt “they genuinely care, they’re interested”, which meant he felt less of “a burden” or “a hinderance” to others.

Caring team of health professionals

Trent described the integrated care providers as a “very professional outfit”, who “actually cared” and took “you as you are”. He listed the range of services he had access to and that were personalised to his needs, including “the gym, walking group, stop smoking, anger control and art group”. Trent thought it was good that, “they’re all taking to each other”, this meant “you can’t pull the wool over their eyes. They all know. No point telling a fib or trying to be better than what you are”. I had a sense that for Trent, being honest with himself was a different way of being, as was being honest with others. He seemed to appreciate that the integrated care team could see through his stories and were talking to each other.

Motivating

Trent found that his experiences meant that he was motivated to come back to the integrated care clinic. Trent said he noticed he was “watching the clock. I wanna come here”, furthermore he kept “coming”. Rather than being forced or instructed, Trent felt they had given, “me the tools”. Trent felt he was building habits and doing it himself, he said, “they don’t make me do it. They put it in your head without realising mentally”. Trent believed, “I[‘m] gonna [sic] get stronger” and had found purpose, saying that his experiences were “life changing, it [has] opened doors, I’ve got a purpose to live”.

5.3.9.2 Research Focus Question 2: “In what ways did Trent perceive his experiences of integrated care were of use to him?

It was my interpretation that Trent’s experiences of integrated care were useful because they reinforced each other, guiding him towards applying the new behaviours and skills in his everyday life in a way that he genuinely believed he was “doing it” himself. In addition, being able to reach out to the integrated care team when he felt he needed to reinforce his personal responsibility and minimised a sense of dependency or placing blame on others, was useful. The following codes from the first cycle analysis best reflect what I interpreted Trent had found to be most useful.

Making it is easy to adopt healthy habits.

Having timely and “free access to patches, pretend cigarettes” and “every piece of stuff you want” was useful for Trent, in that it made it easier for him to adopt the new desired behaviours. Learning self-management techniques like “breathing methods” that he could use when feeling “frustrated” or “angry” were also useful in helping him control his temper and keeping him on track with his healthy habits. Trent recognised that some behaviours were now becoming automatic, “I’m doing without realising. I’m sitting there doing stretches without even knowing I’m doing it. It’s become automatic – rather than you having to think about it”.

Thinking positively

I found that learning to think positively and setting achievable goals were useful for keeping Trent motivated and feeling like the changes were “doable” and within his control. Trent described himself as motivated to avoid getting worse, “I don’t wanna [sic] get worse – [I want to] get healthy or stay healthy”. He recognised the benefits of thinking positively and taking one step at a time, “keep moving, do stuff, be happy”. Trent said “they’ve given me the tools to not think negative[ly]. I’ll take it when it comes. If it happens, it happens. You follow that road”. I interpreted that believing that “tomorrow is a different day” was useful for Trent.

Able to reach out when I needed

Knowing that, “if there is anything wrong, let us know, the door is open” was useful for Trent. He provided an example of an unexpected situation where he had self-initiated contact with the integrated care team after he had experienced a crisis after receiving bad news. Trent explained that the “[integrated care clinic] had told me ‘If you’re feeling really bad, ring this number’”, he said that he found himself telling “them honestly the things I’ve done, that’s not normally like me”. Trent shared that he felt he was shifting from not taking responsibility or looking to blame something else, towards being honest with himself and taking action.

In response to his call, Trent said that the integrated care team contacted his doctor, and then they told him “to go to the doctor” and now he has “a mental health care plan”. Trent perceived knowing that everyone was talking to each other as positive, because he believed they all had his best interests in mind. This also motivated him “to tell it how it is”.

5.3.9.3 Research Focus Question 3: How Trent Evaluated his Experiences of Integrated Care and Why

As Trent’s experiences of integrated care were across a number of programs, he was able to notice how each of the programs were individually and collectively influencing his behaviours and habits. Drawing on his experiences, Trent felt strongly that the integrated health service was “hard to find out about” and “needs to be promoted”. Trent credited the clinic for keeping him alive, which he said was also noticed by his mother, “My mum says that too”. Table 5.19 below presents what I interpreted as being important to Trent from his experiences of integrated care and the measures he actively used to assess and monitor his experiences.

Table 5.19: How Trent evaluated and monitored his experiences of integrated care

What Matters and Why	Measures
Feeling like I am somebody. **Why?** I know what it feels like to be seen and treated like I am not human, an object.	**Self-Assessment** People know my name. I feel accepted – "They're interested – [they] take an interest in you". I feel respected "they take you as you are". I feel welcomed. I feel cared for I feel heard, "I've got a say".
Not being a burden to others. **Why?** I want to be in control, take responsibility for my actions and the influence I have on others.	**Self-assessment** Noticing that I am doing exercises without thinking about it. I can control my temper. I don't feel frustrated. I am taking responsibility – I am seeking out help, being honest with what is happening. Feedback from mum (trusted person) I don't feel like I am a burden to anyone. I am "not a hinderance'

5.3.9.4 What is This a Case of: Interpreting the Implications from Trent's Account of his Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Trent's interview transcript, I interpreted that the meaning of integrated care for Trent was a lifeline, he believed it had kept him alive and given him purpose. The purpose integrated care served was that he had the lived experiences of self-improvement through adopting a positive mindset and healthy behaviours. He had started rebuilding relationships with supports like his mother, and he was recognising the positives of being honest and that if you falter it was not the end, it was ok to just reach out.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Trent had shared with me in the context of this research, was "feeling care is a lifeline".

5.3.10 Carmen’s Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Carmen’s meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Carmen’s interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Carmen’s attribute coding, Table 5.20, provides a general descriptive introduction to Carmen and her everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Carmen’s first cycle coding is included in Appendix L (see

Table L10: Carmen’s Experience of Integrated Care).

Table 5.20: First cycle interpretative findings: Carmen’s attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Carmen (C)	Date: Mar 2019 Location: Integrated Care Unit Transport: own car Interview length: 43 mins	60–65	Female	Own home, lived with husband	Retired teacher	Social activities, swimming, children and grandchildren, exercising – walking, social-media	GP referral (on request from Carmen)	Around 18 months	Diabetic Clinic, Bulbuwil healthy lifestyle program	Same GP for more than 34 years

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Carmen’s words with my observations and sense making. The exert below from my research journal (Figure 5.13) gives insights into how I was gradually making sense of Carmen within the wider lifeworld she was describing to me, and how I tried to re-construct and connect the pieces to her integrated care experiences, as the interview progressed.

Figure 5.13 Researcher’s Journal Excerpt: Getting to know Carmen.

I noted that Carmen was welcoming and enthusiastic, introducing herself as being in her mid-sixties. She explained she was medically retired about 25 years ago from school teaching. Carmen lived with her husband and had adult children. She described her family life as being “very stressful” over a “long time, 40 years”. Carmen was diagnosed as a diabetic about five years ago and had been managing with regular doctor visits and blood tests. Carmen said she had been seeing her general practitioner for 34 years, she described him as a “very busy man with a lot of people to look after”. About 18 months ago, Carmen’s diabetes was not responding to the lifestyle changes she had introduced, so she was “put on medication, tablets”. It was around this time that she realised that her “diabetes gets affected by her stress” and that “just to survive” she needed to make some “drastic changes” in her life. She said, “I realised, ‘I’m in trouble here’”.

It was my privilege, that in a calm and free-flowing manner, Carmen took the time to share her struggles, her worries, her sadness, and joy with me. I did not truly appreciate till afterwards, when immersing myself in my notes and the interview, the journey Carmen had taken me on. In re-reading the thoughts and words Carmen shared with me, I was taken aback by the complexity, the hidden layers of a person’s life. I felt a mix of naivety and honour that I had had this opportunity to sit with Carmen and get acquainted.

Carmen shared how she had made sense of her life, and how she had learned to live it. She described that her approach to life was to hold back and manage herself, until she felt she was “in trouble”, or her “survival was at risk”, then she would “attack”. I got a sense that

Carmen had been self-managing her “troubles” for many years. She mentioned the need to attack her habits, that she was careful who she spoke to about what, and that she always started with doubting her own capabilities. Carmen reflected, “I’m a real ‘doubting Thomas’. It’s my own doubt of my ability”. Carmen also mentioned that she was a medically retired schoolteacher. I am not aware of the full circumstances; however, I interpreted that her experiences as a teacher or with bureaucratic structures were not all positive.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Carmen and her story.

5.3.10.1 Research Focus Question 1: How did Carmen make meaning of her integrated care experience?

Carmen was reflective when describing her integrated care experiences. At the time of the interview, she noted that she had been enrolled with the integrated care programs for around 18 months. I had a sense that over this time she was continuously and critically processing her thoughts and feelings. Carmen had shared she enjoyed learning and was always interested in ways to improve her health. She also preferred to use data for monitoring her progress, like a “finger-prick” for testing her diabetes to see if she was keeping on track.

Carmen gave me the impression of being self and emotionally aware. She described herself as curious by nature, it was Carmen who found out about the integrated care programs after becoming increasingly frustrated with the hospital’s outpatient diabetic clinic, so she asked her GP to refer her. When she felt her access to some of the programs was being threatened, she spoke up, “I identified as – at the end, I burst into tears and said, ‘Yeah, but I’m Aboriginal’, and then they just swung into the resources that were available to me as being Aboriginal”. I interpreted from this experience that Carmen did not always choose to disclose her descent. Carmen explained that her parents were from the “stolen generation” and that she had been isolated from the Aboriginal community growing up. She also shared that she was surprised to learn about the disproportionate health-related risks of Aboriginal people, she said it, “seems like [there are] a lot of medical issues with Aboriginal people”. I interpreted this to perhaps be an indication of her cultural isolation or limited exposure. I was uncertain of the full circumstances of her isolation; however, she described the integrated care experience of being around her people, language, and culture as “joy”. It brought back memories for her.

From the first cycle analysis, the following codes stood out about how Carmen made meaning of her integrated care experiences.

Feeling safe

The feeling of safety I interpreted to be multidimensional for Carmen. Safety meant she felt her health and well-being were being “genuinely” and “holistically” cared for. Carmen said “I feel cared for. They’re interested in my whole body; it all seems integrated into my whole well-being”. Carmen said this was different to her GP’s way of caring, which was more about just doing the “job” or solving “the problem”. Safety was about her deciding to whom, when, and what she talked about, it felt private with no questions asked, “You don’t have to tell everyone everything, and yet if you want to tell someone something, they just quietly go away and get it”. Carmen felt she could, “ask any question without judgement”. I sensed that safety was also about feeling like family, like you fit in. Carmen reflected after attending the Bulbuwil Aboriginal lifestyle program, “I got what they were joking about – their terminology”. She said she felt “connected” to others.

Empowered to do things.

Carmen explained that her previous health care and life experiences were about being told what she could not do. Carmen shared, “I was always told I couldn’t cook”, yet what her experiences of integrated care have meant was that she felt “encouraged and “more empowered to do things”. Carmen explained, “[integrated care] their philosophy is to get you to enjoy food and not make it a burden. It’s different to when you go to the doctor. The doctor says, “don’t eat too many carbs ... don’t eat too[much]…”. I interpreted that Carmen was responding to not being given rules to follow, rather she was learning how to manage her own situation, “how to research what a good meal was” . Carmen said, “they always give me hope here. I think that’s the exciting thing, they’re empowering me to believe that I can be different in the future”. Carmen felt her experiences were preventing her health getting worse, she explained, “they’re helping me to take responsibility for my own health”.

Access to a knowledgeable and professional service

Carmen said, “I love their [integrated care] professionalism”. I interpreted that Carmen felt that she had permission to voice her thoughts, “I like [that] you can disagree on something with a staff member, but they will always explain why they disagree”. This explanation was important for Carmen’s “24 hours of every day” involvement in her care. Carmen shared that feeling listened to had not been a common experience for her, “when you deal with that building [hospital], it’s bureaucracy. When you deal with integrated care, its community and inclusiveness, they listen to the client". Carmen described the integrated care staff as "knowledgeable and available. They're informed and know where to go, who to put me in contact with". She was told that "we [integrated care] are here to help anytime... just come up". Carmen described a positive experience of contacting the service out of hours and felt confident that this would always be the case. She recalled, "Yes, I've rung up and asked for someone to talk to. I've now got the phone numbers of people I can contact" and "I've always been able to get onto someone". These experiences meant so much to Carmen that maintaining access to the integrated care programs was informing her future life plans.

5.3.10.2 Research Focus Question 2: "In what ways did Carmen perceive her experiences of integrated care were of use to her?

I interpreted that what Carmen perceived to be useful from her integrated care experiences was that she had felt empowered, could take ownership, and that she "knew" her options, in what she needed from the service and how to get it, and what she needed to do. Carmen said, "I think it educated me on what diabetes is and how to attack it". What was useful to Carmen was the practicality of her experiences, in that she was able to adapt to her circumstances and be creative where necessary. I assumed that this approach aligned well with her education and teaching background. The following codes from the first cycle analysis best reflect what I interpreted Carmen had found to be most useful.

All doable

It stood out to me that Carmen felt it was useful in how everything about integrated care was doable within her everyday living. Carmen explained, "the fact that you don't have to run a marathon to get some exercise. I might do exercise in a chair, whenever I am watching TV. You don't have to have all the big machines – you can use a can of baked beans for weights". Embedding exercises into her daily routines like "walking around the clothesline" were also useful. Carmen liked that she was able to read the food labels when shopping, deciding which were the "healthy ingredients" and then "cook them for my husband and myself". Carmen found it useful that she could teach others the exercises she did in the pool, making it practical and sociable.

Expressing confidence

I found that for Carmen, the integrated care programs had provided her with a sense that she was able and prepared to protect and manage her health going into the future. Carmen explained, "as I look into the future, I'm excited about being able to say I can cook; about being able to say I did wake up in the morning and feel ok; about not just my weight, but my whole physical being, being healthier". She also found confidence in expressing her "emotions, feelings, and thoughts through art". Carmen was proud that she was able to share this experience, her creative expression, with her community and family.

It's my choice

Carmen mentioned to me several times how she was consistently told what she should or should not do, and what was good or not good for her. What Carmen had found useful was that she was ready to take responsibility, "It's about attacking my lifestyle at my own pace and for my benefit and those around me". Carmen was aware "it's my choice and it's up to me. When you say the future, I guess it's up to me. This [integrated care] is a wonderful crutch, but they say you still got to pick-up the crutches and walk, that's not their description, that's mine". In having had an extended, over 18 months' experience of the integrated care programs, I interpreted that she was shifting towards recognising the service as a resource for her, rather than her being dependent on the resources.

5.3.10.3 Research Focus Question 3): How Carmen Evaluated her Experiences of Integrated Care and Why

In understanding that Carmen's experiences of integrated care were now taking the form of a lifestyle rather than a series of programs, the focus of Carmen's evaluations had started to shift from her individual needs towards societal impact. I interpreted that Carmen was expressing a sense of ownership or investment in the integrated care clinic. Table 5.21 below presents what I interpreted as being important to Carmen from her experiences of integrated care and the measures she actively used to assess and monitor her experiences. This is followed by a summary in Table 5.22 of Carmen's thoughts and ideas for improving the service overall. Carmen said that she responded positively to the survey she was sent about the service; however, she had not been involved in any other discussions about improvement.

Table 5.21: How Carmen evaluated and monitored her experiences of integrated care

What Matters and Why	Measures
Self-belief – that I can **Why?** Because the future is up to me – it's my choice.	**Self-assessment** Comparison to other experiences (GP and hospital) I feel empowered – it's the way I'm treated – I am listened to, I feel cared for, they are interested in my whole well-being. I can ask questions – they are open to explaining things to me, guiding me. I can have a different opinion – it's about taking responsibility rather than follow rules.

	I have hope – I can manage my own situation. I am connected to my language and memories. I can creatively express my emotions.
I am being healthier. **Why?** I am informed, educated, and confident in my ability to manage my health 24 hours a day.	**Self-Assessment** I am not waiting till things get unmanageable. I have a routine and I am taking preventative actions. I am regularly monitoring my blood sugar, exercise, diet, sleep and taking proportionate action. I have reduced or avoided gaining weight, or the diabetes sequel. I have avoided going to hospital. I am connected – physically, emotionally, spiritually – to myself and my community. I am aware of medical issues Aboriginal people are more susceptible to and actively protecting myself.

Table 5.22: Carmen's thoughts and ideas on improvement opportunities for the integrated care service

Improvement opportunity	Carmen's improvement ideas
Parking is the hugest problem, stress for me.	**Idea** – they could set up a centre away from the hospital – like a centre in the community.
There is so much potential and yet to get here is stressful. The transport is a big issue because it's not near a railway station – you've got to drive, you've got to park. I always try and give a half hour extra.	**Idea** – provide vouchers to use at the parking station
We need to extend the service. Get people before they end up in hospital. The earlier we intervene with things like diabetes and mental health – early intervention – for example, my grandson has Down's Syndrome, and the focus is early intervention rather than waiting to treat.	**Idea** – increase the number of rooms within the integrated care unit, allowing more people and more preventative services
I couldn't even guess how they would evaluate this service. When I fill in the survey, I'm always very positive, because it's wonderful.	The question I would like to ask is, "Why hasn't the government put money in?". They try to put band aids over stuff that is already broken. Why not soothing cream

	before it gets broken – these sorts of services do that.
I don't have much faith in government funding. But integrated care, they're changing people's lives and you can't measure it (tick the boxes or manipulate the numbers) because its immeasurable.	**Ideas for measures:** We're not going to end up on the suicide list because there's been a change. There's an intervention point. We're not going to end up without a leg because of diabetes. We're more informed. I'd be interested to go back to my doctor (GP) and see whether I have visited him less than before. I've been seeing my GP for 34 years.

5.3.10.4 What is This a Case of: Interpreting the Implications from Carmen's Account of her Experiences

The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Carmen's interview transcript, I interpreted that for Carmen, the meaning of integrated care was an intellectual and emotional experience that challenged her rules, understandings, and behaviours that had framed her life. I sensed that she was respectfully disarmed, with her world being "safely" turned upside down, and rather than falling uncontrollably, she was guided with genuine care. For Carmen, the purpose of integrated care was a sense of positivity, purpose, and pride in what she was doing for herself and for others. I interpreted that rather than attacking the problem, feeling stressed, or that her survival was threatened, Carmen was more confident in her ability, in expressing her emotions creatively, and was hopeful that collectively, people could listen and learn together.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Carmen had shared with me in the context of this research, was "self-belief is a butterfly".

5.3.11 Neil's Meaning and Experiences of Integrated Care: An Interpretative Account

Following the same format, re-presented below is an interpretive account of Neil's meaning and experiences of integrated care. This account is the product of my engagement in the iterative and analytical synthesis of Neil's interview transcript, my interview field notes, reflexive journal notes, and the first cycle analysis coding processes. Neil’s attribute coding, Table 5.23, provides a general descriptive introduction to Neil and his everyday circumstances relevant to the phenomenon of interest, being her experiences of integrated care. For reference, a detailed table of Neil’s first cycle coding is included in Appendix L (see Table L11: Neil’s Experience of Integrated Care).

Table 5.23: First cycle interpretative findings: Neil’s attribute codes.

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Neil (N)	Date: Mar 2019 Location: Integrated Care Unit Transport: walked Interview length: 24 mins	60–65	Male	Own home, lived alone	Retired from Navy	Exercising artist – painter and short film maker Son and daughter up north	Hospital/ Emergency Department referral – “they knocked on my door’	At least a year	Bulbuwil healthy lifestyle program	Cardiologist

The findings that I am presenting are an interpretative account resulting from the gradual fusion of Neil’s words with my observations and sense making. The exert below from my research journal (Figure 5.14) gives insights into how I was gradually making sense of Neil within the wider lifeworld he was describing to me, and how I tried to re-construct and connect the pieces to his integrated care experiences, as the interview progressed.

Figure 5.14 Researcher’s Journal Excerpt: Getting to know Neil.

When we commenced the interview, Neil was eager to get started. He described himself as in his early sixties. He spoke quietly, his voice was deep in tone, and he appeared to consider his words before he said them. He was of medium height, with a lean, yet muscular build. He described himself as fit. He served for many years in the defence forces and was now retired from the Navy. He had always maintained an exercise regime and eaten well. He laughed in saying, “I’ve always been a good cook. I’ll never starve”.

Neil lived alone, he had two children, a son and a daughter, who lived in Northern NSW. He said “I’ve got no one here, really. So, I’m thinking very, very seriously of going. So, it’ll be good to be near them. I’ll be a bit happier, I suppose”.

Neil shared that he was an artist and had exhibited his work in a gallery “on the west bank of Paris”. He also assisted with the art classes that were part of the Bulbuwil program and the integrated care service had bought some of his art to display in the common room. Neil had written feature film scripts and won awards for his short films. His prize-winning short film was called “Traditional Aboriginal Art: Fact or Fiction?”. He shared his frustrations in trying to secure funding to film a feature length script. He said he could be blunt in stating what appeared obvious. Neil said that his art, his health, and his future were connected, explaining that he refuses to give in. “I’m just going to keep going until I die, really”.

In getting acquainted with Neil, several times, he referred to his many years serving in the Navy. He felt that the Navy had, and continued to be, a positive influence on his health and his life. Neil told me, “I’ve always exercised. Been fit. Most of it in the military, the Navy. They didn’t mind if you drank like a fish, which we did, but they also encouraged sports and activity. So, I’ve always been pretty active my whole life”. In addition to the Navy leaving an impression on his daily activities, I felt that the Navy’s values may also have embedded within his moral compass, or perhaps the alignment of values was why he joined the Navy. I am not sure. However, Neil spoke respectfully of those whose intentions he believed were to help others, and he valued courage and integrity. Neil felt strongly that you should fight for what you believe is right, to stand up to injustices, and not back down. Neil seemed to have an active mind, he found new ideas or different ways of looking at things motivating. He enjoyed strategising what would be helpful for him in the future.

In the next section I have signposted the findings from the first three research focus questions which provided the structure for the progressive focusing of my interpretations. The section concludes with my interpretive summation, and I present the metaphor I created that keeps me connected to Neil and his story.

5.3.11.1 Research Focus Question 1: How did Neil make meaning of his integrated care experience?

Neil was certain that his experiences of the integrated care cardiac rehabilitation or the Bulbuwil lifestyle programs were not medical treatment. Neil believed that there purpose was to provide him with access to the gym and equipment, and motivation to keep active. From Neil’s perspective, he did not have a need for, or go looking for, the integrated care programs, they came to him. Neil recalled,

> Well, I remember [integrated care staff] came around to my apartment and knocked on the door and told me about it. I just can’t remember how they got my name down. I was probably in hospital here. Because my heart fibrillates every so often, they put me in. And they said, “Would you like to come along to the gym?” [for] cardiac rehabilitation. So that was it… I’m not really sick. They told me I had a minor heart attack, but I didn’t even know.

Neil was not able to say how long he had been attending the integrated care programs, “Oh, gee. I don’t know. I don’t keep records or dates for these [visits to integrated care]. It’s got to be a year at least”. I interpreted this as meaning that Neil felt he made the choice to attend, they had blended into his routine, rather than feeling like an appointment that he had to attend. From the first cycle analysis, the following codes stood out about how Neil made meaning of his integrated care experiences.

I'm choosing to do something healthy

When Neil described his integrated care experiences, he talked about the cooking classes, exercises, art projects, and social activities, "So, coming here is doing something, and it's also gym. It's healthy". Neil commented that after observing and testing his abilities, the integrated care staff had then "designed a series of exercises" for him. I interpreted that Neil felt he was choosing to turn up to the integrated care programs, and they were enjoyable and personalised. Neil was also certain, "well, it's not for medical reasons. They can't prescribe things or that sort of thing. As I said, they're not doctors or anything". In Neil's view, medical treatment was his annual visit to the cardiologist, where "he tries to kill me once a year with a stress test" or when he had to take medications. In the way Neil described his medical experiences, I interpreted that he felt he had less of a choice, and it was not always enjoyable.

Keeping positive

Neil's took an active interest in life; I would say he was self-driven and creative. He was motivated by doing things that resulted in improvement. He recognised that maintaining a positive frame of mind was important, "Well, if you're enjoying yourself rather than sitting at home grumbling, that's got to be good for you". His integrated care experiences meant he was actively avoiding, "sit(ting) down and feeling sorry for myself". Neil said that "[integrated care] keeps you active". Neil used the words "enjoy" and "enjoyable" to describe the social interactions he experienced within the integrated care programs he attended. Neil commented positively that the integrated care staff had invited him to share his creative and artistic talents, including leading an art class, as well as purchasing and displaying Neil's original Aboriginal artwork. I interpreted that this was an important acknowledgement of Neil, his craft, and his commitment to the cause of protecting the authenticity of Aboriginal art, which then contributed to his sense of positivity towards the service.

5.3.11.2 Research Focus Question 2: "In what ways did Neil perceive his experiences of integrated care were of use to him?

The way in which Neil described the integrated care programs he attended, being the gym, cooking, art classes, was they were an extension of his own lifestyle. He chose to participate rather than being made to. He engaged with some activities because they were useful activities to do at home, "I take the different stretches home", while some experiences, like the cooking classes, he found to be of limited use, "I never tell [integrated care staff] this because she's terrific at cooking, but I haven't really learned anything [laughter]". However, he did say that he found the "social contact" where they "all sit around, [and] have a bit of a yarn when it's over", as being enjoyable. Neil perceived his experiences of integrated care were useful for him in the following ways.

I'm doing alright

Neil recognised that keeping active was important for his future health. He felt that he was still "reasonably fit and healthy" and that it was useful that he was able to maintain his exercise routine at home while coming to the integrated care program once a week. His experiences of integrated care reinforced or complemented his own approach to looking after himself. The integrated care clinic provided him with useful data that confirmed what he had deduced, he explained, "And they did my density test a while back and everything. I['ve] got the bones of an 18-year-old. I said, 'Really? Oh, because I've never had a broken bone'". Neil used what he learned or was exposed to during his integrated care visits to complete a mental checklist that confirmed his health routine was effective. Neil reflected, "So, I got the good diet, the exercise. I keep my mind busy, as well. Yeah, I don't know. Probably being nearer to the family, but I'm sort of looking at that now. I'm doing all right".

Gives me ideas

Neil reflected that what he had found of most use was, "probably information, knowing what's available. Yeah, it just hit me, I'm going to have to look into that. But yeah, like I said, I haven't really used the whole service, so I don't really know what it's about, actually. So it's probably just going to the gym, really. Yeah. I'll have to see what else is available". I interpreted that Neil was realising in the moment that he did not actually know all the options available to him yet; however, he was confident he would be able to find out more. With concern for others, Neil shared that he had not known about the integrated care programs before they came to him, his reasoning was if you were not sick, you were unlikely to be looking for something to make you better. Neil reinforced his belief, "and I'm not really sick", and yet he had benefited, so others may to. He offered the improvement idea of putting "more information about what it's about", so others can "really look into it".

Being someone who liked to think things through, it was useful for Neil's planning to think about what he should be thinking about so he could keep "fit and healthy" in the future. Neil explained pragmatically,

> I walk up here, but there's going to come a time when I won't be able to walk up, so I won't be able to. I've always looked into the future. It's something I've always been

> able to do for some reason. And I know in five years' time, if I'm still alive, that I probably won't be able to walk up here. I don't have a car anymore. And then, so really, it's just how you're going to get around? That's one thing I'm looking at now.

Neil gave the impression that he would always find a way. Neil seemed surprised when I asked if he had had to contact the integrated care service in between his visits. I felt that Neil could not imagine a situation where he could not come up with ideas himself to solve a problem. He said he "possibly" had their contact number, "but, yeah, no, I've never had to ring anybody up".

Neil referred a number of times to how much he enjoyed the social interactions that the integrated care programs provided. I interpreted that these feelings motivated him in "thinking very seriously" about progressing his plan to move closer to his family. Neil said, "I've got no one here, really. So I'm thinking very, very seriously of going. So it'll be good to be near them. I'll be a bit happier, I suppose".

5.3.11.3 Research Focus Question 3): How Neil Evaluated his Experiences of Integrated Care and Why

Neil was constantly making sense as to how useful thing were now and then looking into the future considering different scenarios and strategies that would enable him to remain "fit and healthy". I interpreted that this was Neil evaluating his experiences. In relation to integrated care, Neil was not able to say how long or how often he attended, it was simply a useful thing he was doing now, and that he was thinking about how he could keep doing in the future. Table 5.24 below presents what I interpreted as being important to Neil from his experiences of integrated care and the measures he actively used to assess and monitor his experiences.

Table 5.24: How Neil evaluated and monitored his experiences of integrated care

What Matters and Why	Measures
Doing what's good for me. **Why?** I've got no one else, I know what I need, I need to work out how to do it, then I'll be ok.	**Self-assessment** Feeling "a bit happier" – "if you're enjoying yourself rather than sitting at home grumbling, that's got to be good for you". Feeling enjoyment – I am feeling in control/confident in myself, I am not fighting to be heard, I am making choices about being physical, eating well, social contact and art. Program is designed for me, for keeping me "fit and healthy". I can do it myself. It feels healthy, it's not about being treating illness, or needing medical advice/assistance.

It’s my idea. **Why**? Neil was creative, a thinker, a protector of what was authentic expression – he held himself to account.	**Self-assessment** I feel I am able to live by my values/code. I am thinking of ideas and thinking my way around things – not being done to me. They get me – I feel respected – my art is on display. I am helping others (art class). I know that it is here – I could initiate if I chose – I have I/C business card with contact details.

5.3.11.4 What is This a Case of: Interpreting the Implications from Neil’s Account of his Experiences

The research’s overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* From immersing and reflecting on Neil’s interview transcript, I interpreted that the meaning of integrated care was that it was a positive way of “doing healthy”. That similar to his experience of the Navy, there were rules and expectations, yet he was ultimately accountable for his behaviours. I felt that he recognised that the staff and what they were doing was authentic, there were no ulterior motives. This meant he could relax, and he surprised himself by enjoying the experience. I interpreted that the purpose his integrated care experiences served was providing a greater awareness of the value of social interactions. His previous strategies were all about doing, fighting for a cause, and avoiding sitting by himself and feeling grumpy. Now, he had had the experience of sitting with others and enjoying the experience. He was looking to the future, and his experiences gave him ideas to play with, in how he could best life his live his way.

The metaphor that I created, as a result of thinking deeply about what was the essence of the story that Neil had shared with me in the context of this research, was “forward-thinking is code”.

5.4 RESEARCHER’S INSIGHTS AND UNDERSTANDINGS FROM REFLECTING ON THE PROCESS.

The research methods served the purpose of enabling iterative, reflective, interactions between the participants’ perceptions of their social realities and my interpretations to better understand the phenomena of interest, or at least the significance or relationships within. The previous section shared my in-depth and detailed data interpretations, while keeping the participants' voices and experiences central to the interpretative account. The following insights and understandings have been included as a way of being transparent and explicit in how I experienced the micro-analysis processes and the insights and understandings that emerged.

5.4.1 Each Participant was Unique and Complex in Their own Way

From first contact with the participants, it was evident that they were each unique and complex people. The interview process was personal, as was how they experienced the integrated health service. A thought that kept reoccurring to me, was that each participant's experience of integrated care was not a stand-alone, or a neatly bounded, event. Their experiences of integrated care were entangled within the larger realities of their everyday lives. An image I conjured was that of the integrated care services spiralling in unison with the person's everyday lives, not quite touching, then being drawn in to serve the person's needs and reconstructed within each person's frame of reference and realities going forward.

5.4.2 Made Me Nervous

The process of progressively focusing, drawing in and then out, examining the participants' codes, and interpreting them within the focus of the research questions was intriguing, invigorating, and yet, made me somewhat nervous. I was taken aback by the frankness, depth, and honesty within the thoughts, feelings, and experiences shared by the participants during the interview. I had intentionally adopted the position of a "passionate participant" (Lincoln et al., 2011, p. 101) as a way of promoting a sense of safety and agency for the participants. I was curious, was it the empathic and conversational approach I had adopted that was influencing the openness of our interactions, or was something else happening that I was not fully aware of as yet? I also lived the experience of the often referenced "weight of the privilege", of listening to the participants and feeling somewhat inadequate in my ability to interpret and re-present their meaning and experiences.

5.4.3 What Difference Does a Role Make?

The rich and meaningful insights, the whole person, that the research participants freely and openly shared with me when we had only just met played on my mind. I noted in my reflective journal that this was a different experience to my usual health care provider-patient interactions. Although I pride myself in being person-centred in my approach, I could not recall ever entering so quickly into such an in-depth and personal exchange during a clinical interaction. I thought about how the information shared by the research participants would have been valuable when forming a care or discharge plan.

I also wondered whether being in the role of the researcher meant that the study participants interacted differently with me, or perhaps I was different with them as a researcher than as I would be as their health provider. In this social situation, they were in the role of a volunteer, who had expressed interest in being part of, contributing to, research about their experiences. Does this situation influence the dynamics of our social interactions? I needed them to complete my research, I wonder if they had something they needed from me. Was I missing something? How could I explore this better?

I reflected on whether as a healthcare provider, if I had truly appreciated the information-rich asset that the person was when in their patient role? I appreciated that I was simplifying the dynamics of the situation, and that there were many other obvious and hidden forces playing out in the background of this social interaction. I was also aware, and encouraged, from my experiences that a small change can make a big difference, and that it can reverberate through a system when there is a shared interest in improving (Patterson, 2015).

5.4.4 My Gestalt Moment

Reflecting on the participants Trent and Carmen, who had shared their experiences of identifying their Aboriginal descent, and the meaning this held for them, I found myself thinking beyond the immediate interactions that were being retold to the broader societal and cultural interactions. I reflected on what made things noticeable, and the potential of not noticing something that was different, maybe ignoring something that you may be familiar with, or the possibility of just not noticing something altogether.

In progressively focusing on the words and the meaning that the participants shared, I found that my thoughts and interpretations also became infused with societal, historical, and cultural influences. My gestalt moment was the realisation that each participant's words held unique meaning. I was drawn back to, and now had a greater understanding of, Riessman's (2005) challenge of researchers that adopt thematic analysis as their primary method. Researchers are cautioned that if their method only focuses on the participant's words, then they will group those words into codes and categories as if everyone means the same thing by the words they use, then the researcher has adopted a scientific, objectivist approach, which means that the method is reinforcing the belief of universal meaning and silences the ambiguities, or those whose words “that don’t fit” (Riessman, 2005, p. 3). I felt like a trap had been revealed that I could have easily slipped into. My research was aligned with the interpretivist belief that people interpret their reality relative to their particular circumstances and may represent it in different ways. Thus, in response, I mentally slowed down, I was very cautious and deliberate in how I interpreted meaning and held myself up to being questioned by my supervisors and peers as to whether I was forcing data to fit a code or whether the code reflected the fusion of my interpretations with the participants’ meanings.

5.4.5 Can we Ever Accurately Understand Another’s Meaning or Just Make Shared Sense?

As I became more familiar with the interview process, I found I was also increasingly aware of the discipline required to quieten my mind to be fully present, while at the same time actively enabling and interacting with the participants as they retold their experiences. I became conscious of the possible influence I maybe having, or my line of questioning may have, on how participants framed their responses. It was interesting that the participants did not appear to notice my dilemma. Many times, the participants laughed when recalling their own words and actions, and they would check-in to make sure I was following their storyline and if I was alright.

I found myself reflecting on what I had read by Catherine Riessman (2005) in *Narrative, Memory and Everyday Life* when I was planning my research. Riessman (2005) proposed that “narratives do not mirror, they refract the past” and that “the “truths” of narrative accounts are not in their faithful representations of a past world, but in the shifting connections they forge among past, present, and future” (p. 6). These words had stuck with me and now resurfaced. I again appreciated the privilege of these experiences of listening to another’s memory, of observing people re-constructing their experiences, forging connections between experiences that had happened over time. I also reflected on the concept of “truth”. I reflected on my concern when designing the research for protecting the participants’ truths. It was important to me to privilege the voice of the people who accessed the integrated care service and their truths, rather than that of those who delivered, managed, or funded the service.

Questions emerged about the concepts of seeking accuracy or even looking for uniformity of thought amongst the experiences and meaning of individuals. Was this even plausible when trying to understand different groups of peoples lived experiences of a health service? Furthermore, what is the risk of leaving voices out, or privileging one voice over another? I sat with the thought that this research aimed to shine a light on a critical perspective that had been missing, it was not about telling the “true” story. The research process revealed the individuality and intensity of the participants’ experiences and meaning to me, as well as their broader societal insights and the opportunities for improvement they noticed. I felt both concern and hope for the future. I could feel myself leaning into the concept of the *Framework on Integrated People-Centred Health Services* (World Health Organisation, 2016 a) and the promotion of participatory approaches like co-production, that on scale this was a step in the direction that needed to be travelled. I imagined co-production as the entwining of the individual, the health services and other people, services, or groups of significance to that individual, each maintaining their integrity, yet being flexible. This image was dynamic and over time. It was also unique to each individual. It was a messy, yet self-organising image that did not require managing, but did require shared understanding and empathy.

5.5 CONCLUSION

Guided by the research’s overall qualitative data analysis plan (**Error! Reference source not found.**), this chapter detailed the first and most significant phase of findings. The interpretive accounts re-presented for each of the 11 participants emerged from engaging in the iterative and analytical synthesis of my interpretations, impressions, researcher journal notes, participant transcripts, and codes. One at a time, using the same structure, each participant’s meaning, and experiences were re-presented. In my role as the researcher, I sought to make sense of what the participants shared through the lens of my own beliefs, thoughts, and lived experiences, and to reflect, confirm, and challenge my interpretations of meaning through taking informal and formal opportunities to engage with my supervisors and peers.

The iterative processes of coding, classifying, and sorting resulted in entangling the participants’ and my thoughts and words until a fused interpretation took shape. An audit trail of each participant’s voice and meaning was maintained to ensure their words and story remained central to their case (see Appendix L: First Cycle Analysis - 11 x Coding Participant Interviews). Table 5.25. and 5.26. summarise the first cycle interpretive findings.

As summarised in Table 5.25 the manual classification and sorting of the participants’ basic descriptive information allowed for greater appreciation of the participants and their circumstances relevant to their experiences of integrated care. Table 5.26 summarises the codes identified from the progressive focusing of each participant’s interpretative account using the first three research focus questions to provide structure. The metaphors created as a way of speculating what I had interpreted as being the meaning of the participants experiences of integrated care are also included in this table. The data in both of these tables provided me with the opportunity to gain a deeper understanding of each participant as a person, and how they made meaning of their experiences of integrated care within the context of their everyday lives.

Table 5.25. First cycle interpretative findings: Participant attribute coding

Participant	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Anne	Date: March 2017 Location: Integrated Care Unit Transport: own car Interview length: 54 mins	75–80	Female	Own home, with husband	Carer	Gardening, regular exercise, being "a detective'	Dermatologist referral (specialist)	~ eight visits since Dec 2016, attended every few weeks over 4-month period	Wound Clinic	General practitioner, community nurse, chemist, plastic surgeon
Helen	Date: April 2017 Location: Integrated Care Unit Transport:: two buses and walked Interview length: 78 mins	75–80	Female	Own home, alone	Retired	Studied biology, social activities, learning skills and languages, two children	Self-referral via GP	~ three visits over 4-month period and initially attended senior week	Wound Clinic	GP practice with seven doctors, chemist
Gloria	Date: May 2017 Location: Diabetic Clinic Transport: own car Interview length: 57 mins	70–75	Female	Own home, alone with dog	Retired registered nurse	Art (painting), visiting friend in aged care facility, attending art exhibitions	Orthopaedic (specialist). Inpatient referral extended to outpatient	Approximately four months as an outpatient	Wound Clinic	GP, rheumatologist, orthopaedic
Lucy	Date: Oct 2017 Location: Integrated Care Unit Transport: own car Interview length: 69 mins	60+	Female	Own home, with husband	Retired librarian	Reading, regular exercise, social activities, volunteering, two daughters	Self-referral (recommended by family)	Visited three times over a 4-month period	Skin Cancer Clinic	GP had retired –now did not have a regular GP
Darren	Date: Feb 2018 Location: integrated care U=unit Transport: own car (travelled 120km) Interview length: 49 mins	35–40	Male	Lived with father in family home	Part-time, university qualified	Visited mother in aged care	Plastic surgeon referral (specialist)	Attending for six months	Wound Clinic	GP, pharmacist, specialist gastroenterology

Participant	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Pepe	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 18 mins	45–50	Male	Own home, with family	Full-time, own, architect business.	Researching, exercise aids	GP referral	A couple of years ago and been ongoing. Initially visited weekly, then moved to alternate visits with the community nurse	Wound Clinic	GPs, community nurse, specialist (vascular surgeon)
Sally	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 24 mins	50–55	Female	Own home, with husband	Full-time, own retail business	Alternative health, spiritual healing	Self-initiated GP referral (recommended by a friend)	Third visit	Wound Clinic	Integrative GP Acupuncturist and Herbalist Oncologist
Beth	Date: Feb 2018 Location: Integrated Care Unit Transport: own car Interview length: 32 mins	80–85	Female	Own home, lived alone (widow)	Retired (was left well provided for by husband)	Gardening, pilates, shopping, researching, volunteering, has six children and has grandchildren	Inpatient referral then self-referral as an outpatient –	Had been attending on and off over a couple of years	Wound Clinic	Same GP for more than 20 years, Community Nurse, Specialists, (lungs/osteoporosis/ colorectal)
Trent	Date: July 2018 Location: Integrated care unit Transport: a lift Interview Length: 37 mins	40–45	Male	Lived with mother in family home	Unemployed tradesman	Walking group, social activities	Hospital referral as an outpatient attending hand clinic	Approx. 18 months	Bulbuwil healthy lifestyle program	GP, specialists, endocrine/gastro/neurosurgeon, pharmacy
Carmen	Date: March 2019 Location: Integrated Care Unit Transport: own car Interview length: 43 mins	60–65	Female	Own home, lived with husband	Retired teacher	Social activities, swimming, children and grandchildren, exercising – walking, social-media	GP referral (on request from Carmen)	Around 18 months	Diabetic Clinic, Bulbuwil healthy lifestyle program	Same GP for more than 34 years

Participant	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Neil	Date: March 2019 Location: Integrated Care Unit Transport: walked Interview length: 24 mins	60–65	Male	Own home, lived alone	Retired from Navy	Exercising artist – painter and short film maker Son and daughter up north	Hospital/ Emergency Department referral – “they knocked on my door’	At least a year	Bulbuwil healthy lifestyle program	Cardiologist

Table 5.26 First cycle interpretative findings: Progressive focusing of each participant interpretative account

Research Sub-Questions	**Research Participants**										
	Anne	Helen	Gloria	Lucy	Darren	Pepe	Sally	Beth	Trent	Carmen	Neil
Q1 Meaning of experiences of integrated care	Abiding by rules	Giving it a go	We have a thing	Making decisions	Being prepared	Good use of time	Getting professional advice	I’m in good hands	Feeling welcomed	Feeling safe	I’m choosing to do something healthy
	Knowing my place	Explaining why	I know what’s going on	Reassuring	Balancing support and service	Feels personal	Feeling understood and respected (acceptance)	Feeling trusted	Feeling like I matter	Empowered to do things.	Keeping positive
		Directing it myself			Being aware		Asking questions	Appealing design	Caring team of health professionals	Access to a knowledgeable and professional service	
		Not Knowing			Being disappointed				Motivating		
Q2 Useful experiences from integrated care	Keeping informed	Feeling safe	Finding comfort from pain	Being proactive – protecting skin (self)	Having instructions	Reliable methodology	New approaches to healing	Knowing backup is close by	Making it is easy to adopt healthy habits	All doable	I’m doing alright.
	Having choices and permission to act	Having a diagnosis	Setting things up	Taking preventative action. Protecting others	Having what I need	Early intervention plan – option to come in	Choosing how to invest time and money	Keeping myself healthy	Thinking positively	Expressing confidence	Gives me ideas

Q2 Useful experiences from integrated care	Anne	Helen	Gloria	Lucy	Darren	Pepe	Sally	Beth	Trent	Carmen	Neil
	Positive experience	Thinking ahead	Knowing them	They know who you are	Keeping health manageable	Helping healing	Gives me confidence		Able to reach out when I needed	It's my choice	
Q3 What mattered most from experiences of integrated care	I now know… what to look for and what actions to take	My thinking and actions will result in benefits for me	I've everything set up – I'm OK	I am taking action	I have access to what I need	My care is customised and promotes healing	Knowing that what I am doing is good, it's promoting healing	I feel I'm in good hands	Feeling like I am somebody	Self-belief – that I can [feels empowered]	Doing what's good for me
	Good use of my time	I have received a 'good' diagnosis.	I know what's going on	I am making decisions	I can personally manage my health	I can attend to my care needs and initiate early intervention	I can live my life my way	I'm keeping myself healthy	Not being a burden to others	I am being healthier	It's my idea
	Good value	I know what I have to do for me going forward	I have access to what I need								
Metaphor	Time is health	Process is reliability	Vulnerability is fuel	Anticipating is avoiding	Unreliable information is a virus	Progress is hope	Respect is a healer	Perfect is Picasso	Feeling care is a lifeline	Self-belief is a butterfly	Forward-thinking is code
Vignette/additional information		Unexpected event vignette – Helpful if I'd known.		Problems or opportunities you have noticed vignette – Times are changing – Are health services?						Table of improvement opportunities	

The significance of this phase of the research was that the method sought to shine a light on what is more often missing in integrated care services' narratives – how the participant makes sense of their experiences. The literature review found that an individuals' personal perspectives of their experiences and what was important to them, were often missing in the design or evaluation of integrated health services. The research's overall framing question was, *What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* The research processes deepened my understanding and curiosity. I definitely had the sense that there was still more to understand. Yet, the findings also revealed unique perspectives on how the experience of integrated care were lived within someone's life.

The use of metaphors to speculate on my interpretations of each participant experiences of integrated care was both challenging, yet surprisingly effective in opening up my thinking to new possibilities. Guided by Swedberg (2014), the metaphors summarised in Table 5.15 were created with words that I believed interacted with each other. I initially resonated with this, as the findings were an interaction or entanglement between my interpretations and the participants meanings. After re-presenting all 11 participant findings and readying to shift to the second cycle of analytic synthesis, in Chapter 6, I move to speculating on a "meso" metaphor for integrated care that emerged from the entanglement of all of the participants' experiences.

The following chapter presents the findings from the second and final cycle of coding, which progressed from analysing the participants' meanings and experiences of integrated care to focus on constructing patterns, themes, and interpretative assertions from across the participant cohort. The findings in Chapter 6 are structured in response to the fourth research focus question, *"Looking across the participants, were there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe them."*.

Chapter 6: Interpretative Findings – Second Cycle – Looking across the Participants' Experiences

6.1 INTRODUCTION

In this chapter, I present the final phase of analysis and the research findings. I first take the opportunity to briefly re-orientate the reader with how I interacted with the research method. Interpretative case study research design enabled me the movement to collect data particular to my inquiry, while also the freedom to be curious and interactive as meanings emerged through the data analysis. It allowed me to gradually construct master themes, a metaphor and, where possible, assert claims as to what this research is a case of. My drivers were wanting to gain insights from a little referenced source and offer an empirical perspective capable of contributing to or refining the existing theories in use.

With an emphasis on interpretation, case study design was chosen as my research method because it has been proven useful in exploring little-researched phenomenon within the context of health services (Lalor et al., 2013). Contemporary health services are described as "messy" settings, because they are complex social systems situated in a constant state of transformation (Rolfe et al., 2008). In seeking to understand something, I adopted Stake's (2010) approach to case study design. His conditions were that the case was functioning as a bounded system, he noted that the functional parts of this system did not have to be working well or rationally (Stake, 2010). Integrated care met the criteria of being a complex real-world situation, it was specific, and its functions were bounded by the literature, and by geographical and bureaucratically defined boundaries (Luck et al., 2006; Stake, 1995; Yin, 2014).

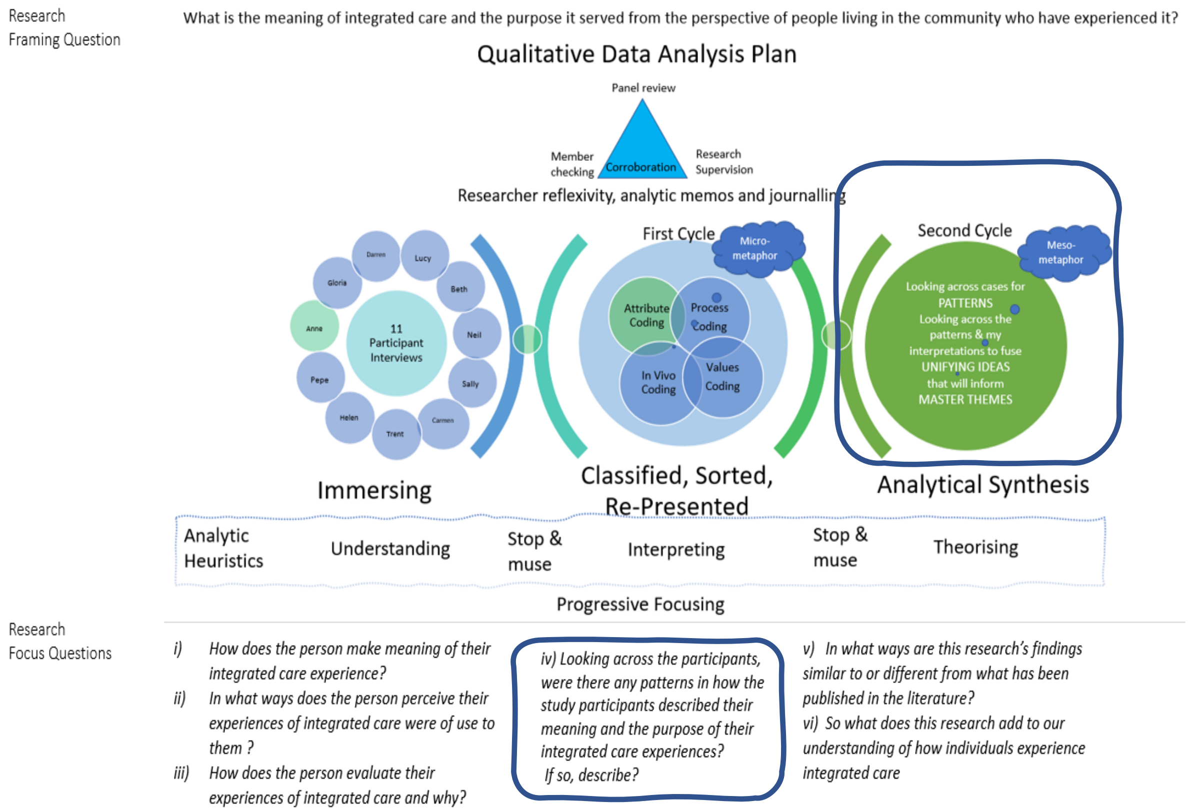
My research interest was embedded within the case of integrated care, in that my interest was to better understand how integrated care works from the perspective of those who have lived the experience. The case was therefore instrumental to gaining this deeper understanding. Stake (1995) called this an instrumental case study, which differentiates from an intrinsic case study, where the inquiry is fundamentally to learn about the particular case.

To this point, I methodically sought and analysed the personal meanings from different people about their integrated care experiences, how they made sense of what had happened, and how this worked for them. Chapter 5 detailed the progressive focusing of each of the 11 participants' first cycle coding, shining a light on what was interpreted as being meaningful and of use for each person. Being an interpretative inquiry, this was followed by the fusion of the participants' words, the sense I made of them, and their relative significance to the research's focus of inquiry. The resulting interpretative data were organised using the structure of the first three research focus questions.

6.2 THE SECOND CYCLE OF ANALYSIS.

This chapter presents what I have called the second cycle of interpretive findings. The qualitative data analysis plan (Figure 6.1) illustrates how the second cycle of analysis shifted focus from analysing each individual dataset separately to bringing their experiences and meaning together. This is where I looked to deepen my insights and understandings of how integrated care was experienced across the study participants to construct master themes, a meso-metaphor and, where possible, interpretive claims to support, challenge, and develop theory. Stake (2010) was an advocate for seeking out multiple interpretations or realities, he felt that as a qualitative researcher taking a constructivist position, that being exposed to different perspectives could only deepen and enrichen my understandings. One of the attractions of case study method is the appreciation that life happens in the real-world and is lived through the lens of the individual, and if the desire is to gain a comprehensive understanding requires multiple perspectives where the meaning and utility of their experiences may vary (Lucas et al., 2018). Taking this approach to building depth within the study's findings also offered the benefit of creating more opportunities for the reader to connect with and visualise their own interpretations of the essence of integrated care. Similar to the first cycle, guided by Stake (2010), this second cycle had planned order, yet continued to be iterative and remained open to emerging and novel interpretations.

Figure 6.1 Qualitative Data Analysis Plan: Highlighting the Second Cycle Analysis


Research Framing Question

What is the meaning of integrated care and the purpose it served from the perspective of people living in the community who have experienced it?

Research Focus Questions

i) How does the person make meaning of their integrated care experience?

ii) In what ways does the person perceive their experiences of integrated care were of use to them ?

iii) How does the person evaluate their experiences of integrated care and why?

iv) Looking across the participants, were there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe?

v) In what ways are this research's findings similar to or different from what has been published in the literature?

vi) So what does this research add to our understanding of how individuals experience integrated care

6.2.1 Second Cycle of Analysis: Process and Structure for Presenting Master Themes

The second cycle analysis addressed Research Focus Question 4, *"Looking across the participants, were there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe them"*. I had not pre-determined the themes before the analysis commenced. Instead, guided by the study's qualitative data analysis plan (Figure 6.1) the second cycle's focus was about the interpretative analysis and pattern identification as a way of drawing on the different participants' perceptions to construct a deeper and richer understanding of the lived experience of integrated care; exploring how integrated care worked from looking across the group's perspectives. I closely examined the first cycle analysis findings detailed in Tables 5.14 and 5.15. These tables displayed the participants' attribute codes and the first cycle of analysis findings. I revisited how each person had made sense of their integrated care experiences, what it had meant to them, and the purpose or use it served.

To do this, I adopted Saldana and Omasta's (2018) approach to analytic inquiry by applying inductive thinking to search for patterns within the participants' different perspectives of their experiences, and then used deductive thinking to construct and explain any of the patterns found. I also applied abductive thinking. Both Saldana (2016) and Swedberg (2014) were persistent in promoting abductive thinking processes as a way of being playful, creatively experimenting, and breaking free from mental habits. This was most useful when re-constructing novel ideas, as was required in emergently constructing the "master" themes.

With quality and trustworthiness being a cornerstone of my research plan, I attempted to capture the messiness and the complexity of constructing, deconstructing, and reconstructed my thinking as I formed my impressions. After many iterations, to provide the reader with an evidence trail, I designed a table to present the findings from the cycles of data analysis and synthesis, as illustrated in Table 6.1.

Table 6.1 Format developed for organising second cycle analysis findings.

PATTERNS OF IDEAS SOURCE: PARTICIPANT INTERVIEW TRANSCRIPT AND DATA CORPUS (INCLUDING COMMONALITIES OR DIFFERENCES)	**AN EXPLANATION** SOURCE: RESEARCHERS INTERPRETATIONS OF WHAT WAS GOING ON (INCLUDING ANY SURPRISES)	**UNIFYING IDEAS** SOURCE: FUSION OF PARTICIPANT AND RESEARCHERS' IDEAS	**MASTER THEME**

The table was a simple and effective structure for visually organising the second cycle findings. Starting from the left of the table, ensuring the participants voice was ever present within the evidence trail, the first column hosted the patterns of ideas, including commonalities and differences, drawn from across the data corpus and supported by participant excerpts. I aimed to include between two to five participant quotes per idea. Moving to the right, the next column provided a brief explanation of the sense that I was making, including any surprises, of each pattern of ideas. I drew on my journal and analytic memos, which I found to be the most effective way to expand and capture my sense making. The next column represented the rigorous back and forth reflective cycles I engaged in as a means of fusing the participants and my meaning into unifying ideas. The final column was the master theme, which was where I grouped the unifying ideas. The intention of the master theme was to both nest and transcend the unifying ideas, maintaining the connection to both the participants experience and responding to the research question.

Below in Table 6.2, I have provided an example of how I constructed the master theme, which is a synthesis of what the participants integrated care experiences meant to them. This example shows the process and structure I described above and its application in developing the master theme, "I am involved my way". The table detailing the comprehensive analysis of all the master themes can be found in Appendix M: Second Cycle Analysis and Synthesis

Participants' Meaning and Purpose Master Themes Further on in this chapter, in the presentation of the second cycle findings, each of the master themes are addressed, highlighting the data linkages and thinking that influenced their development.

Table 6.2 Second cycle analysis: Example of how Master Theme "I am involved my way" was constructed
(see Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes)

PATTERNS OF IDEAS SOURCE: PARTICIPANT INTERVIEW TRANSCRIPTS AND DATA CORPUS (INCLUDING COMMONALITIES OR DIFFERENCES)	**AN EXPLANATION** SOURCE: RESEARCHER'S INTERPRETATIONS OF WHAT WAS GOING ON (INCLUDING ANY SURPRISES)	**UNIFYING IDEAS** SOURCE: FUSION OF PARTICIPANT AND RESEARCHERS' IDEAS	**MASTER THEME**
FEELS PERSONAL (P) – "I am part of the process". Compared to GP group practice who "don't really know me". WE HAVE A THING (G) – "When making changes he'd say, 'how did that feel'. He'd ask, 'was that alright last time'". ASKING QUESTIONS (S) felt "respected" and "supported" by the integrated care clinic, in how they knew "how I want to do it – that's good". ACCEPTANCE) (S) – preferred finding "alternative ways" for herself and friends. "They actually said, 'Well, they do look okay, so keep doing what you're doing'," and that was good to hear". EMPOWERED TO DO THINGS (C) "they are not giving me rules to follow. I was always told I couldn't cook", yet what her experiences of integrated care meant was that she felt "encouraged and "more empowered to do things". [NOT] A GOOD USE OF TIME (P) –noticed that he was being visited by different community nurses who he had to spend time "briefing" and "explaining" the wound dressing to. He raised concerns that inconsistency could prolong his healing, and suggested improvements to the process.	What stood out to me was that each person was involved in a way that felt right for them. There was consistency in expressing that it felt like they had a say; were playing their part their way; they were asking, listening, being heard. They were speaking up – sharing concerns regarding practices of limited value to their health, providing suggestions for improvement – taking accountability to problem solve. I imagined participants were experiencing feeling influential/having freedom/sense of agency/being part of a democratic system (in that they have the power to participate in decision-making) It was like there was a spirit of collaborative in the relationships; they were in this together; with a desire to improve themself and service logistics/processes	**I have a sense of personal agency.**	**I am involved my way.**
EXPLAINING WHY (H) "I'm a bit of an analytical person, I ask questions", "I want to know why, particularly if it's not working, I've got to do something you know". REASSURING (L) – staff explained "look we've really had a good look. There's nothing there". They then invited, "we don't expect to see you but you're welcome", this was important as "I don't want to be seen as one of those worriers who turn up on the doorstep everyday… It comes from how you want to be seen". BALANCING SUPPORT AND SERVICES (D) – referred to "information as key" and being "methodical". He felt anxious on his first visit, he had a lot of thoughts going through his mind. "I did feel	There was a consistent pattern in that it felt like the right approach for that participant. It was what they needed at that time and provided them with the assurance and guidance they required. Whether this was data, information, or feeling invited or part of something, or a blend. I related this pattern to what I understood to be a person-centred approach. I formed the impression that each person's needs, preferences, and health goals were influencing their	**My needs were being met** [personalised]	

overwhelmed yet at the same time supported – the balance was good." FEELING SAFE (C) sought out opportunities for getting a "finger-prick" for testing her diabetes to see if she was keeping on track. The sense of feeling personally safe was multidimensional. Described her processes of continuously and critically processing her thoughts and feelings. FEELING CARED FOR (T) "Your part of a group and it's like a family. It something really special", "You don't feel like you're a burden to anyone. They genuinely care, they're interested".	involvement in, and expectations of, their integrated care experience.		
ABIDING BY THE RULES AND KNOWING MY PLACE (A) "It's like the same as going to the doctors", "it's a job for them", a "free" "friendly" service. "I provide the wound", "social conversation" and "[was] available when they were available". "I don't complain, I don't make suggestions or suggest changes." (A) EXPLAINING WHY (H) "The GP's treatment is the same, it's no different from what the (integrated care) clinic was doing"; however, what was different was that "it (integrated care) feels very individual, not standard treatment'".	There was a pattern in that it was personal, and it was different for each person. To make sense of their experiences, they each drew on and made comparison to their previous experiences. I drew on Anne and Helen's accounts to provide examples of how the construct of the integrated care service was understood to be familiar to their GP clinic. It was interestingly, in how they made sense of their experiences of the same wound clinic It was evident that they were influenced by their personal objectives and goals. Anne sought expertise to progress her healing and would do whatever had to be done. Helen saw herself as the expert and was seeking to tap into different thinking and options specific to her personal needs. The structure and the responsiveness of the service meant both of their needs were met, just differently.	**I could achieve my goals, my way.**	

6.2.2 Second Cycle Analysis: Process and Structure for Presenting the Meso-Metaphor

Replicating the approach taken in the first cycle of analysis, the creation of the "meso-metaphor" required an intuitive and immersive approach to analysis. This was an extension of what I had learned during the first cycle analysis in how to practically apply Swedberg's (2014) novel approach to speculating and adopting an interactional view that encouraged entanglement of meanings and words. The intent behind creating the metaphor was to stimulate people to pause and provide space to think differently, to be playful with what they may have previously thought to be common or known, and to let new understandings emerge.

To do this, I revisited the 11 "micro metaphors" created for each participant's integrated care experience (Table 6.3) in the first cycle. I then applied the same approach for the second cycle; however, I shifted my focus from the participant to pay attention to the interacting patterns of ideas that had emerged from across the participants' integrated care experiences.

Table 6.3 First cycle analysis: Participant metaphors

Research Participants	**First Cycle: Participant micro-metaphors created from interpretations of their integrated care experiences**
Anne	"time is health"
Helen	"process is reliability"
Gloria	"vulnerability is fuel"
Lucy	"anticipating is avoiding"
Darren	"unreliable information is a virus"
Pepe	"progress is hope"
Sally	"respect is a healer"
Beth	"perfect is Picasso"
Trent	"feeling care is a lifeline"
Carmen	"self-belief is a butterfly"
Neil	"forward-thinking is code"

The meso-metaphor I created is presented later in this chapter, in the presentation of the second cycle findings. As cautioned by Swedberg (2014), the power of the metaphor was discovery rather than justification. My intent was to challenge my thinking, to surface any hidden heuristic rules, and open up possibilities for new understandings about integrated care from the unique perspectives of those who had experienced the health service.

6.3 THE SECOND CYCLE ANALYSIS: FINDINGS

The second cycle analysis findings are presented in this section. The detailed evidence trails of the progressive focusing undertaken using the systematic analytic and interpretive approaches described can be found in Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes In staying true to the research questions, and to better understand the phenomena, the master themes are presented with the initial focus on the participants meaning, followed by the purpose or use their integrated care experiences served. This section concludes with the "meso-metaphor" I created for integrated care.

6.3.1 Second Cycle Findings: Master Themes

The master themes were the outcome of the repeated process of reviewing the data corpus to find patterns in how the different participants described the meaning and purpose of their integrated care experiences. As described earlier, these patterns were then fused with my impressions of their meaning to form unifying ideas, and through processes of abductive thinking, took on a new identity known as a master theme. This approach resulted in 11 master themes from across the participants' accounts of their integrated care experiences. The themes were not organised in any hierarchical order. The significance of the themes and their contribution to better understanding what integrated care meant and the purpose it served for the participants are discussed here, including presenting participants' excerpts from Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes to ensure the findings stay close to their empirical source.

6.3.1.1 Synthesis of Participants Accounts of What Their Integrated Care Experiences Meant to Them

Six of the 11 master themes (Table 6.4) were accounted for by the synthesis of what the participants' integrated care experiences meant to them. Below, I briefly expand on each of the master themes individually, followed by the insights that emerged from looking across the participants' accounts of their lived experiences as a group.

Table 6.4 Second cycle synthesis master themes: Participants accounts of their integrated care experiences.

	Master Themes
What did the participants' integrated care experiences mean to them?	I am involved my way
	I have peace of mind
	I am being vigilant
	I analyse and adjust (my involvement to fit the situation)
	I am benefitting
	I am choosing (to make changes that will benefit my health and life goals)

Master Theme: I am involved my way

The master theme "I am involved my way" situates the person at the centre of their integrated care experiences. Each participants involvement was a unique expression of their previous life experiences, their current circumstances, and future aspirations. This meant it felt right for them and it also meant that for another person to understand the meaning of their experiences, they would have to ask them. Feeling empowered, or a sense of personal agency did not lessen the perceived value of working in partnership with their integrated care provider, it just meant they felt as if they had a choice and a voice.

The unique ways participants expressed their meaning included for Pepe, his integrated care experience meant "I am part of the process", which meant he could contribute ideas for "how to improve consistency in the process". For Helen, it meant she could "know why", which meant she could "do something"; while for Trent it meant not "feeling like you're a burden to anyone", which meant he felt "part of a group".

Being involved their way did not mean things would stay the same. What participants were looking for from their integrated care experience, what they were willing or able to invest, and how they played their role varied and changed over time. There was also an appreciation that there would the need for give and take, meaning that both the person and provider needed to play their part and be willing to share their knowledge and resources. This meant that the responsiveness of the integrated care service, in being able to relate to that person as an individual and recognise their unique needs, was more important to the participants experience than the services structural features.

Master Theme: I have peace of mind

I interpreted the pursuit of "peace of mind" as being connected to the pervasive sense of responsibility that participants carried in self-managing their health. Participants came from different perspectives; however, there was a shared belief that "qualified", "experienced", "knowledgeable" integrated care providers "know what they are talking about". As an example, for Lucy being able to "relax and forget about it", rather than "worry" or "panic" was important. Peace of mind was associated with participants experiencing a sense of safety and security. Carmen explained this meant to her, "you've got a safe place".

Professionalism was felt, heard, and observed in various ways. I interpreted that the participants mostly self-assessed their integrated care providers' professionalism using a personal criterion based on previous life experiences. Most broached the assumption of their integrated care providers’ professionalism as a given. This assessment was reinforced if communication was observed between health staff. Trent, who attended the Bulbuwil healthy lifestyle program, assessed the health staff as being “very professional outfit”, this was linked to his observation that “they’re all taking to each other”.

Each participant referenced their personal role in protecting or progressing their health and life goals. The term “stewardship” came to mind, in that they were carefully discerning who could be trusted, or as Beth said, who they could put their “complete faith” in. I did not get a sense that “peace of mind” equated to the participants handing over their responsibility, they welcomed the professionals’ unique contributions; however, continued to see themselves as central to their health care.

Master Theme: I am being vigilant

Vigilance was determined as a master theme because it was broadly expressed as something that participants brought to their integrated care experiences, something that resulted from their experiences and what their experiences meant to them. For most, integrated care meant that they were watching out for their health and personal safety. They were all monitoring their health in some way and were prepared to act. The way in which they responded was personal. For example, Pepe was vigilant in his “monitoring for infection”; while Darren and Helen shared specific scenarios of how their vigilance played out within their integrated care experiences. In their cases, they were potentially placed at risk of harm through communication errors, including incorrect or missing information. Darren expressed how he was “quite disappointed to be honest”. Both took back full control of their circumstances, initiated corrective action, and were prepared to provide feedback to the service. When reflecting on the outcomes of her integrated care experiences, it was Helen’s view that any progress in treatment was, “because of my common sense of what I’ve chosen to do rather than what they (integrated care) said to do”. I was surprised that the experience of a near miss from being harmed did not mean they were not positive about their overall experience.

It was my interpretation that vigilance was linked to the master themes of “I have peace of mind” and “I’m involved my way”, in that integrated care meant sharing the management of their health care; however, the person retained their accountability for taking action to preserve their health and safety.

Master Theme: I analyse and adjust

This master theme refers to the participant's awareness and acceptance that their integrated care experiences did not mean that they should expect the same experiences or play the same role in other health settings or interactions. They saw their integrated care experiences as being bounded. This was not expressed as a concern; it was just how things were. In contrast to the open communication they described within their integrated care experiences, there was uncertainty regarding whether there was any communication between the integrated care providers and their general practitioner or referring doctor. Gloria, a retired nurse, stated confidently, "they haven't talked, but they know". Carmen, a retired schoolteacher, shared that she knew because, "I have to have a new case management plan every year. They must talk, but I wouldn't know"; while Anne, a housewife and carer, was happy to bridge any gaps through being the courier of information. Anne was instructed by her integrated care provider, "next time you go [to your GP] just hand him this".

Within what was described as the amendable circumstances of their integrated care experiences, participants were each differently, yet actively, engaged in seeking information personal to their health care from their providers. This meant they were able to "ask questions" and receive "explanations". In Carmen's case, she recognised the unique value proposition that her integrated care experiences were offering her and shared what this meant for her. Her integrated care experiences meant she felt appreciated, "I feel a bit more appreciated. It's not that my doctor doesn't appreciate me, but he is there just to solve the problem". The value Carmen placed on feeling a sense of being appreciated rather than a problem to be solved meant that she was prepared to adjust her future life plans to enable her to keep accessing the service, "I have actually thought about moving down the coast – but it would be away from this service, [I'm] not worried about leaving my GP, because my GP will move on".

Master Theme: I am benefitting

Each participant associated their integrated care experience as meaning that they were benefitting in some way. What was identified as a benefit from their integrated care and how this benefit was experienced and evaluated by the participants was consistently personal to their circumstances. It was evident that each person had a unique sense making framework, some people leant towards an analytical approach, while others leant into their feelings. Getting to know each person's professional, business, trade background, and/or life experiences and interests was useful in better understanding the meaning they shared about their experiences of integrated care, and to appreciate how they connected what was happening now to what they imagined to be important in the future. For example, Helen, who had studied biology, found it beneficial to know the “facts” and the “rationale”; while Pepe, who had his own architecture business, saw the benefits in “efficiency” and was looking for “return on investment” and “value-add to what” he was doing. For Gloria, who did not “have a family that are going to help me”, it was of benefit to “know them [integrated care] all” so she felt “I’ve everything set up – I’m OK”.

Master Theme: I am choosing

The participants consistently spoke to their integrated care experiences as meaning that they were making choices and expanding their choice options related to their current health and for the future. Five of the 11 participants had in some way self-referred themselves to the integrated care service. Three of these participants had requested their GP write the referral, one participant accessed the service as an inpatient and made her own appointment because she thought she could, and the fifth participant accessed the skin cancer clinic which allowed for self-referral.

It was difficult for most to separate their involvement in their health from their everyday life activities. Carmen said, “I’m involved in my own health. So, my involvement is not just the hours I spend here [integrated care], but 24 hours of every day, of every week, month, year”. For Sally, treating her skin lesions was a “full-time job”, that it was all she “thinks about”. Their integrated care experiences meant they were increasing their options, Lucy would “watch people, try and take on board [what they were doing]”, while for Sally, it meant she could “check things I have researched”. Trent felt they had “given him the tools”; while for Neil, it meant another way of choosing to be healthy that he found “enjoyable”. For some, their experiences were life changing. For Trent it meant he was choosing to live, “it makes you want to keep going” because “I’ve got a purpose to live”.

6.3.1.2 Master Themes Discussion: Synthesis of Participants Meaning

Having studied the particularity or the uniqueness of how each participant accounted for their integrated care experiences in the first cycle analysis, and now in the second cycle looking across the different participants accounts of their lived experiences as a group, I was confounded by how to arrange the master themes in order of significance or relevance to the research questions. A consistent pattern relevant across the six master themes for participants’ meaning was that each person made sense of their experiences through their personal frames of reference. It was my view, that this frame was influenced by their personal biography, values system, and previous experiences, it was also constrained within their current resources and circumstances, and motivated by their daily living goals, hopes, and aspirations. I have included excerpts from Anne’s interview transcript to illustrate the connectivity I identified between the participant, what was important to them, and what integrated care meant to them (Figure 6.2). You may note that each of the master themes were present to varying degrees at different times within Anne’s interview transcript. My assertion is that the significance was not in the frequency or commonality with others, it was in the particular relevance the themes held to that participant in that moment.

Figure 6.2 What Integrated Care Meant to Anne: An Excerpt From Anne’s Interview Transcript

For Anne (75–80 yrs.) “Health is everything.”

“I have a fear of tripping, falling, breaking.”

“I have put rails in the bath and shower, no mats, rail on the front step, the back steps have a slope with two rails. Anytime I see a rail now, I use it. I take particular care – small steps.”.

“I have a neighbour I look out for, as she is on her own.”

“It’s just neighbourly, we are good mates.”

“To stay in your own home as long as you can is very important.”

“It’s very important, I’m a carer for my husband. “I’m his carer’’.

Being involved means “to do things to make your body better or whatever’s the problem”.

“He said, ‘I think you should go to the wound clinic’ [integrated care], and so I went there.”

“I don’t complain, I don’t make suggestions or suggest changes.”

“I will go along with them because they’ve got the experience and professional knowledge.”

“I see most times the wound has improved. It’s got smaller. And what they’ve done has been beneficial and its healing. And that what they’re doing is right”.

Question: “How are you involved?” Anne: “Well, at the moment, I am bathing my nose twice a day [laughter], put ointment on it twice a day, cream on my legs, So that’s no big deal. I’ve got a bit of emphysema, I had a chest infection at one stage and she [physiotherapist] told me to get a bottle, put water in it with a straw, and blow bubbles in it. So, I do that every day. I walk every day, every morning, [for] about 20 mins. I’ve got a few feet problems, so sometimes it gives me a bit of penance, but I do it. I just do it by habit. It’s just part of the routine of the day”.

“I talk to myself – motivate, So that’s kind of my health gig.”

“Definitely staying at home is good, psychologically, you’re in your comfort zone.”.

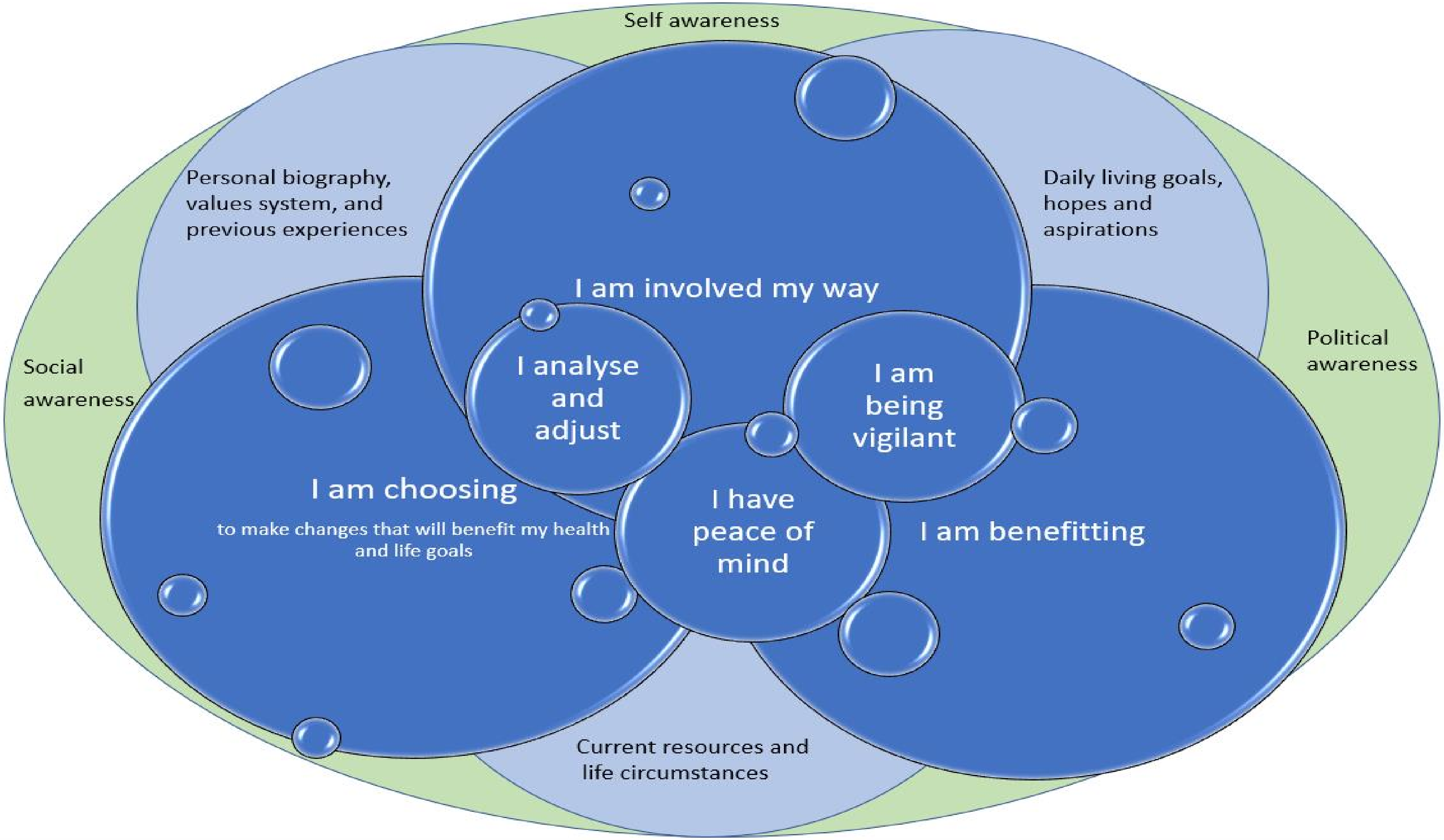
“I know my health [integrated care] team and they know me. That the plan’s to stay home.”

A consequence of intentionally engaging with inductive, deductive, and abductive thinking in the second cycle of analysis, was that when I was attempting to make sense of how the participants made meaning of their experiences, what surfaced unexpectedly was how the participants seemed to be self, socially, and politically aware. There seemed to be an appreciation of the fragile balance of interconnecting systems, which kept everything connected and moving, or as Darren said “symbiotic”. I was interested in whether the participant’s daily living responsibilities heightened the necessity to be conscious of the moving parts of their life world. These personal systems of knowing, and being, stood out to me as being influential or embedded within the meaning that they had made of their integrated care experiences. Participants knew they needed to interact and build relationships with others if they were going to successfully live in their world and live out their life goals. I liken this to them being stewards of their personal health system, vigilantly and proactively advocating for and being guardians of their health and their life goals.

A tentative claim that was building for me was that in summarising the study participants’ meaning, I interpreted that integrated care meant they were choosing to advance their current and future health goals through actively avoiding or anticipating any threats to their health and life goals and carefully sharing their world; in particular, the management of their current health needs with a qualified, experienced-in-the-field professional who may also serve to be a useful contact in the future. They were forecasting and managing the limitations and securing the health of their dynamic living-system.

A rudimentary illustration of how I imagined this dynamic living-system working is depicted in Figure 6.3. In the diagram, the three master themes, “I am involved my way”, “I am benefitting” and “I am choosing” are larger shapes, as there was greater consistency within these patterns of ideas. The other three master themes, being “I have peace of mind” , “I am being vigilant”, and “I analyse and adjust” are represented in smaller shapes, as there was less consistency than the other three, yet they were significant in the context of the participants’ experiences and meaning. They also held the potential to be either an enabler or disruptor to the other master themes. The master themes are nested within the participants’ daily living systems, and then the broader socio-political systems of daily living.

Figure 6.3 Participants' Meaning Master Themes: Illustrating how Their Meaning is Nested Within and Amongst Their Living Systems



6.3.1.3 Synthesis of Participants Accounts of the Purpose Their Integrated Care Experiences Served

The five remaining master themes (Table 6.5) accounted for what purpose their integrated care experiences served for the participants. By this, I was looking to understand what the participants found to be particularly useful or of practical benefit from their experiences. Below, I briefly expand on each of the master themes individually, followed by the insights that emerged from looking across the participants' accounts of their lived experiences as a group.

Table 6.5 Second cycle synthesis master themes: Participants accounts of the purpose their integrated care experiences served.

	Master Themes
What purpose did their integrated care experiences serve?	Equipping me (with the knowledge, skills, and strategies to self- manage effectively and efficiently my current health care needs)
	Giving me hope (providing practical and creative ways that I can adapt and enjoy when maintaining my health and well-being at home)
	Putting things in place (providing actions to protect me now and my future health)
	Inspiring advocacy (stimulating me to think about ideas and test out improvements that will benefit me and others and to protect and promote the service)
	Recognising what is important (everything is connected, holistic, in that how they think, behave, interact with others has consequences for their health and future)

Master Theme: Equipping me

Being equipped to personally manage their health care was fundamentally important to the participants. Their needs were pragmatic and personal. The integrated care experiences provided them with personal and clinical information in a form that was most useful for them to be able to monitor their progress and to quickly identify when things were not progressing as was anticipated. For example, Anne's wounds "were never painful", Gloria "cannot see" hers, Sally felt more confident if they "looked at the wounds…telling me that it looks ok". They found being equipped with observational data was most useful. While Helen preferred "having a treatment plan with instructions on it", Pepe found the "methodology useful", and Darren said his "instruction manual was definitely useful, probably the most useful". They found being equipped with a step-by-step guide gave them confidence. Being equipped also served the purpose of avoiding infection, wasting time and money and, importantly, delaying progress. Knowing when to escalate for review and having a known person to contact served the purpose of providing a sense of certainty and confidence when self-managing their treatment at home. Those who had previous experience of their health deteriorating or delays in seeking treatment felt better equipped to initiate anticipatory actions. There was consistent reference to wanting to invest wisely in their health. Self-managing healthcare can be a resource intensive responsibility. Being equipped with "products and supplies" was useful for testing and estimating the amount of time and money that was reasonable and the amount of inconvenience within their daily activities was tolerable, this had relevance in the short and in the longer-term self-management of their health.

Master Theme: Giving me hope

Feeling like they were learning was a purpose shared by all participants when they were asked to describe what they had found of greatest use or service to them from their integrated care experiences. There was commonality, in that a core purpose of seeking out the integrated care service was because their health or living goals were not progressing as planned or had been disrupted and they needed something new, different, or they had missed something that needed to be rectified so they could get "back on track". Darren had found it useful that he had "learned a lot and did not want to make the same mistakes again". It was useful that any skills, behaviours, or strategies learned were practical and could be adapted and integrated into their daily living and social activities. Carmen was motivated when realised she did not "have to run a marathon", that "walking around the clothesline" was just as effective and she enjoyed that she could "go visit a friend, we can do it together". Anne found it was useful to learn about slowing down, about "making time to heal". Lucy was motivated by learning about what she needed to do to avoid a future that featured "spending hours visiting doctor surgeries". Learning through setting meaningful, achievable, and measurable milestones was useful in generating positivity and hopefulness, which then fed a sense of self-belief and determination. Trent found it helpful to practice adopting a different mindset, he made a habit of repeating the mantra, "the road doesn't just stop here. Tomorrow is a different day". Connecting learning to their goals and aspirations was useful for Gloria and Pepe, who were scanning the latest technology and innovations, thinking creatively about what "would be good for me in the long term".

Master Theme: Putting things in place

This master theme related to the integrated care experiences serving the purpose of helping the participants to calculate what would be the most beneficial actions for them to take now in relation to personally managing their health, and what would also be helpful for the future. Participants consistently stated that getting to know their integrated care provider and for them to be known in return would be the “safest”, “reassuring”, “lifeline” they could put in place. Most participants had varied or absent relationships with a local GP. I interpreted that this contributed to the perceived benefit of being known by your integrated care provider. Lucy described how her GP had retired and she had not been able to find another GP who she “connected with”. Sally’s GP specialised in integrative medicine and was not familiar with wound care, “He doesn’t… He doesn’t know about that. He doesn’t know anything about the actual wound care”. Helen’s GP was now one of seven within a group practice, which might explain why she did not keep them informed regarding the integrated care she had accessed. Carmen explained that her GP of 34 years was “a very busy man with a lot of people to look after”; in contrast, Carmen commented how useful her integrated care experiences were as she felt “genuinely” and “holistically” cared for. There was a consistent theme that the participants were aware of the risk of not having a known health provider who also knew them, their needs, and preferences. Hence, they were planning to take measured action by strategically and intentionally building their personal health network. Participants also consistently raised that information exchange between the integrated care providers and the GP was mostly invisible, which I interpreted as potentially heightening their interest in forming human relationships with their provider as a way of ensuring their needs and what was important to them were communicated. Thus, their integrated care experiences served the purpose of laying the foundations of human-to-human connections.

Master Themes: Inspiring advocacy

When asked to evaluate their integrated care experiences, it was common for the participants to take the opportunity to advocate for the service, responding positively, regardless of any personal concerns they may have experienced. The participants all believed that their integrated care experiences had triggered ideas that were useful for them in their day-to-day lives and in regard to their health needs. They also had ideas about how others could benefit from the service. Participants were positively motivated, they wanted to promote and protect this “free service” that they had found valuable. Those who shared that they had responded to the integrated care service survey were proud that they had been an advocate for the service and ticked all the boxes. Some stated that they would have been happy to talk to their care providers about their concerns, though they chose not to raise concerns via the survey.

Most participants had shared improvement ideas for the integrated care service during their interviews, ranging from “car parking”, “location”, “traffic speed zones”, “advertising”, “types of services” and how the service was operated and funded. Carmen discussed her struggle to communicate the personal significance of her integrated care experiences using the survey and an appreciation that the "immeasurable" elements may jeopardise "government funding", and hence, future access. Each of the participants could provide examples about how integrated care worked for them, including what criteria they used to self-assess their experiences. There was a consistent pattern that their interactions with the integrated care service held a personal value related to the impact it had on their goals and daily lives. I interpreted that the participants' insights and ideas were mostly unique to the participant, and yet would also be of general benefit to the integrated care service.

Master Theme: Recognising what is important

This master theme related to the participants' realisation that everything was connected, and every action taken or not had consequences. The integrated care experiences served the purpose of creating the space for the participants to critically reflect on their mindsets, habits, and choices related to self-managing their health, and what changes they could and needed to make in their daily lives. There was a shared appreciation of taking "preventative action" and recognition that their health and future healthiness was connected to other aspects of their lives. Social connections were shared as bringing much joy, whether they were new connections or re-establishing old connections. Being creative, and engaging in the arts and other activities that connected with their sense of spirit, culture, and community were also identified as empowering and important contributors to their health.

6.3.1.4 Master Themes Discussion: Synthesis of the Purpose Participants Experiences Served

In looking across the different perspectives for patterns in the purpose that the integrated care experiences served, each person's life goals and aspirations remained present as personal organising principles and drivers. In spite of each person's uniqueness, there were consistent patterns across the group in what they perceived as being useful to them. For example, it was useful for all participants to "know", to know the techniques that the integrated care providers used, and to know what they looked for and how they measured progress. The analysis revealed the pattern that self-managing your health was a considerable investment for each person, whereby they were constantly assessing the perceived utility within the context of the time, cost, and disruption that their health treatment offered. They were constantly looking for alternatives or innovations that could help them to reach their goal or sustain changes. Participants were aware of or sensing that contemporary models of group general practices and the retirement of GPs threatened their sense of feeling known by or connected to their GP. I interpreted that the participants were intentionally investing in building relationships with their integrated care providers as a fail-safe. All participants placed great importance on establishing human relations and the sense of being connected to others. I interpreted this as activating their steward of health or guardian role, with the relationships offering a form of protection that then gave peace of mind when self-managing their health at home.

A tentative claim that was building for me was that in summarising the perceived purpose of their integrated care experiences, I interpreted that the purpose integrated care served was to improve their current position, and to make progress against what had motivated, hindered, or been missing for them in advancing their health and life goals. The purpose integrated care served was nestled within each person's meaning. Integrated care provided the mechanisms for putting their meaning into action. The participants' purposes also served to generate a practical energy, they shared ideas and improvements that went beyond serving their self-interests. The participants were thinking about others, their circumstances, there was a sense of empathy and advocacy. There were imagining how others could benefit through having similar experiences to their own integrated care experiences. Social connectedness was found to amplify the perceived benefits of their health care and their sense of well-being. Integrated care was useful, sometimes directly, yet mostly indirectly, in reducing social isolation through supporting new social interactions or enabling existing interactions to continue. The purpose that their integrated care experiences served for them were at times unexpected, while at other times profound. I did not get a sense that the insights from their experiences were being shared with the service. Influenced by the many learnings and insights I had experienced through listening to their experiences, I saw this as a significant missed opportunity.

6.3.2 Second Cycle Findings: Researchers Reflections and Claims

The qualitative data analysis plan laid out a robust and deliberate approach to mining the research data – the participants' lived experiences of integrated care – as a way of immersing myself in their experiences and building a greater understanding of the meaning these experiences held for them and the purpose being served; how they understood integrated care worked for them. I then looked across the participants seeking patterns and unifying ideas that resulted in the master themes presented through gaining a better understanding of how it worked from their multiple realities.

6.3.2.1 It Is All Connected

The analytic processes were effective in drawing out and constructing master themes that were entangled within the different participants accounts of their integrated care experiences. What had become progressively evident throughout the analysis was that each participant's sense of meaning and purpose attributed to their integrated care experiences was also embedded within their life-world and goals. In Figure 6.4., I illustrate the pattern that emerged across the master themes, in that the purpose their integrated care experiences served was primarily to make practical progress, including providing intel and generating ideas that were of personal benefit.

Figure 6.4 The Relationships Between Participants' Meaning, Purpose, and Their Integrated Care Experiences

Simply put, their personal meaning was their desired outcome, and the purpose served was to use their integrated care experiences to move closer to this outcome. This suggested to me that although each person had perceived their experiences differently, emphasising different parts during the interview, there was the commonality in that nearly everything experienced was intentional, and linked to their meaning. Furthermore, it was evident that the participants were thinking beyond their personal benefit to considering the needs of others. There was a sense of neighbourly or community spirit, of looking out for each other. Their experiences had armed them with information and ideas that would be of benefit to others.

6.3.2.2 It Is Their Reality

This long path of data collection, analysis, and reflexive practices led me to a greater appreciation that the significance the participant placed on their experiences were generative processes of understanding. It was about how they had unpacked their actions and interactions into what they were thinking and feeling, then expressing them in what they believed to be happening. I felt and interpreted that the participants were unlikely to have previously paused to think back on and then bring forward the story of their integrated care experience, what it meant to them, and the purpose it served. Through the interpretative analysis, some participants stood out as having a more structured framework, while others had a system of interrelated personal beliefs and heuristic rules that they drew on to make sense of their integrated care experiences and their everyday life. For example, after numerous re-readings of Darren's interview transcript, I noticed a pattern in how he made sense of and then retold his experiences. Summarised in Figure 6.5, in my analytic memo I had called this his health belief model; however, it could also be called Darren's approach to life, which he then applied to his health.

Figure 6.5 Darren's Personal Health Belief Model as Interpreted From His Interview Transcript

Darren's integrated care experience: Personal health belief model in action

- I can be educated/instructed/coached.
- I can add to/complement from other sources.
- I can access the medication/supplies/support I need.
- I am able to make choices/accept consequences – self-manage my time
- I can access information/expertise required to get results.
- I cannot afford to get sick or have mishaps. This is not good use of my time or resources.
- Technology can enable information transfer — reduce risk/inefficiency — over under/wrong treatment.

What surprised me was that the integrated care experiences were collectively significant across the participants, in that they formed part of their systems of living. They served the purpose of meeting an immediate need and an anticipated need, simultaneously. It felt like their integrated care experiences were potential pivot points in their personal life that revealed their vulnerabilities and resourcefulness. The impression that formed was that each participant was intentionally and actively involved and influencing their integrated care experiences in their own way. How they went about this reflected their life's circumstances and sense of responsibility for themselves and to others. For example, Lucy helped me to understand that to her "avoiding" was an intentional, proactive strategy.

6.3.2.3 What Have I Learnt

In thinking back to what drew me to this research, my initial curiosity was to better understand what it was like for people to experience integrated care in their context, what it meant in their everyday life. The study method enabled me to gain a much better understanding. I now appreciate both the universality and the somewhat radical intent of the WHO’s (2016 a) definition of people-centred care:

> **People-centred care**: an approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and respects social preferences. People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services (p. 2).

I also have a greater appreciation of how embedded and personal these experiences are when lived, and how entangled they are within a person’s life world. What stood out was that every health interaction should be people-centred and approached in the spirit of co-production (WHO 2016 a). At the most basic level, it is about getting to know the person first; followed by the person letting themself be known and agreeing on what the best use of their time, resources, and expertise would be, and how to keep both on track.

> **Co-production of health:** care that is delivered in an equal and reciprocal relationship between professionals, people using care services, their families, and the communities to which they belong. It implies a long-term relationship between people, providers, and health systems where information, decision-making and service delivery become shared. (WHO, 2016 a, p.4)

To summarise what I learned from the study findings, the statement of claim that I constructed throughout the discussion is presented below, accompanied by a brief narrative.

Statement of claim

All of the study participants were living at home and attending to their health. They had all enrolled with an integrated care program, visiting a minimum of three times. Most were looking to improve their immediate health status through making progress against what was motivating, hindering, or believed to be missing for them in advancing their health and life goals.

They were highly invested, in the immediate and longer-term, in the pursuit of value-add health care for themselves and others. Their personal metrics and insights were both empirical and experiential interpretations of their everyday reality.

They expressed a sense of hope, empathy, ideas, and logic that would provide valuable contributions to reorientating a health service towards a people-centred philosophy that aims to serve the health care needs of people living in the community.

Participants made assumptions rather than having evidence to support the concept of integrated care being a coordinated experience beyond their immediate care experiences when interacting with different health care settings and providers. Participants tended to position themselves as modelling integration and responsiveness, rather than the health services.

Accompanying narrative

Participants described their responsibility as being like the 24/7 guardians of their health. Integrated care meant they were choosing to advance their current and future health goals, which meant they were taking action to avoid or anticipate any perceived threats to their health and life goals through carefully letting someone have influence within their precious lifeworld.

Although some were referred to the integrated health service, there was a sense of choice in accessing the service to attend to their immediate health needs. They vigilantly applied their personal criteria, which was a combination of their biography, personal values system, previous experiences, and availability of resources to closely monitor and assess their progress.

If they determined the service provider to be an experienced-in-the-field professional with good interpersonal communication skills who was interested in them as a person and who contributed reliable, accurate and useful information, then they were likely to be assessed as a worthwhile investment of their time and resources.

Participants had the agency to adjust their criteria or would tolerate some variations if they deemed the benefits to them outweighed the possible risks. Once the participant had determined the integrated care service to be a trusted resource, it was then incorporated as an enabler to progress personal health goals and as a resource within their health network, and they would promote the service to others. Planning forward, knowing the service and the service knowing them gave them the greatest peace of mind.

The participants shared an understanding that the integrated health service was not operating beyond this service as an integrated health system and that they would need to adapt their approach and expectations when attending other health services.

6.3.3 Second Cycle Findings: Creating a Meso-Metaphor

My initial decision to create a metaphor was inspired by Swedberg's (2014) ideas and approaches to theorising in the social sciences. Creating metaphors was not something I was practiced at doing, it was a new way of thinking. When reflecting on the approach and experience from the first cycle analysis micro metaphors, where I crafted a metaphor for each participant's integrated care experiences, I found the process to be both challenging, yet effective. I was challenged to question what meaning I attributed to words and was surprised by my unconscious mental short cuts and the speed in which the mind links words and meaning, which reinforced the importance of context to me. Swedberg (2014) said that the use of metaphors in theorising is in the "context of discovery", of looking for new ways to connect meaning to a phenomenon (p. 17). I found the process of creating the metaphor was effective in generating novel ideas in how to interpret each person's experiences of their integrated care experiences.

6.3.3.1 Building Curiosity and Creating Space for New Meanings to Emerge

One of the things that drew me to this research was the realisation that the practice of understanding what is important to an individual, their voice and perspective, is often marginalised or missing from the research and evaluations that inform service design (Birrell & Heenan, 2014; Consumers Health Forum of Australia, 2013; Evans et al., 2014; Goodwin et al., 2014; National Voices, 2015; Redding, 2013; Wigens, 2016; Wilson et al., 2009). I was conscious that the absence of their voice, their perception of value or assessment of risk, would mean that the voices of the funders, managers, clinicians or academic would be privileged (Brannelly & Matthews, 2010; Ferrer, 2015). Acknowledging the human tendency to give attention to what is known or aligned with personal beliefs in elevating an unfamiliar voice, I was mindful that it may be difficult to comprehend what was being said. Meaning that the new voice, the person's meaning, may get lost or be quickly coded into something else. The new voices would then be connected to old meanings that the listener was more familiar with. This is a recognised phenomenon, it is not necessarily intentional, it is just that the code for this new voice may not exist in their consciousness (Metzgar, 2013). In my attempt to avoid this occurring, I looked for a playful yet respectful way to introduce words that would emphasise their novelty, to the nudge the listener to pause and question, “I wonder what this means?”.

In this second cycle analysis, I brought together the participants’ different realities to gain a wider and deeper understanding as to the meaning and purpose of their integrated care experiences. I looked for patterns within the group’s individual experiences. The master themes presented earlier expressed the complex interactions between the participants words and meaning. The process was provocative, I discovered new understandings that made me curious to understand better; “I am wondering”. In creating the meso-metaphor, my intent was to bring these new understandings to life; rather than transfer meaning between words, I was looking to surprise and inspire deeper thought.

6.3.3.2 The Person is the Steward; Integrated Care is an Embodied Experience

The second cycle findings presented integrated care as a dynamic, interactive, and deeply personal experience that was person lead. Through the discussion of the master themes, I gradually built a summative interpretative claim as to what I learned about how integrated care works from the perspectives of the study’s participants. Integrated care meant they were choosing to advance their current and future health goals, and they were benefitting in that they were better equipped to anticipate or avoid any threats to their health and life goals. They were each forecasting and managing the limitations and securing the health of their dynamic living-system. I believe that the meaning and purpose of a person’s integrated care experiences cannot be truly understood without the voice of the person experiencing it.

The meso-metaphor I created “*The person is the steward; integrated care is an embodied experience”* was formed from an entanglement of immersing myself in the study data and findings. I propose that when functioning well, integrated care forms part of a person’s ecosystem. It serves to protect, nourish, restore, advance, and sustain life goals, inclusive of what is important to their health. In this study, the participants took the lead and were responsive, continuously gathering, processing, transferring, adapting, and adopting information that informed how they perceived, felt, and interacted with their integrated care experiences. They were the agents of their experiences. This metaphor made me wonder!

6.3.3.3 Integrated Care is not a Coordinated or Connected Well-Functioning System in Itself

A proposition from the findings is that participants were mostly living their own experiences of integrating the model of care into their lifeworld. This study re-presented 11 unique integrated care experiences of the same integrated health service. Each saw the value of the experience for themselves, the potential for others, and had ideas or feedback about how to improve the experience. However, there was not a pattern of people feeling that beyond their immediate experiences that integrated care was part of a coordinated or connected system. Many had secured access to the service through their own personal research, networks, or actions. Their primary care providers and the participants were unlikely to have been aware of the service's existence prior. For most, they understood that integrated cares communication, including its information pathways with other parts of their personal health system, were not obvious or reliable. The integrated health service's feedback mechanisms were primarily understood as a way that people could protect what was available to them and secure availability for others. The study participants could see threats and opportunities for integrated care as a model of care delivery. The metaphor's focus was the person, rather than the model of care, because from the person's perspective it was mostly their efforts that made integrated care work for them. It is important that my metaphor does not encourage the assumption that integrated care was a coordinated or connected well-functioning system in itself from the participants' perspectives.

6.4 METHODOLOGICAL INTEGRITY

In presenting the first and second cycles of analysis and findings, I purposively discussed the triangulation or corroboration strategies embedded in the study design for protecting the integrity of this qualitative health services research. I consistently adopted Stake's (2010) position as the case study method guiding the research. Adopting an interpretivist approach, Stake's (2010) stance sought to understand meaning and processes as perceived from different perspectives, trying to understand individual and shared social meanings (Crowe et al., 2011). In taking this position, the study context and situation formed the background; while the content, such as "the activity or group or relationship" was the foreground (Stake, 2010, p. 50). The study focused on gaining a deeper understanding of how the participants understood their experiences, with the goal of building a holistic understanding of a phenomenon that was continuously evolving.

Other case study researchers whose position I considered and then discounted were Ragin (1992), whose focus was on the "casing" of what was to be studied, rather than the methodology or data collection techniques; while Yin's (2009) approach to case study inquiry focused more on looking for explanations, asking "why" research questions, where the researcher was looking for links and tracing them over time. Regardless of how I positioned the research, it was consistently reported in the literature that the methodological flexibility that case study research features is also the greatest limitation in achieving quality case study research. To counter this, securing supervision from experienced researchers was widely recommended and was the main strategy I adopted throughout the research, as well as the use of structured frameworks where any changes to the design could be clearly articulated to enhance trustworthiness and transparency (Paquette-Warren et al., 2016). I adopted Stakes (1995) recommendations to engage with and seek convergence where possible using different forms of corroboration, such as data sources, investigators, theories, and/or methodological triangulation.

6.4.1 Establishing Trustworthiness and Transparency

In Chapter 1, I presented the tentative research on a page (Figure 1.1 Research on a Page – A Tentative Plan), which was structurally designed to situate the research. It signposted the connections and interactions between the research design elements and the research question. For transparency, it was important that I recognised and referenced what I had brought to the study as an interpretive researcher. In Chapter 2, I expanded on my personal and professional biography, my experience, and critical subjectivity.

Following the review of the literature in Chapter 3, I clearly detailed the amendments I made to the tentative research plan in Chapter 4 (Figure 4.1 Updated Research on a Page Figure 4.1 Updated Research on a Page). The qualitative data analysis plan (Figure 4.2) was the structure that guided the progressively focused cycles of data analysis and synthesis presented in Chapters 5 and Chapter 6. The plan required a discipline approach, balanced by embedding reflexivity and abductive thinking (Stake, 2010). Throughout the research processes, I diligently maintained a detailed evidence trail, always staying close to the participants' words and perceptions. I signposted in the research report where I sought clarity and convergence through engaging with people who held different perspectives to explore my interpretations and to examine my approach. This included orchestrating formal and informal opportunities to critically examine my research design, methods, and interpretative findings. Each participants' detailed interpretative account (see Appendix L and Appendix M) was provided to allow the reader to join me in immersing in the study and I invited the reader to engage with my novel approaches, such as creating metaphors.

6.4.2 Continuously Monitoring Research Quality

In addition to the structures purposively designed for this study, I was guided by an existing criterion for qualitative research. The Consolidated Criteria for Reporting Qualitative Research (COREQ) qualitative research checklist enabled me to plan for and continuously monitor the quality of my research (Tong et al., 2007). Table 6.8 shows how the COREQ domains were used to routinely inform, review, and reflect on how I approached the method of data collection, data analysis, and reporting of the research findings (Tong et al., 2007). The structure the checklist provided ensured I comprehensively detailed the aspects of the study that could assure the reader of the quality of the research. This approach is also recognised as being useful for guiding future researchers who may be looking to learn from or duplicate the study methods.

Table 6.6 Signposting where the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist three domains guided the research method and reporting

COREQ Domain	COREQ Item	Location in the research
1 Research team and reflexivity	Personal characteristics of the qualitative researcher	Chapter 2: The researcher
	Relationship with participants	Chapter 4: Research protocol
2 Study design	Theoretical framework	Chapter 1: Research conceptual framework: Research on a page – A tentative plan Chapter 4: Interactive research Model: Research on a page V2
	Setting	Chapter 4: Research protocol
	Data collection	Chapter 4: Research protocol
3: Analysis and findings	Data analysis	Chapter 4: Qualitative data analysis plan
	Reporting	Chapter 5: Interpretative findings – First Cycle: The participant accounts of their experience. Chapter 6: Interpretative findings – Second Cycle – Looking across the participants

Adapted from the Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups, Tong et al., 2007, pp. 351–356

6.4.3 Summary

Integrity was particularly important when it came to summarising the understandings that resulted from engaging with the research design and interpretative method. Stake (2010) argued that an interpretive claim’s trustworthiness can be enhanced through exploring how different people from different backgrounds understood what was being described; however, it was important that the claim was not positioned as being an explanation rather it represents what could be best said “in a qualitative voice” (Stake, 2010, p. 169).

Another way of describing the product of my processes of summarising, is the development of theoretical propositions, which have been described as rich summative statements. Saldana and Omasta (2018) explained that when theorising, you are logically organising your insights to respond to the question “What did you learn?” (p.261). They also suggested that the language used should reflect the variations within the empirical data and be tentative in nature in what is being proposed (Saldana & Omasta, 2018). Both approaches require any statement of claim to be underpinned by empirical evidence. To support this, throughout the study, particular attention was paid to providing detailed accounts of the research method, including the research protocol presented in Chapter 4, and the processes of analysis, synthesis, and interpretations in chapters 5and 6. As cautioned by Saldana and Omasta (2018), summarising and condensing the study’s qualitative data into a one- or two-line statements can prove challenging. Therefore, the proposed statement of claim for the research, was accompanied by a narrative that also served to bring transparency to my thinking processes.

Finally, careful consideration was given to constructing a personal experience for those who will read this research with the goal that “the person feels as if it happened to themselves” (Stake, 1995, p.85). I am hopeful that my approach enables the reader to make connections with the data and the findings, and that they can then apply them to general situations they are familiar with and explore their meaning further.

6.5 CONCLUSION

In this chapter, I presented the second and final phase of analysis, and the research findings. My drivers were to gain deep and rich insights from a little referenced source and offer an empirical perspective capable of contributing to or refining the existing theories in use. My approach included immersing myself, with methodological integrity, in the study participants accounts of their lived experiences in order to construct master themes, a meso-metaphor and, where possible, an interpretive claim to support theory development.

The qualitative data analysis plan was shown to be effective. The second cycle analysis produced a total of 11 master themes; six of the master themes accounted for the patterns identified within the participants meaning and five of the master themes accounted for the purpose the participants perceived that integrated care served for them. This approach revealed that integrated care experiences were unique for each participant; however, there were patterns in how they made sense of these and that their purpose served their meaning. The participants' meanings were nested within their broader life-world, and the participants' purpose was to deliver on their meaning; it was all connected.

The multiple readings of the study findings provided me with an intimate familiarity with each participant's data, and through exploring across the participants' experiences for patterns, I then developed a deeper holistic sense of the data corpus. I began building this study's claim that the meaning and purpose of a person's integrated care experiences cannot be truly understood without that person's voice. To present what I learned from the study, I constructed a statement of claim that was accompanied by a brief narrative to situate the claim within the empirical evidence and the context of the research.

Finally, I again engaged with Swedberg's (2014) abductive thinking processes to create a novel and provocative entanglement of words that I believe captures the essence of integrated care, what it is a case of. Landing on the metaphor "The person is the steward; integrated care is an embodied experience", I propose that from the participants' perspectives, it was mostly the person who made integrated care work, and each person went about it slightly differently. When functioning well, it formed part of that person's ecosystem.

I interpreted from the participants integrated care experiences that integrated care was not always reliable, not everyone had known about the service, and it was not clear how the service communicated with other parts of the health system. In difference to the dynamic living ecosystem that each person had in place, integrated care as a health service was not found to be a connected well-functioning system in itself.

In the following concluding chapter, I respond to the final research focus questions. I also discuss the ways in which the research findings are similar to or differ from what has been published in the literature, and what the research adds to understanding of how individuals experience integrated care.

Chapter 7: Discussion and Conclusions

7.1 INTRODUCTION

"The person is the steward; integrated care is an embodied experience"

This research sought to understand the case of the lived experiences of integrated care through privileging the voice and lived experiences of individuals who resided independently in their home in the community. The findings of this research provided deep insights into the unique lifeworld of 11 individuals, with a focus on their meaning and perspectives related to their interactions with the same geographically located integrated health service. Exploring the study participants' accounts of their lived experiences, revealed that their integrated care experiences were anchored to them as individuals, in their stories and their truth as they knew, felt, and retold it. This was a consistent pattern.

Across their accounts of their lived experiences, I interpreted the person as being an agent for their health, this included being a vigilant steward of their integrated care experiences, intentionally using this experience to gain the greatest benefit for their overarching health and life goals. The insights the participants expressed revealed degrees of socio-political awareness, fiscal accountability, emotional intelligence, criticality, and creativity in their approaches and sense making. They were the experts in navigating their complex lives. Their integrated care experiences served their personal meaning, their immediate and anticipated health needs, and life goals. The perceived benefits of their experiences were personal, with each person watchfully monitoring and assessing the service's effectiveness and efficiency in making progress towards their desired outcome. I did not get a sense that the participants had completely understood their experiences in the moment of experiencing them. How they were making sense of and making integrated care work for them was an emergent construct, facilitated by our semi-structured interview conversation and their imaginations.

As retold by the participants, health was their constant companion along their life course. The experience of health care, as offered by the integrated care programs, was perceived mostly as an enabler and resource for their immediate and future health, including their well-being. In their words, their integrated care experiences seemed similar to other forms of health care. It was not perfect, there was room for improvement. It was something they saw personal benefit in joining forces with, something they wanted to preserve, and that they could see others benefiting from. Integrated care served a purpose, it contributed to and supported their health. How integrated care related to other forms of health care was not clear to the participants, or was of great concern to them.

In this concluding chapter, I returned to the literature that was reviewed to inform the research question and qualitative data analysis plan. In acknowledging that this research spanned eight years, I also updated the literature review to ensure the latest thinking and new understandings were referenced. I synthesised the research findings with the literature and discuss the value and implications of the study and argue the contributions that this study offers to enrich and deepen our understanding of how people living at home self-managing their health perceive their integrated care experiences. I present insights and propositions from applying my research method, including how this research and its findings advance existing understandings and implications for theory and practice. Finally, I summarise the strengths and limitations of the research, and provide closing comments.

7.2 ADDRESSING THE RESEARCH QUESTIONS.

Guided by what I had learned from the literature review in Chapter 3, the research design introduced in Chapter 1 was refined to ensure the goal of respecting and privileging the voices and perspectives of individuals was central and explicit in every interaction. The question that framed this research privileged the participants perspectives in asking, "*What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?*".

Chapter 4 detailed how the literature guided the refinement of the research protocol to ensure that the research would always be kept close to the participants' voices and that their voices would guide any theoretical insights or practical implications that the research offered. The six research focus questions provided the structure that allowed me to move between answering the research question and continuing to be responsive to the participants' experiences. Research Focus Questions 1 to 4 guided the generation of the study's empirical findings, as presented in Chapters 5 and 6. This chapter focuses on Research Focus Questions 5 and 6. Here, I interpret the study's findings and consider them in relation to the literature that informed the research question and design, as well as any recent developments in the field. The research goal, framing question, and focus questions were in dynamic relation. In Table 7.1 I have signposted their interactions and where each focus question's findings were presented in the thesis.

Table 7.1 Signposting the interactions between the research goals, questions, and findings

Research Goal and Research Framing Question	Research Focus Questions	Signposting Responses to Each Research Focus Question Within the Thesis
The goal of this research was to respect the person and privilege their voice and perspectives in order to gain a greater insight into the phenomenon – personal experience of an integrated health service. The framing question of this research was, *"What is the meaning of integrated care and what the purpose does it serve from the perspective of people living in the community who have experienced it?*	1. How does the person make meaning of their integrated care experience? 2. In what ways does the person perceive their experiences of integrated care were of use to them? 3. How does the person evaluate their experiences of integrated care and why?	Chapter 5 First cycle data analysis interpretive findings (Appendix L: First Cycle Analysis - 11 x Coding Participant Interview
	4. Looking across the participants, are there any patterns in how the study participants described their meaning and the purpose of their integrated care experiences? If so, describe them.	Chapter 6 – Second cycle analysis interpretive findings (Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes
	5. In what ways are this research's findings similar to or different from what has been published in the literature?	Chapter 3 – Literature review findings (Appendix F: Literature Review Synthesised Findings Chapter 7 (7.2.1 to 7.2.5) Comparing the research findings with the 2008–2018 literature review findings, including consideration of any recent developments in the literature 2018–2023.
	6. What does this research add to understanding of how people experience integrated care?	Chapter 7 (7.2.6) How this research and its findings advances existing understandings, including implications for theory and practice

7.2.1 Situating the research and its findings in light of the literature, then and now

Noting that people around the globe are still making sense of what the legacy for health services will be as a result of the COVID-19 pandemic, it was considered important to take steps to situate my research's findings within the context of the contemporary literature and changing health care landscape. I completed my original literature search in July 2018, where I included the limit of looking back over the past 10 years. My research interviews were completed from March 2017 to March 2019, which was pre-COVID-19. I took leave of absence from my research during the peak of the COVID-19 pandemic in NSW, early 2020 till late 2021. To identify any developments in the field that were published between July 2018 and July 2023, I re-ran the original search strategy. A summary of the results and findings from this new search of the literature is provided in Table 7.2. To assist the reader, I have included a summary of my research findings and the findings from the 2008–2018 literature search in the table alongside the 2018–2023 literature search findings. In the following section, I address Research Focus Question 5 and expand on Table 7.2's summary of findings and discuss their similarities and differences in light of the research question.

Table 7.2 Situating the research findings within the literature, then and now

Research thesis	**Research literature review *(2008–2018)***	**Recent Developments in the literature (2018–2023)**
The *research goal* was to respect the person and privilege their voice and perspectives in order to gain a greater insight into a phenomenon – understanding the personal experience of integrated care by adopting the perspective of the person (patient). The overarching question that framed the research was, *"What is the meaning of integrated care and what purpose does it serve from the perspective of people living in the community who have experienced it?* *The six research focus questions* outlined in Table 7.2, enabled an iterative and progressive approach that allowed the research question to be explored while attending to the research goal of privileging the study participants' voices and being responsive to their experiences.	The literature review had three primary objectives. *Objective 1.* To identify pragmatic approaches (that have been applied in real-life settings) to examining how individuals construct their expectations and/or experiences of an integrated model of health care delivery across a range of settings. *Objective 2.* To understand how the study method elicited personal meaning to identify person-level outcomes that reflected issues and outcomes important to the individual. *Objective 3.* To propose recommendations on the benefits and insights that person-level outcomes offer integrated model of health care delivery across a range of settings. *Literature Review Inclusion Criteria* *Population:* All adults (older than 18 years) living in the community *Phenomena of Interest:* Studies that investigated the perspectives of individuals whose health needs were suitable for or who had accessed an integrated model of health care delivery to determine how individuals constructed their needs and wants (what was important to them) and/or their experience of the model of care, focusing on issues and outcomes important to the individual. *Context:* Studies that described primary or secondary level health care service as being an "integrated model of health care delivery': an outpatient, primary health, community, or home setting where more than one provider of care or health care service aimed to deliver a coordinated, multidisciplinary, person-centred experience of care. These settings could be located in any country or cultural or geographical context. *The* Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement and checklist guided the systematic review strategy (Chapter 3 Figure 3.1)	A rapid review approach with a specific interest in what was novel or new, and whether it confirmed, refuted, or extended previous findings was undertaken as a way of timely synthesising any recent developments in the literature and summarising the findings (Featherstone et al., 2015). This approach met the objective of understanding developments in the field relevant to the research question and initial literature review completed in 2018. The three-step search strategy used in the original literature review was modified as follows: *Step 1:* The original search strategy was re-run. Only searches that had time limits were amended. For example, searches with limits of the past 10 years (2008–2018) were altered to limits of the past five years (2018–2023) for the new search. The re-run Ovid MEDLINE search strategy has been provided as an example below (Table 7.3). *Step 2*: Modified, in that additional search words were not explored. *Step 3:* Modified, in that hand searches of reference lists and bibliographies were undertaken, with literature reviews and editorials not excluded. One reviewer (KP) completed the selection, extraction, and appraisal of the literature, under the supervision of experienced academics

Analytic Method: Synthesis through progressive focusing guided by the three heuristics of understanding, interpreting and theorising (Stake, 2010; Saldana & Omasta, 2018; Swedberg, 2014).	**Analytic Method:** Synthesis through meta-aggregation methodology (Lockwood et al., 2015).	**Analytic synthesis:** Meta-analyses in order to summarise and present each study's findings in a comparable way (Featherstone et al., 2015).
Qualitative Data Analysis Plan: **Understanding**: In the context of discovery, immersion in the 11-participant data sets individually included establishing self-reflexivity practices that continued throughout the analysis. **Interpreting:** First cycle analysis focused on Research Focus Questions 1 to 3. This included classifying, sorting, and re-representing data to create interpretative accounts and a micro-metaphor for each participant's integrated care experiences. Second cycle analysis focused on Research Focus Question 4. This included looking for and explaining patterns of ideas from across the data sets. Fusing the participants and researcher's meaning into unifying ideas and construction of master themes. **Theorising:** A meso-metaphor was created using abductive thinking processes from the entanglement of the pattern of ideas across the participants' integrated care experiences. This included creative exploration through the emergent development of a declarative statement of summative synthesis and statement of claim, supported by the empirical findings.	**Qualitative Literature Synthesis** Following extraction of the general characteristics such as the citation details, setting, participants, aim/research question and methodology for each study, Lockwood et al.'s (2015, p.184) three-step process to data synthesis in meta-aggregative review was applied to the five qualitative studies that met the search strategy inclusion criteria and were considered eligible. **Step 1:** The empirical findings from each paper were identified and extracted, along with a unit of data that supported each finding. One hundred and fifteen findings were extracted from the five included studies. **Step 2:** The empirical findings from across the papers were collated into groups of similar findings. Twenty-seven categories were created from the 115 findings. **Step 3:** The 27 categories were grouped into 10 synthesised findings that were then developed into indicatory statements, appropriate for informing policy or practice development.	**Literature synthesis** Saldana and Omasta's (2018) approach to rapidly reviewing and condensing large amounts of evidence was followed. They recommended drawing out only what was deemed relevant. Thus, only findings directly related to, or contributing to, the research question and to situating the research findings in the present were included in the synthesis. The 44 papers considered of interest due to their relevance and novelty in relation to the original literature review and the study findings were organised into a table (Appendix N: Developments in the literature 2018-2023 – The publications were organised into four categories: o Directly relevant to this research (n=1) o Indirectly relevant, yet of interest to this research (n=21) o Relevant literature reviews (n=5) o Relevant editorial and evaluation synthesis (n=3) The findings from the literature are summarised briefly below. Key insights from the literature are also expanded on in this chapter's discussion of the overall study in 7.2.4.
Research findings The findings from this research are presented as the interpretations and emerging theories constructed as a product of the analytic synthesis of the empirical data. 1. Interpreting: What meaning did the participants make of their experiences of integrated care? **i) Unifying ideas** **Master Themes**	**Literature review (2008–2018) findings** *Objective 1 Findings:* The five included studies applied a qualitative approach. To answer their research questions, they all used in-depth structured interviews. The methodology used across the studies varied; however, each approach included speaking directly to the person who had experienced the health care service. Each study adapted an established methodology to align with their study design and research questions. Three of the studies used data management systems to aid coding and organising data.	**Literature review (2018–2023) findings** Summary of developments and novel findings *i) Increase in interest in the field.* The 2008–2018 advanced search was re-run with limits amended to the period 2018–2023. This resulted in an increased frequency in all key search terms. As shown in Table 7.4, using the Ovid MEDLINE re-run search as an example, the largest % increases was with the terms, care navigation.mp (>255%); People cent*.mp.(>224%); personalise*.mp. (154%); person cent*.mp. (153%); and person-centered.mp. (147.4%). Of relevance to this

(Fusion of Participants & Researcher)	(Synthesis)
I have a sense of personal agency. My needs were being met [personalised]. I could achieve my goals, my way.	*I am involved my way*
I had access to someone I knew I could trust to guide me [an experienced professional]. I had access to explanations I knew I could trust [authoritative explanations]. I could trust the staff [a professional service].	*I have peace of mind*
I am prepared to step up and initiate action.	*I am being vigilant*
I understand that beyond the integrated care service the roles I played would be different.	*I analyse and adjust my involvement to fit the situation*
Benefiting from the health care professional's logic and critical thinking skills [aligned with thinking/ sensing processes]. Benefiting from establishing a genuine human connection with my health care professionals [aligned with feeling/ intuitive processes].	*I am benefitting*
I was motivated. I was expanding my self- management capabilities. I was choosing to be healthy.	*I am choosing* to make changes that will benefit my health and life goals

2. Interpreting: What purposes did their experiences of integrated care serve for the participants

Unifying ideas (Fusion of Participants and Researcher)	**Master Themes** (Synthesis)
Providing me with the personal information I needed to assess my progress and the urgency of any actions. Guiding me step-by-step on what to do when self-managing my health care treatments and what to look for. Supporting me to invest wisely in my health care treatments.	*Equipping me* with the knowledge, skills, and strategies to self- manage effectively and efficiently my current health care needs

Objective 2 Findings: The use of an interview guide was a common feature of the included papers. Interviews took place in person in a familiar place, such as the home or clinic that the participant had previously visited. The interviews ranged from 20 minutes to 90 minutes. All included papers explored the participants' views about their health and related health care experiences in person. Other questions included exploring what the participant had expected and what was important to them in general, not health specific. Participants were prompted to describe the service in their own words, what it offered them, and what a better or an ideal model might look like for them. Another approach was to encourage reflection on previous experiences and to ask questions that explored how the participant made sense of their experience.

Objective 3 Findings: The synthesis of the empirical findings from the five included studies (Burridge et al., 2016; Petch et al., 2013; Spiers et al., 2015; Spoorenberg et al., 2015; Yarborough et al., 2016) resulted in the development of indicatory statements of equal significance, including a summation of the core elements of an integrated model of health care delivery that mattered most from the patients' perspectives.

1. People may have common needs, wants and fears; however, what matters most is knowing and respecting the person and their right to self-determination.
2. Social contact with other people is highly valued; experiencing the giving and receiving of support and companionship that is meaningful for that person, at that time.
3. It is important that the cognitive, physical, and emotional effort of change is recognised and that it is understood that a person's perception, acceptance, and engagement with change is personal and may vary over time.
4. Having basic daily living needs met is consistently the first priority. A person is unlikely to feel motivated or able to engage until basic needs are met.

research, the term integrated health.mp. increased by 70% and "Delivery of Health Care, Integrated"/or integrated care.mp. increased by 43.4%. The increased use of these terms suggests an increase in activity and/or interest in the field.

ii) COVID-19, waiting to see what sticks.

The COVID-19 pandemic was not a key search term for this review. There was limited reference to the COVID-19 pandemic in the papers identified in the re-run of the search terms. It was identified as contributing to delays in the timeline of a co-produced literature review (Merner et al., 2023). It was discussed as to the potential implications for healthcare design and delivery and in regard to its potential impact on uptake of health policy, related to integration potentially being better supported by health services (Lewis et al., 2021).

iii) 'Integrated care is by definition person-centred" (van der Viegel-Brouwer et al., 2020 p.2.)

This comment by van der Vlegel-Brouwer et al. (2020) was from the International Journal of Integrated Care editorial and reflected a noticeable shift towards coupling the terms "integrated" and "person" within the papers reviewed. For example, studies explored individuals' readiness for "integrated person-centred care" (Power et al., 2020), or the health systems readiness for "integrated, person-centred, and coordinated care". A framework was drafted to advance understanding of the patient-centredness phenomenon in the context of integrated care Youssef et al., 2020) "Person-Centered and Integrated Care" was described as a process that would benefit from a "person-centered integrated care quality framework" to evaluate such processes (Berntsen et al., 2018. Another study looked to evaluate the effects from accessing a "population-based, person-centred and integrated care service" (Spoorenberg et al., 2018). Some studies did not mention "integrated" at all, preferring to use "evidence informed, person-centred health and social care" (Sather et al., 2019) or "person-centred coordinated health care" (Phelan et al., 2021).

iv) *"There is currently a heterogeneous body of literature with the term integrated care used by different authors to mean different things" (Hughes et al., 2020 p.448).*

This statement by Hughes et al. (2020) summarised the persistent elusiveness in defining integrated care. The lack of definitional

Teaching me practical skills and Do It Yourself (DIY) strategies for now and the future. Generating positivity and hope that I am progressing in achieving my future health and well-being goals.	*Giving me hope* practical and creative ways that I can adapt and enjoy when maintaining my health and well-being at home
Preparing a "just in case" plan of action that I can self- initiate if necessary. Making personal connections gives me a sense of being known and that I am welcomed to reconnect in the future (safety net).	*Putting things in place,* actions to protect me now and my future health
Playing my role in keeping the "free service" going for myself and others. Raising my awareness of opportunities and threats for the continuation of the integrated care service. Provoking me to think about ways that the operations of the service could be improved for the benefit of all.	*Inspired advocacy,* stimulating me to think about ideas and test out improvements that will benefit me, others and to protect and promote the service
Bringing to my consciousness what was working and what further work needed to be done to protect my health and how I can look out for others. Introducing or reminding me of the benefits of being socially connected for my overall health and well-being.	*Recognising what was important,* everything is connected, holistic, how they think, behave, interact with others has consequences for their health and future

3. Theorising: Creating a meso-metaphor

"The person is the steward; integrated care is an embodied experience"

4. Theorising: Interpretative Statement of Claim

All of the study participants were living at home, attending to their health, and had enrolled with an integrated care

5. Mobility and accessibility are highly valued, they are associated with a person's sense of independence, autonomy, and freedom.
6. A person's perspective on their independence influences their sense of self and their social value.
7. You cannot predict what matters most to a person or what should be their focus with confidence. Every interaction or intervention may result in intended or unintended consequences. Developing skills and techniques that enable a person to actively engage in iterative processes of planning, implementing, and evaluating change is empowering.
8. Self-development and learning new skills are important for preserving and achieving a sense of control, choice, confidence, and well-being.
9. Regular contact with a trusted professional is important.
10. There are core elements of an integrated model of health care delivery that matter from the patient's perspective:
    - respect for the person, their lived experiences, their situation, and their perspective;
    - valuing the person's health and social care needs equally;
    - commitment to working as partners in multidisciplinary teams and fostering collegiate working relationships across the health and social care systems; and
    - genuine engagement with the community as partners and assets, inviting collaboration through codesign and seeking input and feedback in the co-production, delivery, and continuous improvement of health services

clarity and little to no shared understanding of what integrated care meant between and across individuals, carers, health care providers, and policy makers was a common driver for, and finding from, the papers reviewed (Henderson et al., 2023). Consistent with the 2008–2018 review, the needs of individuals as perceived by them, were unlikely to have contributed to defining integrated care or its features. Henderson et al.'s (2021) literature review found only two papers, (Petch et al., 2013; Spiers et al., 2015) that explored the individuals' perceptions of their health as voiced by them. Both of these were included papers in the 2008–2018 literature review.

A development in the field was the shift from attempting to define the organising structures or predict the outcomes of integrated care towards framing integrated care as heuristic and relational practices that emerge from the complex contexts and human interactions of health care delivery (Hughes et al., 2020; van der Vlegel-Brouwer et al., 2020).

v) Consumers actively participating in research.

A development in the field was that the reviewed studies were more likely to engage with a range of perspectives through codesigning and partnering with individuals and community groups than in 2008–2018. Engagement ranged from being a formal research partner to engaging at specific phases such as the analysis or framing the findings and implications for practice. Sather et al. (2019) applied a novel approach in their study, whereby consumers positioned themselves along a continuum constructed from the overall participants experiences. Consumers used this position as a way of describing their experiences; what was happening and what it meant to them.

vi) Every person is different.

A novel finding from the studies was that when asked, individuals were unlikely to be aware of or were found to be holding different views about what integrated care was, or what it meant (Oksavik et al., 2021). Individuals' heterogeneous understandings were described as expressions of personal values and deep-seated behaviours, preferences, and expectations that were more likely to identify with traditional models of care, rather than being specific to integrated care (Tuzzio et al., 2021.

vi) *Need for thinking differently*

program, visiting a minimum of three times. Most were looking to improve their immediate health status by making progress against what was motivating, hindering, or believed to be missing for them in advancing their health and life goals. They were highly invested, in the immediate and longer-term, in the pursuit of value-add health care for themselves and others. Their personal metrics and insights were both empirical and experiential interpretations of their everyday reality. They expressed a sense of hope, empathy, ideas, and logic that would bring valuable contributions to reorientating a health service towards a people-centred philosophy that aimed to serve the health care needs of people living in the community. There were mainly assumptions rather than evidence to support the concept of integrated care being a coordinated experience beyond their immediate care experiences when interacting with different health care settings and providers. The participants tended to position themselves as modelling integration and responsiveness, rather than the health services.		A development in the field was that studies were adapting existing data collection tools and techniques (e.g., visual scales; goal planning) to better engage individuals in their care. Studies were also exploring novel theories (e.g. game theory) or looking to extend existing theories (e.g. health practices) or the application of theories differently (e.g. person-centred care theory) to explain the phenomenon. *vii) More similar than different" (Davis et al., 2018 p.3)* Davis et al. (2018) was the only study that would have been eligible for the 2008–2018 review. The study's findings were generally consistent with my research findings. They reported that individuals felt cared for when they had been seen as a person, living their complex lives, and that their health was a holistic part of this life, in that it was inclusive of their physical, emotional, and social circumstances. They perceived personal benefits, including new skills and interpersonal benefits that enabled them "to come in and out of care as needed" (Davis et al. 2018, p.7). It was also important to share their learnings and extend their benefits to family and friends. Convenience, proximity, continuity and trusting relationships with and within the clinical team, and cost were reported as enablers. Their prior experiences of health care influenced their expectations and behaviours. Davis et al. (2018) proposed that how engagement was enabled rather than the specific integrated care service delivered benefits of significance to the individuals. They recommended spending time in facilitating interpersonal matches between the individual and their care provider, and prioritising continuity of care structures that facilitated rapport building. The significance and impact of interpersonal communication and forming personal relationships was a consistent finding across the reviewed papers. A sense of power imbalances was identified as a constraint for individuals' involvement or feeling heard in decision-making. It was consistently important to be meaningfully involved in decisions about their health and health care. What was important to individuals was personal, their values and needs were generally heterogeneous, as were individuals' health goals and their evaluation of health outcomes.

Table 7.4 Re-run of Ovid MEDLINE advanced search illustrating difference in search results from June 2018 to June 2023

#	Research Ovid MEDLINE(R) Advanced Search limited to English language	<1946 to June 09, 2023> **Results from 9 June 2018**	<1946 to June 09, 2023> **Results from 10 June 2023**	Difference in # search results from June 2018 to June 2023	Percentage (%) difference in # search results from June 2018 to June 2023
1.	"delivery of health care, integrated"/or integrated care.mp.	13,308	19,081	5,773	43.4%
2.	integrated health.mp.	2,783	4,743	1,960	70%
3.	coordinated care.mp.	1,013	1,639	626	62%
4.	comprehensive health care/or comprehensive care.mp.	9,206	11,315	2,109	23%
5.	seamless care.mp	134	192	58	43%
6.	tiers of care.mp.	6	10	4	66.7%
7.	care navigation.mp	40	142	102	255%
8.	patient participation/ or patient perspective*.mp.	25,470	35,469	9,999	39%
9.	service user*.mp.	4,059	7,079	3,020	74%
10.	consumer*.mp.	89,666	130,874	41,208	46%
11.	individual*.mp.	1,326,527	1,930,670	604,143	46%
12.	communit*.mp.	535,363	804,985	269,622	50%
13.	citizen*.mp.	16,983	28,978	11,995	71%
14.	client*.mp.	49,689	66,967	17,278	35%
15.	Patient-centered care/or patient-centered.mp.	24,247	39,468	15,221	63%
16.	patient-centered.mp.	24,247	39,468	15,221	63%
17.	person-centered.mp.	2,207	5,460	3,253	147.4%
18.	community participation/or people centered.mp.	15,871	18,637	2,766	17%
19.	1 or 2 or 3 or 4 or 5 or 6 or 7	25,266	35,216	9,950	
20.	8 or 9 or 10 or 11 or 12 or 13 or 14	1,921,645	2,806,649	885,004	
21.	15 or 16 or 17 or 18	41,685	62,182	20,497	
22.	19 and 20 and 21	605	923	318	
23.	limit 22 to last # years	364 (2008–2018)	320 (2018–2023)	320	
24.	19 and 20	8,150	11,761	3,611	
25.	limit 24 to last # years	3,943 (2008–2018)	3,720 (2018–2023)	3,720	
26.	experience*.mp.	910,711	1,322,660	411,949	45%
27.	patient outcome*.mp.	42,706	73,327	30,621	72%
28.	involvement*.mp.	402,402	526,737	124,335	31%
29.	people cent*.mp.	160	518	358	224%
30.	patient cent*.mp.	28,480	48,231	19,751	69.4%
31.	person cent*.mp.	3,929	9,937	6,008	153%
32.	opinion*.mp.	102,069	144,766	42,697	42%
33.	view*.mp.	414,052	546,622	132,570	32%

34.	personalise*.mp.	3,335	8,455	5,120	154%
35.	personalize*.mp.	28,903	68,755	39,852	138%
36.	26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35	1,826,950	2,574,037	747,087	
37.	limit 36 to last # years	891,623 (2008-2018)	783,074 (2018-2023)	783,074	
38.	23 and 37	340	309	309	
39.	limit 38 to dataset	0	0	0	
40.	limit 38 to “all adult (19 plus years)”	106	100	100	

Note: The content of Medline (Ovid) is equivalent to that accessed through the PubMed interface.
.mp – stands for multi-purpose. An advanced search without specifying a particular field, Ovid defaults to a .MP search, which searches several fields at once. The fields searched by a .MP search may vary, but in general, a .MP search looks in the Title, Original Title, Abstract, Subject Heading, Name of Substance, and Registry Word fields.
Truncation symbol * (asterisk) An advance search technique, using * will search across multiple fields for words starting with the search letters and then retrieve any alternate endings.

7.2.2 Research Focus Question 5: In What Ways are the Findings of this Research Similar to or Different from what has been Published in the Literature?

As summarised in Table 7.3, the findings from my research were similar, yet not the same as the findings from the studies identified in the 2008–2018 literature review, and the subsequent 2018–2023 review. Although limited in number, the literature served as my guide. It helped me to better understand how researchers had designed their studies so that the voices and perspectives of individuals who had recent direct experience of an integrated health service could be privileged. The literature also showed how researchers had interpreted the individuals’ perspectives of their integrated care experiences and the personal significance this held for them.

The 2008–2018 systematic review identified five eligible publications (Burridge et al., 2016; Petch et al., 2013; Spiers et al., 2015; Spoorenberg et al., 2015; Yarborough et al., 2016) and the 2018–2023 rapid review of the literature identified one further paper (Davis et al., 2018). The references for the six papers are provided in Table 7.4. In addition to the included papers, the extensive and then rapid searches provided important insights into the different perspectives held and approaches being taken to better understand integrated care as a concept, as a structure, or a service that had the potential to improve the patient experience and their outcomes. A sample of the papers identified in the 2018–2023 rapid review and the insights they offered is provided in Appendix N**:** Developments in the literature 2018-2023 – . Although they would not have met the inclusion criteria for this research, these papers provided me with a sense of the context and of the opinions, ideas, and empirical evidence that was publicly accessible.

Table 7.4 References for the six included papers from the 2008–2018 and 2018–2023 literature searches

1	Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2016). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations, 19*(1), 74–86. https://doi.org/10.1111/hex.12331
2	Petch, A., Cook, A., & Miller, E. (2013). Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health & Social Care in the Community, 21*(6), 623–633. https://doi.org/10.1111/hsc.12050
3	Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015). What outcomes are important to people with long-term neurological conditions using integrated health and social care? *Health and Social Care in the Community, 23*(5), 559-568. https://doi.org/10.1111/hsc.12171
4	Spoorenberg, S. L., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS One, 10*(10), e0137803. https://doi.org/10.1371/journal.pone.0137803
5	Yarborough, B. J. H., Yarborough, M. T., Janoff, S. L., & Green, C. A. (2016). Getting By, Getting Back, and Getting On: Matching Mental Health Services to Consumers" Recovery Goals. Psychiatric Rehabilitation Journal, 39(2), 97–104. https://doi.org/10.1037/prj0000160
6	Davis, M. M., Gunn, R., Gowen, L. K., Miller, B. F., Green, L. A., & Cohen, D. J. (2018). A qualitative study of patient experiences of care in integrated behavioral health and primary care settings: More similar than different. *Translational Behavioral Medicine, 8*(5), 649-659. https://doi.org/10.1093/tbm/ibx001

Before I address Research Focus Question 5, I will expand on the summary of the themes from the 2018–2023 literature review provided in Table 7.3. I will also present a focused discussion related to the global COVID19 pandemic and new understandings and developments in the context of my research. This is followed by discussing my research findings in light of the overall literature, and I then address the final research focus question by presenting what I propose to be the key contributions of this research.

7.2.3 Developments in the research literature 2018–2023.

The genesis of this research was my curiosity as to what was known about the experience of integrated care from the perspective of those people living in the community who had experienced it. What the initial 2008–2018 systematic review showed was that empirical research that focused on the individual's perspective of their personal experience was rare; however, there was a plethora of commentary offered by experts, academics, and clinicians. In 2023, the literature continued to be critical of the scarcity of health services research designed specifically to understand the experience of health care from the person's perspective (Henderson et al., 2023). The dominant perspective continued to be that of the professional or expert (van der Vlegel-Brouwer et al., 2020). A synthesis of the empirical findings from centrally funded integrated care programs implemented within the United Kingdom (UK), National Health Service (NHS) since 2008, reported that what was defined as required from integrated care and the determinants of effective integrated care continued to be dominated by the views of professionals and that there continued to be minimal evidence of service users being engaged in the design of integrated care programs (Lewis et al., 2021). These findings support that my research remains situated within an under-researched field of health services research.

The rhetoric may have grown stronger, that understanding what individuals are looking for or what they take away from their integrated care experiences is important for progressing public health reforms, and yet it remains under-researched or even missing from the research. For example, with an interest in the experiences of integrated health and social care, Henderson et al. (2021) completed a critical integrative review of literature published between 2007–2018. They reported that from the 20 eligible studies, only two focused on the perspectives of individuals who were directly accessing the service and then privileged their voice throughout (Henderson et al., 2021). The two studies, Petch et al. (2013) and Spiers et al. (2015), were also eligible studies in my 2008–2018 systematic review. This reinforces that the number of studies reporting from the individual's perspective remains scarce. In support of the need to study different stakeholder perspectives separately, Hughes et al., (2020) reported in their systematic hermeneutic review of integrated care strategies and concepts that for individuals directly receiving integrated care, the health care provider, manager, and the policy maker each held different interpretations and could not be considered substitutes for each other or capable of speaking on behalf of others. They each varied in how they experienced integrated care and what aspects they valued most.

Additional to people holding different views, the lack of definitional clarity associated with integrated care within the literature and policy documents, which I identified as problematic in my review of the literature, continues to be a challenge for researchers and health services (Henderson et al., 2023; Stein et al., 2022). A growing trend has emerged towards grouping the concepts of integrated care and person-centred care. On one hand, this aligns with the WHO's (2016 a) *Framework on Integrated People-Centred Health Services*, yet on the other, is criticised for the confusion caused by now combining two poorly defined concepts, with both being inconsistently described and at times being interchanged with each other (Lewis et al., 2021; Phelan et al., 2021). Like my literature review findings, the absence of universal definitions for the terms being used limits the ability to search for, or compare, the empirical evidence (Liljas et al., 2019).

Youssef and colleagues (2020) reported concerns about the reliability of applying existing conceptual frameworks to understand their study's findings, in particular, when there was a lack of consensus as to the definitions of the key concepts used in the frameworks. Their preference was to understand the individuals' experience of the person-centredness of their integrated care through gradually constructing a framework from the meanings that emerged from the study participants perspectives (Youssef et al., 2020). Similarly, Davis and colleagues (2018) explained that they "chose not to use existing theories or models to guide the process because we wanted to understand patients" experiences with integrated care in an unmotivated way" (p. 651). I also adopted this position in my research, whereby the participants' perspectives and words underpinned the construction of themes. Allowing for the individual's meaning to emerge and take shape in this way was also supported by Van Kemenade and van der Vlegel-Brouwer (2019). Drawing on the disciplines of quality management and systems thinking, their proposition was that an individual's meaning was bound to their values, it takes form within the dynamic interactions of the moment, it does not exist before that moment or could it necessarily be predicted (Van Kemenade & van der Vlegel-Brouwer, 2019). They suggested that there was not one, or a single way, to understand what integrated care means to someone. However, the absence of considering different perspectives, in particular, that of the individual who use the service, meant that the definition of what integrated care would remain elusive (Van Kemenade & van der Vlegel-Brouwer, 2019). These developments within the emergence paradigm, provided me with a new and different lens from which to understand the significance of my research, and its contribution to the field.

In addition to the small number of comparable empirical papers, the quality of their research design was questionable. When I applied the CASP (2018) qualitative checklist to appraise the studies identified in the initial 2008–2018 systematic review, there was a consistent lack of clarity in the researcher-participant relationships and poor reporting of researcher reflexivity. I did not exclude any of the studies based on their methodological quality, partly due to the limited number of papers available. The more recent, 2018–2023 rapid review identified four literature reviews that had also reported appraising their sources using the CASP (2018) (Henderson et al., 2021; Liljas et al., 2019; Merner et al., 2023; Moody et al., 2022). In general, the authors described the quality of the included studies as low, with two papers being appraised as high risk of bias and excluded (Liljas et al., 2019). The authors did not exclude the remaining papers.

Ensuring the methodological rigour of my research was at front of mind in designing my research. Informed by the literature, my research enquiry was framed within the qualitative, interpretative paradigms. I undertook in-depth semi-structured interviews with the purposive sample of participants. Data were collected directly from each person in their own words, and I paid particular attention to creating an environment that supported the participants' sense of personal agency within the interview process and setting. The approaches I took were reflected in the contemporary literature, in that participants were asked about their preferences when choosing the time and location of their interview (Tuzzio et al., 2021). Semi-structured and open interview techniques are consistently reported as being effective in encouraging dialogue, whereby the participant and the researcher can share unstructured personal information alongside responding directly to the research questions (Kylén et al., 2022). In the reviewed literature, studies that collected data via individual in-depth interviews reported sample sizes varying from six (Pereira et al., 2021) to 25 (Schneider et al., 2023) purposively selected participants. There was broad acceptance by researchers that an in-depth study of a small number of participants perspectives and experiences could be a greater limitation if your intention was to represent a population, while their studies intentions were to provide insights at the person-level of experience. Similar to my study, the interview length generally varied, taking from 12 minutes (Davis et al.,2018) to two hours (Tuzzio et al., 2021), though the length of the interview was not raised as a limitation in any of the reviewed papers.

Practicing reflexivity and being transparent in recognising and checking in with the researcher, both as a person in their own right as well as a researcher, was a strategy I embedded within this study. My goal was to ensure the research was implemented with integrity from beginning to end, that the study participants could feel psychologically safe to share their experiences and thoughts with me, and that the reader could establish a sense of my personal ethics and my capability to execute the research design. The reviewed health services research literature indicated a growing awareness of the researcher's role and their influence on the research; in particular, on the trustworthiness of the findings (Henderson et al., 2023). However, limited explicit reference to or consideration of the personhood of the researcher within the literature remained.

What was more noticeable in the literature and embedded throughout my research, was reference to triangulation or corroboration processes as being critical to the trustworthiness of the findings (Ginting et al., 2022; Shrivastava et al., 2019) These processes included researchers engaging with different perspectives such as health consumers and citizens, peers and experts in their field, or the research methodology at different times during their research to test their thinking, theorising, and unsurfaced any potential threats to the study design (Davis et al., 2018). A further development in the research was adopting a co-production approach, in that citizens with lived experience were co-researchers (Merner et al., 2023; Moody et al., 2022). Those studies that embedded codesign in their research or parts of the research expressed that the citizens participation and perspectives had enhanced the robustness and rigour of their research findings (Henderson et al. 2023; Phelan et al., 2021).

It was evident from the research literature that in spite of an increased number of publications identified through the re-run of the initial 2008–2018 search, developments in my specific field of inquiry have been slow, with variations in methodological quality noted. Consensus was found in the literature regarding the missing perspective of the individuals who receive integrated care, meaning that there continues to be at best a limited understanding as to what meaning the experience of integrated care holds for them or what really matters to them. The approach I took in only privileging the individuals' perspectives of their integrated care experiences and the purpose it served for them, and for allowing their meaning to emerge throughout the interview and then analysis, remains novel. Hence, in situating my research findings within the literature, I am conscious that my findings may present as similar, yet they will always remain unique to those individuals' perspectives.

7.2.4 Acknowledging the extenuating circumstances of COVID-19

The timeline for this research was impacted by the extenuating circumstances of the COVID-19 global pandemic. In addition to undertaking this research, I work full-time as a health professional with the lead agency for safety and quality in the New South Wales (NSW) health system. During COVID-19, I was required to shift my focus to pay my full attention to contributing to the local responses to the systemic consequences of the global pandemic (Clinical Excellence Commission, 2023). Of significance for the field of health services research, the World Health Organization's (2022 a) *Global pulse survey on continuity of essential health services during the COVID-19 pandemic* interim report stated that no country, health service, or delivery platform, including all major health areas, were "exempt from adverse impact" (p.4). In examining the impact on patient safety, the WHO (2022 b) attributed the COVID-19 pandemic as contributing to reversing global advancements in the delivery of preventative interventions, with a significant impact on vulnerable members of the community.

In NSW, Australia, although a comparably lower number of COVID-19 cases were reported, there was an adverse impact across the health system, reducing health services capacity to deliver essential and non-essential inpatient, outpatient, and community services (Sutherland et al., 2020). In 2013, access to health care was defined as a multidimensional concept, most commonly defined as "the opportunity or ease with which consumers or communities are able to use appropriate services in proportion to their needs' (Levesque et al., 2013, p. 1). A consequence of COVID-19 was the inability for health services to provide the public with the same access to care they were accustomed to or perceived they needed, which over time began influencing the public's health care seeking behaviours, whereby they began to demonstrate reluctance to access care (Sutherland et al., 2020). A qualitative study exploring Australian citizens experiences during the pandemic identified that common reasons for choosing to delay or hesitate in accessing care were related to fear, uncertainty, and the logistics of travel restrictions (Podubinski et al., 2021). Podubinski and colleagues (2021) also reported that public health messaging may also have unintentionally contributed to citizens deciding to avoid health services and to their overall psychological distress.

Beyond the widespread disruption and strain the COVID-19 pandemic placed on health services, it has also been credited with presenting opportunities, and inviting change and innovation. The WHO (2022 b) credited COVID-19 with being the impetus for rapidly introducing transformative and disruptive models of health care delivery into mainstream healthcare. NSW, Australia, reported changes in how health services were being utilised, in that low-value procedures such as routine tonsillectomies were reducing in number, although the authors were unable to predict whether these changes would be sustained (Sutherland et al., 2020). Healthcare providers and citizens were also reported to be the drivers of the rapid expansion of alternative ways of accessing health services in Australia, such as telehealth (Podubinski et al., 2021).

The relevance of the impact of the COVID-19 pandemic on my research can be demonstrated through the experiences of people living with multiple chronic or ongoing conditions in the community. This group of people were recognised as being at greater risk of vulnerability in the event of limited access to primary care, as was the experience during COVID-19 (Peart et al., 2020). Elaine Moody and colleagues (2022) conducted an integrative review focused on the experiences of people living with multimorbidity that was a partnership with individuals living with multimorbidity as co-researchers. It was not an explicit objective of their review to explore patients' perspectives on their COVID-19 experiences. From the 28 sources included in the review, Moody et al. (2022) identified that convenient access to their health care providers, in particular, at short notice or if in urgent need, was important to people living at home with multi-morbidities. Suggestions that study participants proposed for improving access included experimenting with non-traditional approaches, such as telephone consults, email contact, or having access to their care providers after hours and on weekends (Moody et al., 2022). Moody et al.'s (2022) findings from the literature were not dissimilar to my research findings, whereby the participants expressed the importance of being able to access their integrated care service or provider at short notice to clarify or to seek advice regarding their treatment and were open to alternative options if it would improve their access.

When discussing implications for practice related to the theme of access issues, Moody et al. (2022) proposed that acceleration of e-health strategies such as virtual care during the pandemic may be readily adopted by this cohort; however, they also cautioned as to whether a technology solution alone could replace human interactions, in that the participants were most protective of maintaining a relationship with their health care provider and time for conversations specific to their individual needs and circumstances. In asking Australian citizens about their lived experiences with telehealth services during COVID-19, Podubinski et al. (2021) reported mixed responses. In some respects, it was deemed to have improved access. However, it was also not considered appropriate for all health conditions; in particular, those that required physical assessment, because if people had a choice, they would prefer face-to-face consultations (Podubinski et al., 2021).

The brief summary I have provided of the experiences of one group of people living in the community, raised the possibility that many citizens attending to their health at home may have had novel or significantly different health care experiences throughout the COVID-19 pandemic. In the event that the increased uptake of technology, or that the sense of working across traditionally siloed primary, secondary and tertiary systems of care that has featured under the disaster conditions of the COVID-19 pandemic were sustained, Lewis et al. (2021) proposed in their policy paper the possibility that health services could be more receptive to advancing integration as a model of health care delivery.

7.3 DISCUSSION OF RESEARCH FINDINGS IN RELATION TO THE LITERATURE

My research findings have privileged the individuals' perspectives of their experiences of integrated care, what it meant to them, and what was important to them. My findings are generally supportive of the limited research available, as well as offering unique, novel and somewhat provocative interpretations that would benefit from further theorising within this developing field of research. I began my research with curiosity, which was then framed into a question. As I situate my findings in the literature and draw my research to a close, I find I am still curious, with more questions. I have organised my findings below, starting with what I discovered about the participants. I then introduce the reader to my findings when framing the participants as a group; finally, I conclude with the assumptions I have drawn at the population or societal level.

7.3.1 Individual Level Findings: We Are All Different

I found that each participant's experience was unique to them as a person and their circumstances. This phenomenon, being that it cannot be assumed that one person's experiences of the same health service will be understood the same way, or hold the same personal significance as another's, has been reported as being a motivator, an outcome and a limitation within the research (Ginting et al., 2022).

7.3.1.1 It's Personal

I have provided interpretations of how each participant had made sense of their integrated care experience. Each participant's experience was deeply personal and connected to their unique frame of reference, which they had each gradually developed over their life's course. The participants in my study described how it felt to be seen, heard, and acknowledged as human beings with unique health needs, and they supported the literature in that these feelings gave them a sense of being cared for (Neale et al., 2019; Petch et al., 2013; Shrivastava et al., 2019). Just as establishing trusting personal relationships was consistently a central theme in the research literature, it was also significant to each of the study participants when they reflected on their experiences of integrated care (Henderson et al., 2021; Moody et al., 2022; Phelan et al., 2021; Spiers et al., 2015).

The literature supported my interpretation that the way in which participants in this study experienced and evaluated the benefits of integrated care was tightly linked to their personal and interpersonal goals. Similarly, Davis and colleagues (2018) found that it was important to their participants to be seen holistically within the complexity of their life's circumstances rather than neatly siloed into their health conditions. Burridge and colleagues (2016) found that their participants' changing health needs invaded their lives, challenged their values, and required a constant internal renegotiation as to how they constructed their identity and lived their lives. Similar to how I had interpreted my participant interviews, Burridge et al. (2016) found that people tended to make rational sense their way, adapting and personalising advice that they received to fit their personal circumstances and priorities.

7.3.1.2 We All Have a Story

The literature proposes that an individual's frame of reference is likely to be the result of "unconscious cultural conditioning", whereby the person's preferences are unwittingly influenced by their previous experiences, including more traditional models of health care (Power et al., 2020, p. 5). In support, Shrivastava et al. (2019) proposed that individuals' broader socio-cultural experiences and circumstances impact their ability to trust health care providers or heighten their sensitivity or fears related to health care. I also found each person's perspectives to be grounded in their history and biography, which included their own and significant others previous health and life experiences. These previous experiences were then embedded in how they made sense of their recent interactions and how they saw their current and future involvement within their health care. Oksavik et al. (2021) proposed that every person perceives the reality of their situation, such as how they are involved in their health care decisions differently, and that this perception is influenced by their foundational "preferences, values and needs" (p. 10). I propose that the experience of integrated care is a living experience, as it draws from the past, is being shaped in the immediate, and the uncertain future is always present.

7.3.1.3 Change Happens, Knowing What's Happening and Who I can Talk to Helps

When exploring individuals' readiness to engage with an integrated care health service model, Power and colleagues (2020) found that individuals were not resisting the service changes, nor were they fixed in their ways, that each individual was "continuously adapting as they learn how to navigate a healthcare system, which is itself in a state of constant change" (p. 5). Significantly, change was not being framed or judged as positive or negative, change was framed as learning and as a way of being in an evolving social world. Their findings support my study participants' critical appraisal of their experiences and their sense of acceptance that further changes were not unexpected. My research findings support that the participants were interested in changes being made to how health care services were designed or made available to the wider population, that they were aware of and committed to reducing waste, they were looking for reliability and appreciated the impact of a sense of cultural and personal safety (Davis et al., 2018; Hughes et al., 2020; Shrivastava et al., 2019; Tunnicliffe et al., 2017; Yarborough et al., 2016). How participants interpreted the significance of any change varied and was situated within the context of their daily circumstances. I interpreted their everyday lives as expressing the characteristics of complex adaptive systems, and therefore, what was felt to be appropriate and helpful in one moment, may be less significant at other times. In other words, different people had different priorities at different times.

My study findings illustrate some of the daily tensions that each participant navigated in order to progress their health goals, in how they were uniquely "doing" their health in a way that was meaningful to them, while also attending to the "rules of the game" (Hughes et al., 2020, p. 479) as they understood them to be. It was apparent that my study participants did not always fully disclose their motivations or activities to their health care providers. An image that emerged was that the participant and the integrated health service were in dynamic interaction, rather than integrated. What my findings can contribute to the field and to clarifying what integrated care is, is that the study participants had an awareness of integrated care as a relationship, a source of information, rather than as a structure. Change was anticipated.

In my view this relates to the significance of the participants need "to know", including having ready access to reliable information. They were intuitively responding to the sense that change was happening constantly around them, through investing in being known in the moment, and being memorable in the future, through establishing personal relationships with their healthcare provider. I interpreted that each participant was both premediated and spontaneous in navigating change in the moment, they recognised that the quality of the information and their relationships were what mattered most, this was what integrated care offered them.

7.3.2 Group of Individuals Level: We Share Things in Common, Yet We Are Not the Same

My study findings show that it is possible to both hold the uniqueness of the individual, while also surfacing commonalities and connections across a group of people by applying uniformed approaches. The literature claimed that patterns emerged in what was perceived to be helpful or unhelpful across cohorts of participants from their individual experiences of integrated care from the different perspectives collected (Ginting et al., 2022; Petch et al., 2013; Phelan et al., 2021; Schneider et al., 2023; Tuzzio et al., 2021). The literature suggested that patterns of similarity could be identified, regardless of the health service setting, the program experienced, the individual's biography, or personal health needs and goals (Berntsen et al., 2018: Davis et al., 2018; Rogers et al., 2020; Shrivastava et al., 2019).

An example of uniformity, yet difference, in how individuals experienced their health care was through exposure to humane empathic interactions, and the difference was how individuals made sense of and perceived the benefits from these interactions. Similar to the study participants, the literature found that experiencing empathy within their integrated care, was associated with a sense of trustworthiness, safety, personal growth and influenced whether an individual perceived their experiences to be worthwhile investment of their time and limited personal resources (Henderson et al., 2021; Henderson et al., 2023). Perceiving its presence was consistently reported in the literature as leaving a lasting affirming impression and was a consistent source of motivation, while its absence was associated with not feeling listened to, understood or respected (Berntsen et al., 2018; Davis et al., 2018; Ginting et al., 2022; Power et al., 2020; Sather et al., 2019; Spiers et al., 2015; Neale et al., 2019) This literature supports my findings, in that the personal and relational aspects of their integrated care experiences left the greatest impression for the participants in this study, and yet how the importance or impact of these experiences was expressed was unique to their needs, preferences, and values.

7.3.2.1 Goal Setting as a Gateway

Goal setting was found to be receiving increased attention in the literature, it was described as being a practical and uniformed approach for guiding individuals' engagement within their health care. Sather and colleauges (2019) reported that the dialogic processes of goal setting had the greatest impact, in that individuals felt that their "perspectives, hopes and preferences" were able to be expressed and respected. Tuzzio et al. (2021) also supported that when approached as a two-way exchange, goal setting was effective in surfacing individuals' values and their perceptions of risk. Reitkerk et al. (2021) reported that their participant cohort found the processes of goal setting to be intuitive, with each of the 233 participants able to identify at least one goal and to identify target and end goal scores. A visual scale was adapted to support the participants in goal setting to enable individuals' heterogenous goals to be captured and measured over time using a standardised scale. The authors reported that an additional benefit of the goal setting process was that rather than subjective measures of progress or dependency on the health professional's assessment, participants had the experience of self-monitoring their progress using objective measures (Rietkerk, et al., 2021). Moody et al. (2022) found that the process of talking about their goals and reviewing their progress with their healthcare providers was valued and that if given the choice, study participants would prioritise their allocated time to have this conversation with their providers. Schneider et al. (2023) also found that their participants valued receiving personalised data and demonstrated willingness to adjust their goals in collaboration with their health care provider if their circumstances had changed.

A novel finding from my study was that participants did not indicate that they uniformly or formally engaged in goal setting processes within their integrated care experiences; however, they were each able to share their personal goal setting processes and how they served to bridge their health needs with their life goals. This included expressing what they anticipated to gain from or to be the value-add of their experiences. My research participants were consistent in framing their integrated care providers as being useful for providing objective assessments of their progress, and that they found this to be a reliable way of reviewing and adjusting their goals to ensure their desired outcomes were met. Goal setting was intuitively practiced by my cohort of participants; however, it was not a formal process within their integrated care.

In contrast to the literature, my study findings suggest that the participants' goal setting practices sat in the shadows of their interactions with the integrated care service. If my study had privileged the perspectives of the integrated care provider or policy makers, as goal setting was not a formal intervention, this would have been unlikely to have been raised. Similarly, if I had surveyed or interviewed participants about goal setting processes within their model of care, it would have been unlikely to have been raised. In the scenario of my research, the practices of goal setting would only be revealed through understanding the individuals' perspectives of their experiences. My findings also raise the question of whether the benefit of formalised goal setting within integrated care is that it provides a structured format that is of most use for the health care provider when initiating dialogue about care. Goal setting would help health care providers to understand and objectify progress within their integrated care treatment. However, for the individual, holistic goal setting could provide a meaningful way of making explicit the interdependencies and connections between their health and life goals, providing a gateway for the health care provider to understand the person within the context of their life and what matters most to them. My study found that the participants were proficient at navigating the health – life gateway; however, they were always interested in new strategies, resources, or sources of knowledge and expertise.

7.3.2.2 Keeping Sight of the Individual When Collecting Experiences and Measuring Outcomes

As expanded on earlier in this chapter, semi-structured interviews have been shown to be effective in capturing participants unique and personal experiences of health care (Kylén et al., 2022). To find the balance between holding the individuals' perspectives while also better understanding the impact at the population level, researchers have experimented with different research paradigms, including mixed method approaches (Ginting et al., 2022; Henderson et al., 2021). For example, in 2011, a qualitative evaluation of the population-based, person-centred, and integrated care service, Embrace, included interviewing 23 community-living older adults who had been receiving Embrace care for between eight to ten months (Spoorenberg et al., 2015). With the goal of better understanding participants' perspectives and experiences, the researchers found that Embrace gave participants, "a sense of being in control and of being safe and secure" (Spoorenberg et al., 2015, p. 1). Published in 2015, the authors concluded that the Embrace care model was effectively delivering a service that met the needs of older adults (Spoorenberg et al., 2015).

The 2011 Embrace study was followed up with a quantitative evaluation, with data collected between 2012–2013 using eight different questionnaires to "assess patient-reported outcomes in three domains: Health, Well-being and Self-management" (Spoorenberg et al., 2018, p. 4). The authors concluded that the survey data showed that Embrace, "has no clear beneficial effect on patient-reported outcomes. Based on these results, the implementation of integrated care services for older adults cannot be recommended" (Spoorenberg et al., 2018, p. 11). To resolve their dilemma of whether the program was effective, the authors proposed exploring mixed method approaches, which included the development of population level measurement tools specific for the intervention, with the survey questions being framed around person-level outcome measures that originated from the earlier qualitative study of participants' individual experiences (Spoorenberg et al., 2018).

Similar to the Embrace recommendations, Hinsley et al. (2019) found that adopting a codesign approach with people with lived experience of a specific health service in the design of a self-report Patient-Reported Experience Measure (PREM) provided them with critical insights that improved their survey design. Their study proposed that individuals' experiences did not always neatly align with standardised statements, and the inclusion of open-ended questions within the PREM survey allowed their study participants to raise matters that were important to them (Hinsley et al., 2019). The authors reflected that the use of a published framework to guide their focus group discussions was effective; however, it was necessary to be open to experiences that were not captured by the framework (Hinsley et al., 2019). In addition, they noted that the focus group participants were able to readily recall the polarities of their experiences, being their positive and negative experiences, yet they rarely mentioned the neutral or everyday experiences such as the importance of personal hygiene (Hinsley et al., 2019). In my review of Hinsley and colleagues' (2019) paper, it was not clear whether the framework used had guided participants to focus on the polarities of their experiences, or whether this was a limitation of using a focus group approach when the objective was to surface personal experiences.

A finding from Lloyd et al.'s (2019) study that set out to validate their patient-centred coordinated care experience questionnaire recommended that their population level survey would likely be useful at the personal level supporting the individual and their healthcare provider when discussing and planning their treatment goals. Furthermore, Barker and colleagues (2020) reflected that in administering their survey they had not assessed or been mindful of individuals' literacy levels within their study population; while Rogers et al. (2020) shared that their survey provided them with greater insights into their study participants' attitudes; however, they still could not say why people held these beliefs and views. They also cautioned the use of static measures in the context of understanding the dynamics of a person's life, noting that participants reported attitudes related to what they had experienced to date, which could change at any time (Rogers et al., 2020).

These research findings support that the use of pre-existing frameworks and population level surveys could provide useful insights into the personal experience of health care; however, by design, it could also silence the meaning and significance that experience held for each individual that would be better captured through personal conversation. These developments in the literature demonstrate the continued tensions of attempts to capture individual, personal experiences, and outcomes of integrated care through engaging cohorts of people with closed surveys or focus groups. In addressing the limited research associated with integrated care that has privileged the individual's perspective, the qualitative findings from my research provide in-depth understandings of the participants' perspectives. The goal was to capture the finer and unique nuances that reflected value and benefit to the individual. I propose that the intentions of this study would have been sacrificed if I had used a survey or focus group methods. I support that the move in the literature towards co-creation of the research design with the individuals I studied provided the opportunity for improvement.

7.3.2.3 Life is Messy and Complex

The literature also raised concerns that the dynamic complexity of the individuals' lived experiences may be over simplified when applying traditional health services research approaches to the data analysis and synthesis. Moody and colleagues (2022) found that when looking to synthesise the concepts or themes that emerged from the individuals' perceptions of their experiences and what was important to them, that each theme could be interconnected with other themes and that the process of organising these into discrete categories was "somewhat artificial" (p. 2617). I noted that the synthesis of the perceived meaning and purpose of the participants' integrated care experiences that resulted from the literature review and my study were not contradicted by the findings reported in the literature. I remain cautious as to whether this was but a simple explanation for a complex phenomenon, or a tendency to favour what was already known. I benefitted from Swedberg's (2014) practical exercises within the *Art of Social Theory* to guide my reflexivity. I also noticed my vulnerability for taking heuristic shortcuts when in a novel situation and wanting to explain or normalise a complex phenomenon so it can be socially accessible to others. This raised the question as to whether the discrete characteristic of the participants' experiences could explain with certainty what integrated care was from the participants' perspectives, or if it was their unique, yet unpredictable interactions that could only exist under certain conditions.

I found that there was increasing tentativeness in the literature, with researchers discussing the need to respect and protect the complexity of people's descriptions of their everyday experiences, rather than looking to simplify them into a recipe, with the assumption that the individual ingredients could reliably reproduce the same results for any individual in any health service (Hughes et al., 2020; Moody et al., 2022[; Phelan et al., 2021; Stein et al., 2022). As noted previously, there have been limited discussions in the literature regarding the researchers' influence or the impact of favouring traditional methods of health services research when seeking to engage in different conversations and gaining new insights into a complex social interaction, such as the experience of integrated care (van der Vlegel-Brouwer et al., 2020; Van Kemenade & van der Vlegel-Brouwer, 2019).

7.3.3 Society Level: Thinking of Others and Pro-social Behaviours

During their interviews, participants shared their concerns and motivation for how others in their community, both known and unknown to them, could experience the benefits they perceived from their own integrated care experiences. The participants also shared the intrinsic rewards of volunteering, of spending their time in the presence of others, and in making time for engaging in social learning or experiences that were new or different. My method included immersing myself in each person's interview data, and upon reflection, the significance of the connections were initially not obvious nor appreciated , as they were nested within the person's life story. However, as I progressed through the analysis of the participant data, and then when looking for patterns across the data sets, it was evident that there was a strong sense of connection between the self, others, and society. In that what was important to the participants was connected to and driven by a much wider social consciousness.

7.3.3.1 People are Complex, Social Beings

Synthesis of the findings from the five eligible studies identified in the initial 2002–2018 systematic literature review included a process of extracting 115 individual findings, organising them into 27 categories, and then into 10 person-level indicatory outcome statements. One of the statements I developed was, *Social contact with other people is highly valued; experiencing the giving and receiving of support and companionship that is meaningful for that person at that time.* This statement drew from the findings that individuals associate meaningful activities and contact with other people as impacting on their quality of life (Petch et al., 2013) and as bringing a sense of fun into their lives (Spoorenberg et al., 2015). Acknowledging the complexity of people lives, Spiers and colleagues (2015) found that it was important for participants dual roles to be recognised, in that they were not only the recipients of health care, but also held caring and supportive roles for others in their lives. Maintaining existing relationships and expanding their networks was found to be important, this could be establishing peer relationships with individuals who shared similar circumstances related to their health needs, or with friends or social groups (Spiers et al., 2015). Volunteering was found to be linked to an individual's sense of personal well-being, as was being socially active in how they supported their communities and their personal believes, which Spiers and colleagues (2015) described as the collective term of citizenship.

7.3.3.2 Pro-Social Behaviours, Thinking of Benefit(s) for Others and Society

The rapid review of papers published in the past five years (2018–2023) brought to light further examples that individuals hold the capacity for, and are actively negotiating their personal health needs, and the perceived needs of others on a daily basis. Tunnicliffe and colleagues (2017) reported on how 26 adolescents living with similar health conditions prioritised their healthcare and related research agenda. The study included taking part in interviews, focus groups, and a voting exercise, where the study participants expanded on why they had ranked the priorities as they had. The researchers found that participants priorities were "influenced by concerns for themselves as well as their family, other patients, and the wider population" (Tunnicliffe et al., 2017, p. 449), with the participants at times prioritising benefits for their families and others over their personal needs.

My study did not explore participants' prioritisation processes directly, although participants retelling of their experiences did include making connections between their health needs and how improving their health would be of benefit to others they cared for or provided for. Similar to Davis and colleagues' (2018) findings, my study participants did not limit the benefits of integrated care to themselves, rather they actively promoted the service to their family and friends, as well as sharing what they had learned with others. While my study participants did not overtly indicate that it was important that their spouse, children, or friends were included as partners in their integrated care, similar to Tuzzio and colleagues (2021) they did make connections between the importance of these people, their broader sense of well-being, and that they played a role in the well-being of their families.

Neale and colleagues (2019) reported that when exploring how a health service could support their personal needs, the study participants frame of reference was wider than their immediate interactions with the health care program, extending to relationships and structures that connected them with their broader social and community needs, such as housing and transport. A criticism of the development of integrated care over the past 20 years was the continued focus on developing from the micro-level, servicing specific health needs or groups rather than adopting a population health approach and considering the social determinants of health (Stein et al., 2022). The statement, "even a well-funded programme will not thrive if the rest of the system is under-resourced" made by Neale and colleagues (2019) aimed to surface and reinforce the connections "embedded within, the broader social, economic and political systems and structures within which people live and work" (p. 741). This aligned with my study, in that I interpreted the participants as being astute in their awareness of the political, economic, and social influences that impacted the integrated care they were experiencing.

Similar to Shrivastava et al.'s (2019) findings, my study participants were able to share novel and creative ideas for how to improve the design, accessibility, and sustainability of their integrated care program. Having access to a "free service", in that Medicare benefits covered the full cost of the service, was consistently described by the participants as being important to them and attractive to the general community when encouraging engagement with health promotion behaviours (Davis et al., 2018; Shrivastava et al., 2019). Overall, the literature findings support the connections between the self, others, and society that gradually emerged throughout the course of my study. The participants' perceptions of their integrated care experiences provided a gateway to their life world, which offered privileged access to rich and unique insights that extended beyond the immediate interactions with their health care provider or service into their social world.

7.3.4 Summary

In this section, I related my findings to the literature, by presenting the findings starting with the individual level and progressing through to the societal level. It is important to note that there continued to be limited published research available, and furthermore, in being a novel area of research, there was a sense of tentativeness as to whether the methods existed to appropriately collect or truly understand the data that an individual's perspective offers the field of health services research. In situating the findings within the literature, I have a renewed and stronger appreciation of the rich insights that the participants' perspectives of their experiences of integrated care offered, and acknowledgement of the privilege of being invited into their complex social worlds. It has shone a light on my limitations in being a human researcher, researching humans interacting within the constructs of their social world and meanings. In the following section, I address Research Focus Question 6 and summarise how this research adds to existing understanding of how individuals experience integrated care.

7.3.5 Research Focus Question 6: What Does This Research Add to Understanding of How Individuals Experience Integrated Care?

This phenomenological research was underpinned by social constructivism, pragmatism, and feminism perspectives. The participants' experiences of an integrated health service were explored within the conceptualisation that they, as people, were the source and the truth of their experiences. An insight from my research was that each participant's experience, in how they retold it, was multidimensional, complex, and emergent. Integrated care was found to be experienced as a living experience, a dynamic interaction. It was found that each participant's experience was inherently unique and yet infinitely connected to their social world and others.

7.3.5.1 So What Does My Research Offer?

When situated within the published empirical findings, my research offers novel in-depth interpretations of what the phenomenon of the experience of an integrated care service meant from the participants' perspectives. The findings provide insights into the reality and subjective meanings held by the participants, spanning from the personal to the societal level. The findings raise the proposition that an individual's experiences are at their essence integrated, in that they are fused within their everyday life and social world. Collectively the participants' integrated care experiences were perceived as being important for achieving their immediate personal health needs and goals, staying on track with anticipated future health and life goals, and as being a valued resource that offered benefits for their family, friends and community.

Just like goal setting processes were found to be inherently intuitive and informally embedded as a life skill, participants were also routinely and informally engaged with Baim-Lance et al.'s (2019) co-production practices in their personal health care activities, including within their integrated care experiences. My findings offer that, in their everyday lives, participants engaged in a variety of practices that were easily transferrable towards supporting the effectiveness of their integrated care experiences. During their life's course they had experienced navigating change and uncertainty, and had developed and adopted moral codes, behaviours, and practices that had served them in negotiating the complexities of their lives. There was little evidence to support that the participants' adaptive capacities, their resourcefulness, or insights were revealed or recognised within their interactions with the integrated care service.

What was found was that the participants felt their experiences of integrated care had provided them with convenient cost-effective access to health knowledge, expertise, and associated resources that they considered necessary for progressing their health needs and goals. Each participant held personal beliefs and views as to what their role was, and the actions required of them to achieve these goals. Their biography and lived experiences, within and outside of their healthcare interactions, were interpreted as shaping these views. The findings also support that being in relation to another, for example, with their healthcare provider or others associated with their health, was the key determinant of an effective experience. The opportunity to form relationships that fostered a sense of being known as a person was perceived to be an antecedent to building respected trusted and trustworthy relations, which then served as shaping the participant's sense of confidence and peace of mind towards managing future health needs or threats.

During the participants' interviews, they were each able to reflect on the decisions they had made and actions they had initiated in relation to their integrated care experiences. Their descriptions were not linear, they leap frogged back and forward. However, the participants each articulated their logic or emotions that underpinned the daily negotiations within the routine of their everyday lives that related to protecting and advancing their health. They demonstrated a calculated understanding of the resources available to them in order to achieve what they believed to be progress in their health and well-being. Each participant was able to describe what was important to them from their experiences of integrated care, and how they creatively shaped their experiences to achieve this and by what means they measured progress, including when and how they would escalate if concerned.

My research found that the participants were both influenced by, as well as influencing, their experience. How they expressed their sense of agency was rarely explicit or even thought through; however, I interpreted that the participants expressed ownership in how the different parts of their lives were connected, including how they showed up for and what they took away from their integrated care experiences. It was their life, their health. This interpretation of a sense of agency within their everyday and overall experiences has been described in the literature as an aspiration rather than a reality when situated within the context of contemporary health care (Hughes et al., 2020).

My research offers that an individual expresses their agency in how they understand their personal experiences and the purposes they serve for them, and the benefits they see extended to others. I suggest that individuals are likely to moderate and express their agency in the form of stewardship within their integrated care experiences. This is deliberate and an attempt to protect their immediate and longer-term personal health, goals and resources. I also relate to the literature's suggestion that the shift from expressing agency in their everyday life to being stewards within their health interactions is likely a learned response, in that people had been conditioned from previous exposure to paternalistic models of care and health practices (Ginting et al., 2022). My study found that the participants were preserving their agency, they were aware of the power dynamics, they had learned ways of working the system, and were not overly concerned about having to shift their stance. They were pragmatic in explaining that what mattered most to them was to achieve their goals as efficiently as possible.

The participants in my study demonstrated that they were conscious of the incidental costs associated with not addressing their health concerns, as well as the out-of-pocket costs of attending to health needs that are not fully covered by the Medicare benefits scheme. For example, over-the-counter pharmacy supplies and medicines are not covered, some prescribed medications are partially covered, while medical services such as general practitioners and specialist health services delivered outside of the public hospital setting can be charged at a fee beyond the Medicare benefit (van Gool & Hall, 2024). This finding supports the discussions within the literature that an individual's health is bound to their personal wealth (Rogers et al., 2020). It costs money to be healthy, which can contribute to inequities in who has access to health services (Shrivastava et al., 2019). This was reinforced by my study's participants, who shared their careful calculations in comparing the benefit from accessing the integrated care service in the context of the time, resources, and wages they needed to forgo if they accessed another service. The participants were positively motivated towards promoting the service to others and for maintaining a “free service”, which included access to medical supplies with no out-of-pocket expenses being incurred as all costs were covered by the Medicare benefits scheme.

My study findings present integrated care as playing a small yet significant role in an individual’s everyday life. The descriptions suggest a pragmatic, transactional and mostly paternalistic approach continues to preside over health care interactions. The participants’ motivation to be known and in relations with their health care provider, was mostly about gaining access to reliable personalised information and ease of access in the event of the need to escalate an immediate need or seek expert advice related to a new concern.

In summary, rather than the integrated structure of the health service being of greatest importance, as is conventionally prioritised by health service policy, what participants found to be of importance was that integrated care enabled better interactions or relations between the knowledge and experience of the health provider and the individual. From the perceptions shared, it would be difficult to support that the integrated care experienced by study participants was a transformed or reformed model of care or approach to health care. As one participant said, “it was just like going to the doctors”. The findings suggest that the most obvious difference observed from the participants was that the service was convenient, being offered in a community rather than a traditional setting. Some of the integrated care programs experienced were multidisciplinary and some tapped into the creative and social aspects of health and well-being; however, this was fragmented and only offered to discrete groups. Some had access to “free” samples of supplies, which allowed for the products to be tested before incurring the out-of- pocket expense of purchasing.

Given the opportunity, the participants demonstrated that they had the capacity to critically assess the strengths and limitations of their own and the health services effectiveness, and they had ideas and were motivated to contribute to, lead, and test changes. They expressed an understanding of the wider financial and political constraints and were willing to be activists within their community in raising awareness of the service, in sharing their knowledge and experiences with others, and using formal processes such as evaluation surveys to lobby and influence health service decisions. The findings support the proposition that the embodied knowledge, practical experiences, and motivation to innovate and experiment with integration as a relational process capable of transforming health practices sits outside the formal structures of the health service. Taking this perspective, rather than focusing local integration efforts on reorganising internal structures, the focus would be better placed on harnessing the community's innate wisdom and power through supporting social change and enterprise.

7.3.5.2 Propositions

Leading Change from Outside the System: Embodied Health Movements

Over the course of this research, I have observed the International Foundation for Integrated Care 2022–2026 strategy intentionally move away from looking to define integrated care towards adopting a social movement approach that appreciated the dynamic complexities and interdependencies that led to their adoption of guiding principles, "person and community centred, coordinated and with continuity" for integrated care (Lennox-Chhugani, 2021).

A proposition from my findings is that the study participants were best placed and informally demonstrating readiness for advocating as social change agents for integrated care in their local community. Social movements are generally described as groups of individuals who share ideas about what was important and are committed to promoting different types of change (Bell, 2013). This conceptualisation lead me to Brown and colleagues' (2004) work in identifying and categorising advocacy and activist groups organised around health related matters into three ideal types, with the one most relevant to my findings being Embodied Health Movements [EHMs]. The collective identity of this group was to be action-oriented individuals who were challenging from outside the system. Brown et al. (2004) described them as being activists who framed, "their organising efforts and critique of the system through a personal awareness and understanding of their experience" (p. 53).

The relevance to my study's proposition is that EHMs make changes happen by initiating "boundary movements", which means they "blur the boundaries between lay and expert forms of knowledge, and between activists and the state (Brown et al., 2004, p. 54). Examples of EHM social movements include women's health movements and disability rights movements. EHMs are also described as being emergent in nature and crossed the intersections of social constructivism, pragmatism, and feminism perspectives as related to illness experiences and disease processes (Brown et al., 2011). Within this context, the unique lived experience is never fully available to another, some can be shared; however, personal knowledge is what brought moral credibility to the actions of EHMs. Individuals also seek to both challenge and produce new knowledge and bring changes to practice with support from those who hold medical and scientific knowledge (Brown et al., 2004). These perspectives align with my study's proposition that integrated care is an embodied experience, integrated within the individual's life world and circumstances. From this perspective, I propose that community-living individuals are well placed to lead from the outside and collaborate with existing knowledge and power holders to coproduce change, with the core principles and the outcomes being the relationships and dialogue they value.

Mindsets and Method that Embrace Emergence: Adopting Epistemic Fluency

This study's aim was not to offer an ideal integrated care service; however, similar to how I have conceptualised an individual's experiences of health care as being dynamic and emergent in nature, health services research is also moving to describing integrated care as demonstrating the characteristics of complex, adaptive systems (Hugheset al., 2020). When viewed through the lens of the system thinking architype, the limitations of the hierarchical, linear, and competitive principles often associated with traditional approaches to health services design are identified as barriers to overcome when establishing an effective integrated care service. The benefits of recalibrating towards networked structures are proposed as steps towards creating movement and allowing for emergence to be expressed within iterative learning cycles (Braithwaite et al., 2020). The debate questioning the appropriateness of current health services research design and methods has also shifted towards adopting systems thinking perspectives (van der Vlegel-Brouwer et al., 2020).

My research offers a relatively simple, low cost, and high value interaction that has infinite possibilities in that it connects people and worlds. I have demonstrated the wealth of untapped knowledge and resourcefulness that walks into and out of health services daily. The literature supports that you cannot imagine another person's perspectives. My proposition is to pause and listen for the purpose of understanding and allowing for meaning to emerge. I am not proposing that this is easy or guaranteeing enlightenment. It is about discovery. Throughout my research, I have offered my experiences of grappling with the limitations of the methods and mindsets that I have learnt and trusted as a health professional and a researcher in health services. I have shared how I struggled to quieten my mind, to recognise the mental short cuts I tend to lean into, and to be open to novel views, or for understandings to evolve. I became aware of the value I placed on time, and where and how I was choosing to invest my time. I noticed that I had initially been unconsciously listening to understand integrated care as I knew it, with all the mechanisations of a public health service rather than sitting with and understanding the participant's perceptions and what it meant in their life world. I imagine

Ackoff (2004) would have said I was caught up in trying to do the wrong thing righter, rather than noticing what was present before me.

Van Kemenade and van der Vlegel-Brouwer (2019) recommended that integrated care researchers free their minds from being bound to a particular paradigm to experiment and adopt a stance of "epistemic fluency" (p. 362). In this stance, the researcher turns towards the complexity of the moment, which calls for personal and situational awareness, and the discipline to think about your thinking (van Kemenade, 2022). As discussed earlier, within the context of integrated care, each individual is likely to hold different perpsectives as to what is important, including different ways of knowing and being in the world. van Kemenade et al. (2022) encouraged that all stakeholders, for example, individual community members and health care providers, engage collectively with reflexivity practices as a way of making the implicit explict and opening the space for shared meaning to emerge. My proposition is for health services to continue to look for opportunities to welcome and explore different perspectives and ways of knowing that allow for new understandings to be co-created from everyday realities (Iedema et al., 2013). In the spirit of co-production, this thesis proposes that requisites for enabling all voices to be equally heard and valued begin with engaging in reflexive practices to unsurface and free the mind from existing paradigms and heuristics, reciprocity in being open to being known, and humane empathy that enables meanings to emerge and be co-created. My research efforts and findings offer a starting point for future health services research.

7.3.5.3 Summary: Addressing the Research Questions

In bringing this section to a close, I am confident that I have achieved my research goals and that my readers have had the opportunity to join me in gaining deeper and richer understanding of what integrated care means, including the purpose it serves, from the perspectives of a purposive sample of individuals living in the community who experienced the same integrated care service.

I have now responded to each of the six research focus questions, as signposted in Table 7.2. Over the course of the research, each participant's experiences were individually collected and analysed for their meaning, the utility of their experiences and their evaluation. I then examined the participants' responses as a group looking for patterns and new insights. Acknowledging the time span that the research covered and the interruptions of the global pandemic, I then returned to the literature to ensure my findings were considered in the context of the contemporary literature. To make it easier for the reader to orientate themselves, in Table 7.3, I organised the research findings alongside the original literature review findings and the more recent review. This was followed by an exploration of the study's findings within the context of what aligned and what contrasted with the literature. I organised this discussion under three headings, starting with the individual level findings, then group level, and finishing with the societal level findings. I concluded with my response to the final research focus question, where I presented my "so what".

I am hopeful I have cast enough light on the value of seeking to understand the experiences of interacting with health care services from the perspectives of the community-living citizens to excite action and challenge thinking and curiosity to explore further within health services research and practices. I have demonstrated stepping into the space of an interpretative bricoleur, in being responsive and resourceful as I flexed and reflexed in gradually patching together the theory and methods that underpinned my research design. The limited published research available that privileged the participants' experiences and perspectives, and my commitment to staying close to the participants' meaning while the study findings emerged meant that I went through many iterations of sense making to assure trustworthiness of the study design and then findings.

Beyond opening an important gateway from the experience of integrated care into the participants' life worlds, I offered propositions for further consideration. I presented the concept of activating individuals' knowledge and skills to lead and collaborate in social change movements, leading change from outside the system. I also explored the application of systems thinking characteristics to how integrated care research could move towards embracing emergence, and letting go of what was thought to be the right or best solution. I then offered the challenge of engaging in collective reflexivity as way of enabling the re-imagination and then co-production of how the health and social worlds can interact in relational and dialogic ways by blurring boundaries and creating systems of learning. The next section provides a summary of the strengths and limitations of this research.

7.4 RESEARCH STRENGTHS AND LIMITATIONS

7.4.1 Strengths

In reflecting on the strengths of my research, my mind was drawn to the original critical appraisal of the methodological quality of the research articles, which revealed that none of the limited published research available to guide me or to learn from was able to provide me with a level of certainty that the authors’ had critically examined their roles, were appreciative of the potential to influence their research, or that the researchers had engaged in reflexive practices throughout the research. In the 2023 re-run of the literature search, I found four literature reviews that had similarly reported that the included papers were generally of poor quality. With this in mind, in this research I have been explicit in being transparent, starting with sharing my biography in Section 2.2.2 Researcher’s Identity Memo . Here I invested time in revealing to the reader my vulnerabilities as a human researcher seeking to research humans. I designed practical strategies that would assist me to be aware of my presence and power, and signposted to the reader how I was integrating this awareness within my ordinary everyday (Table 2.1.). I then invited the reader to join me. I incorporated self-auditing and invited my critical companion, panel of peers and supervisory panel to also monitor the research and raise any concerns. I have discovered personal thoughts and practices that I was previously unaware of. I found the reflexive practices I developed are now embedded in my way of being, which has impacted on other aspects of my personal and professional life.

Related to my transparency, a strength is the integrity I modelled through adopting Swedberg’s (2014) approach to theorising in the social sciences. I was conscious that in order for me to be an empathic enquirer and active listener for my study participants, I would need to be prepared to be disciplined in my mindfulness practices. As I was the principal tool for my research, I built in a range of Swedberg’s (2014) discovery strategies and Maxwell’s (2013) thought experiments to assist me in staying curious. I also ensured my philosophical and theoretical positioning and how the research was designed was aligned, which meant my research iteratively took shape over time, allowing me to explore my relationships with the pragmatism and feminism perspectives and to determine the most appropriate research design. I found Stake’s (2010) position to be a perfect companion for the perspective of social constructivism and supportive of intersubjectivity. The sociological inspired concept of progressive focusing that Stake (2010) promoted provided space for me to test and strengthen my creative and abductive thinking skills. I was surprised that the point of difference my research design offered from the published research literature was engagement with abductive thinking processes and the creation of metaphors as a speculative provocation for the reader, and as a way of engaging the reader with the study participants’ words and meaning. Swedberg’s (2014) creative thinking processes challenged me in creating metaphors for each of the participants’ experiences of integrated care, and then a synthesised metaphor being, “The person is the steward; integrated care is an embodied experience”.

In practicing social research principles in letting the participants' experiences and perspectives shape the research, rather than starting with a theoretical or empirical framework, I provided space for their meaning to unfold and reveal itself. Rather than empirical explanation, my goal was to observe and attempt to understand the participants meaning and then re-present it as authentically as was possible. I engaged in numerous cycles of reflective engagement, and with Regan's (2012) acts of playfulness I was able to let thoughts go and then let them come as the participants' perspectives and my interpretations fused and took shape.

My research provided me the opportunity to read widely. I discovered that what I had been naturalistically observing within myself and the research participants could be explained by the social theorists Pierre Bourdieu's (1990) perspective and his interplay of the concepts "field, doxa, habitus and capital" that underpinned how individuals construct and then practiced their roles in a given social situation (Franklin et al., 2021, p. 342). I was intrigued that when Bourdieu's (1990) logic of practice was applied to understanding the patient and professionals' interactions in the practice of self-management support for chronic illness, Franklin et al. (2023) had found that in taking this perspective it helped shift from a judging stance, as to whether the individual had access to or lacked the resources to act, and moved the focus towards co-production which resulted in a "more dynamic, relational and socially situated approach' (p. 219). These findings strengthen my resolve, and I recognised the benefits of positioning my research findings alongside a recognised framework that could pique the curiosity of others interested in health services research and reform. This also allows for the possibility of more sociologically informed critique in future iterations of my research.

It has been important to me throughout this research to respect the participants as independently living community members who just happened to use a specific geographically located integrated care service. I believe that in not referring to my study participants by the title of patient, or using the term informant, but giving them the opportunity to choose a name that they wanted to be identified by and then using that name throughout the research when referring to them individually served to reduce them from being objectified as a consequence of the research process. I believe that it helped me to respect their personhood and to imagine them in their social world, which was where they were situated most of the time. After initially starting my thesis and referring to myself in the third person as the researcher, I again reflected, and this time, it raised concerns within me about power and that it was distancing me from owning the intersubjectivity of my position in the research. Hence, I switched to the first person. I also established the practice of talking to the reader, the audience. My intention was to also recognise them as a person and invite them to join me in being curious and discovering, freeing them up to come to their own interpretations. I believe this to be one of the greatest strengths of my research.

7.4.2 Limitations

The research findings should be interpreted within the consideration of a few limitations. The aim of the research was to explore and understand the participants' experiences of integrated care from their personal perspectives. First, the study included a small purposive sample of individuals accessing a variety of integrated care programs located in the same publicly funded, geographically located integrated care service. The intention was not to imply that this is a representative sample; the intention was to preserve each individual's perceived experience of integrated care, in order to fill a gap identified in the empirical evidence. This thesis presents that each participant's experience was bound to their unique biography, their lived experiences, irrespective of the type of integrated care service or the integrated care provider.

This study is limited to the views of those individuals who responded to the expression of interest, while the views of those who have not experienced the specific integrated health service, or those who were not considered eligible to participate in this study, were excluded. In accordance with the research design, the study participants experiences and perspectives progressively shaped the study and the resultant findings. I can only report that I have sufficiently developed an understanding of this specific cohort of participants and within the context of their accounts of their lived experiences related to a specific point in time. Temporality of the findings has been noted, in that the study participants understanding of their experiences will continue to evolve and mature over time, as the individuals experience their life course. The research findings have shown that people experiencing integrated care identify some points of commonality within the meaning and purpose of their experiences, however the essence of each participant's experience remains personal and cannot be replicated outside of their biography.

Throughout the research I have acknowledged the time I invested in bringing to consciousness the influence of my biography and the inherent influence it had on how I made sense of and behaved in the social world. I am conscious that the design of the study limited the time I spent with each study participant. The ease and generosity within which the participants shared their experiences and meaning was unexpected. In the limited time we shared together, each participant allowed me a brief insight into their everyday life. In recognising this privilege, it surfaced for me the significance of this honour and a sense of inadequacy in that there was so much more I did not understand, or perhaps could ever understand. The sense of safety, support, and guidance my research supervisors provided throughout the research was invaluable. This research heightened my awareness of the complexity of people's lives, and the futility of separating the person from their biography when looking to understand the meaning of their experiences. Furthermore, it raised the limitations of studying a specific experience of health care as a standalone event, rather than recognising it within the living ecosystem of the person's life world.

I have reflected on how presenting my findings within the current paradigm of health services research and as part of an academic program, at times created a sense of tension when determining the most effective way to express my findings. I have drawn on the intellect and writings of different social theorist throughout the research. I have also met regularly with methodological experts and informally with a panel of peers, which included individuals living in other communities who were experienced in attending to their chronic health needs at home. I have identified with, and acknowledge the limitations of, the qualitative researcher as the bricoleur (Denzin & Lincoln 2011). I have brought abstract pieces together to create an image that like a kaleidoscope will reveal different patterns to different people over time, rather than producing an installation that can reproduce the same results.

When first designing my research, I had considered collecting and triangulating interview data from integrated care providers or other staff who had contributed to delivering the service. After my literature review, it became apparent that their perspectives would be unique and different to those of the community-living individual. It was also apparent that the perspectives of this group had already been widely researched. After discussions with my supervisory panel, I decided to privilege the individual's voice over all others. I see this as strength of my research, however I acknowledge that others may perceive this to be a limitation.

A limitation, which is aligned with the findings of my research, was that I embarked on this research as a sole researcher. I would recommend future research in this field embeds the principles of coproduction, requiring codesign and partnering with community members and those with lived experiences from the beginning and throughout the research.

7.5 CONCLUSION

To conclude what this research adds to the field of health services research and understanding of how an individual experiences integrated care, I return to Professor Russell L Ackoff (2004), who I introduced to the reader in Chapter 1. His feature article on systems thinking in management used the key words “transforming”, “systems”, and “movement” in the title. In Chapter 1, I shared my initial impressions of what I saw the challenges of engaging in social reorientation and transformational change in the pursuit of achieving the policy aspiration of the WHO’s (2016a) *Integrated People-centred Health Services Framework*. My curiosity was aroused in light of the rapid uptake across the globe of the WHO’s (2016a) framework into local policy, in the absence of having agreed definitions or measures to indicate implementation efforts were on track to deliver the policy. Although I am now aware of the dearth of research that privileges an individual’s perspective of their health care experiences, when I commenced this research, I was surprised that the implementation processes, including establishing governance structures, had commenced before engaging with or seeking the perspectives of the people who would be the beneficiaries of, and whose needs would be the organising principles of this new approach to health services.

Ackoff (2004) published the provocative statement, “almost every problem confronting our society is a result of the fact that our public policy makers are doing the wrong things and trying to do them righter” (p. 2). He went on to say, “it is better to do the right thing wrong than the wrong thing right” (Ackoff, 2004, p. 2). His proposition was that transformation is more than changing what we say and how we practice, it is about changing how we think; in particular, how we engage with systemic patterns of thought. Simply put, he was advocating systems thinking in order to learn and develop. Starting with you, and then generatively building momentum, attracting others. What I offer through my research is my experience of challenging my thinking, of seeking to do the right thing in looking to understand the perspectives of individuals in order to learn more and generate enthusiasm in others to do the same. I propose that individuals within the community are well positioned to initiate social action for change from outside the boundaries of the health system, and that new and flexible methodologies that could accommodate the anticipated pace and movement for change are required.

In 2008, the WHO clarified that integration was meant to be a process, a continuum, rather than an entity, or something you have or have not. In contrast, the literature has shown that across the world, integration now features in most countries public health policy frameworks and has been adopted as a structure for organising people and resources (Stein et al., 2022). It has been framed as a have or a have not, in that only specific services were integrated (Lewis et al., 2021). It was a building not a way of being (Hughes et al., 2020). Rather than partnerships, some voices are elevated, and others remain silenced (Merner et al., 2023). Recent developments in the literature have focused on integration being a heuristic, recognising the benefits of holding diverse perspectives, building collaborative relationships rather than establishing entities (Baim-Lance et al., 2019; Henderson et al., 2023; Hughes et al., 2020; Moody et al. 2022; Stein et al., 2022; van der Vlegel-Brouwer 2020; Youssef et al., 2020). I am not proposing my thinking processes or how I have sought to make sense of the study participants accounts of their integration experiences to be the right way, or necessarily the wrong way. What this research has presented me with is a gateway into the dynamic interplay between the personal, social, and health systems of the everyday person, which are both ordinary and extraordinary acts of integration. In how I have framed and published my research, I am hopeful that you as the reader will emerge from this thesis with “radical and potentially revolutionary visions” in how we can rethink together (Ackoff, 2004, p. 4).

“Health is everything” (Study Participant Anne).

Appendices

Appendix A: Researcher's Memo

Framed by Maxwell's (2013, p. 45) Exercise 2.1 *Researcher's Identity Memo* I have included an examination of my personal goals, experiences, assumptions, feeling and values as they relate to this research. The aim was to provide an insight to the reader, as to why I was doing this research. The aim was also to introduce myself as a person, making my own meanings across my life course. My intent was to be as open and transparent as I could be.

This research was about listening to and understanding from the person their lived experiences and meanings, focusing in on their personal health needs, goals and interactions with an integrated care health service. In adopting an interpretative phenomenological approach, my personal meanings are embedded in this research.

Researcher's Memo

The following memo will include context and critical reflections on personal and professional experiences that are relevant to this research. In *italics* I have shared emerging insights on the meaning and impact of these experiences on my researcher identity.

In the textbox [▭] I will consider the researcher's memo in light of the current research design and identify areas that require consideration. Abstracts from two relevant research projects have been included.

Playing a game

I grew up at a time where being seen and not heard, listening to elders and positions of authority, and fitting in – not standing out, voicing an alternate view, following conventions – were the expectations of the polite and respectful daughter and young girl. At the time this did not overly bother me, I worked out how to work it to my advantage. I had few rebellious moments but was swiftly whipped back into line by my parents. I would say standard for a white Australian middle-class family in the 70's.

My parents set up insurance funds when we were born, for my 3 brothers to go to university, and for my wedding. I finished year 12 high school at 17 years, started my hospital-based nursing training with a group of lively 18-year-olds moving into the nurse's quarters together, no men allowed. I finally had sisters. I completed my training, was engaged at 21 and married at 22.

For the first twenty or so years, looking back I feel that I naively and with a sense of entitlement, had accepted my lot in life.

I would say I was young, doing my best to be a kind and attentive nurse. I can still recall holding a patient's hand, talking shop to him for seven hours whilst he had surgery under a spinal anesthetic. His family sent me a thankyou card and we stayed in contact until I received a handwritten note (that I still have) telling me that he had died. This was not my first death, but the first that was real to me. As a nurse I applied all the rules, and tricks I had learnt as a child, and I was intrinsically and extrinsically rewarded. I saw some people break the rules and be punished; I fitted in.

At the time I did not recognize the paternalistic and autocratic dynamics or the need for validation by others, that I was finding comfort in. I was getting more proficient at playing the game. I was not really aware of my willingness to hand over myself to fit others definitions of what was important.

As a researcher I will need to be aware of being polite and needing to fit- in as being deeply engrained in my biography

As a married woman and homeowner at 22 yrs., I commenced my hospital-based midwifery training in 1987. Interestingly things were similar but so different. My midwifery educator was 'moonlighting' as a home birth midwife, which was very risqué for the time. She shared stories in hushed tones. I was excited and scared for her. My midwife-in-training peers came from different backgrounds, genders and were at different stages in life. Rather than just accepting what was being taught, without question, we shared our experiences and perspectives. Again, I played the game, validated in being awarded highest academic marks and the praise of the Hospital Board.

My midwifery training was energising, I remember feeling a little defiant, recalcitrant, but not really brave enough to challenge the established authority that I was comfortable with and had protected me.

I sort of knew that there was hierarchy or patriarchy that operated within health care. I was trained and accepted that everyone had a role, and it was important to maintain the order *of things, best for everyone. The patient was probably the lowest rank role regarding authority, my role was to make sure they knew the rules and that compliance was expected.*

Thinking now, it's a bit like being in the Matrix movie, everything visible yet invisible, guarding the established distribution of power and authority. The hospital buildings and surrounds, policies, training and the people, staff and the community al guards of the order. It was for our own good.

Personally, in reflecting on what I did not notice, my role as an enforcer and witness, that I was colonized. I do feel ashamed about the victim or powerless mindset that I effortlessly slipped into.

As a researcher, I need to recognise that I have been colonized, with decades of exposure to the culture and practices of Australian public healthcare.
I associate feelings of shame with some of my earlier experiences. I likely have deeply embedded mental models and mechanisms that may interfere or influence what I hear and the meaning I make.
I must be attuned and empathetic, when exploring others lived experiences. That others may have had experiences that range from something they are not proud of, holds residual trauma, feel at peace with or have not ever really thought about before.

Questioning the rules

After graduating from my midwifery training, I left the hospital setting and we moved from the city to a rural setting. Hospital jobs were scarce at this time, and I took a position in the food produce industry as a sole practitioner, work health and safety nurse. Being responsible for a clinic was in stark contrast to the structure and order of the hospital setting. I realized that I had never really had to organize my day, source the resources I needed or be held accountable for a budget.

What was significant about this experience, was that my patients were the employees, they were not necessarily sick, they needed attention so they could keep working. There were families of people, generations working alongside each other. Most had left school early just to secure the job. They looked out for, and after each other. They were suspicious of me as I was considered management. I knew people came to the clinic to check me out and report back. The cafeteria was the hub. My clinic was located next to the cafeteria with a back door into the kitchen. The cook was held in high regard. Her acceptance, and the union organizer's, was critical.

In difference to nursing a person in a hospital for an 8-hour shift, I experienced the privilege of being invited into people's lives. Each person was different in how they went about their lives, how they thought about their health needs, what they invested in, what they would not bother about and why. I learnt so much about people, life and about myself. I experienced the power and fragility of trust.

I was aware that social hierarchy still existed. There were roles and expectations. I was also made aware of my own power and privilege. I think this experience taught me that I had a responsibility and a choice in how I applied and shared my knowledge, experience, and authority. I also became more aware of some of my prejudice, the importance I placed on education and academic knowledge.

I was re-educated to birth and death through experiencing, observing and learning about animals, their primal and tribal instincts, and the role they play in protecting the mother and newborn. I also experienced birth myself. I think that around this time those first seeds of doubt had now spread, my confidence in what I had accepted as truth was quickly being lost. I was curious if there was another way, if there was something I could do or offer. This was unusual, I previously would have been accepting that what I had been told was the only way and it was my role to follow the rules, no more.

As a researcher I am conscious that social hierarchy exists. That the dynamics of power are often subtle, embedded, made sense of in different ways and mostly not openly addressed. It will be important to be trustworthy and to establish trust with participants.
In listening and analysis of data, I need to be open, non-judgmental, and empathetic of different ways of knowing and how and why a person sees their role, understands what is important to them, and the actions they take.

Challenging the game and re-imagining the players

Of relevance to this research, I then returned to the rural hospital setting as a Midwife, but I was different. I personally and systematically questioned what I had been taught during my hospital training and childhood, which I had realised were really an extension of each other. I recognised I was competent in the mechanics of birth, pharmacology and in taking control in what was defined in the bio-medical model to be serious or life-threatening situations. I committed to also understanding the nature of birth and birthing. I sought out alternate perspectives. I did this through reading books, attending formal and informal training, talking with people who had different views and practices, and spending time with women and their families.

Underpinned by my passion for knowledge and my discovered awareness of the need to be a critical, active learner, I took on the role of midwifery clinical educator. I expanded this role to include both staff development and supporting the development of women and families in the form of antenatal classes.

Although I thought myself as being cynical and astute, with the advantage of insights and experiences of health professional cultures, I still did not notice things. For example, the customs and practices of hording or withholding of power and knowledge from people, as a way of looking after them, it was for the best. I had to learn from experience again that these practices were self-serving. This was my first experience in using research methods to explain what was really happening, being experienced. I drew out different perspectives using a survey questionnaire. The survey demonstrated a significant difference between the perspectives of the health care providers and the women (Patterson & Logan-Sinclair, 2003). I credit the women's collective perspectives, the presenting of the findings at public forums and publishing of the research, as contributing factors to women being provided with their antenatal record to carry with them, and then the eventual co-design of a shared-care midwifery model of care for well women.

This experience was quite liberating, I built confidence in questioning myself and in not taking for granted what others, in particular those with power and in authority, shared with me.

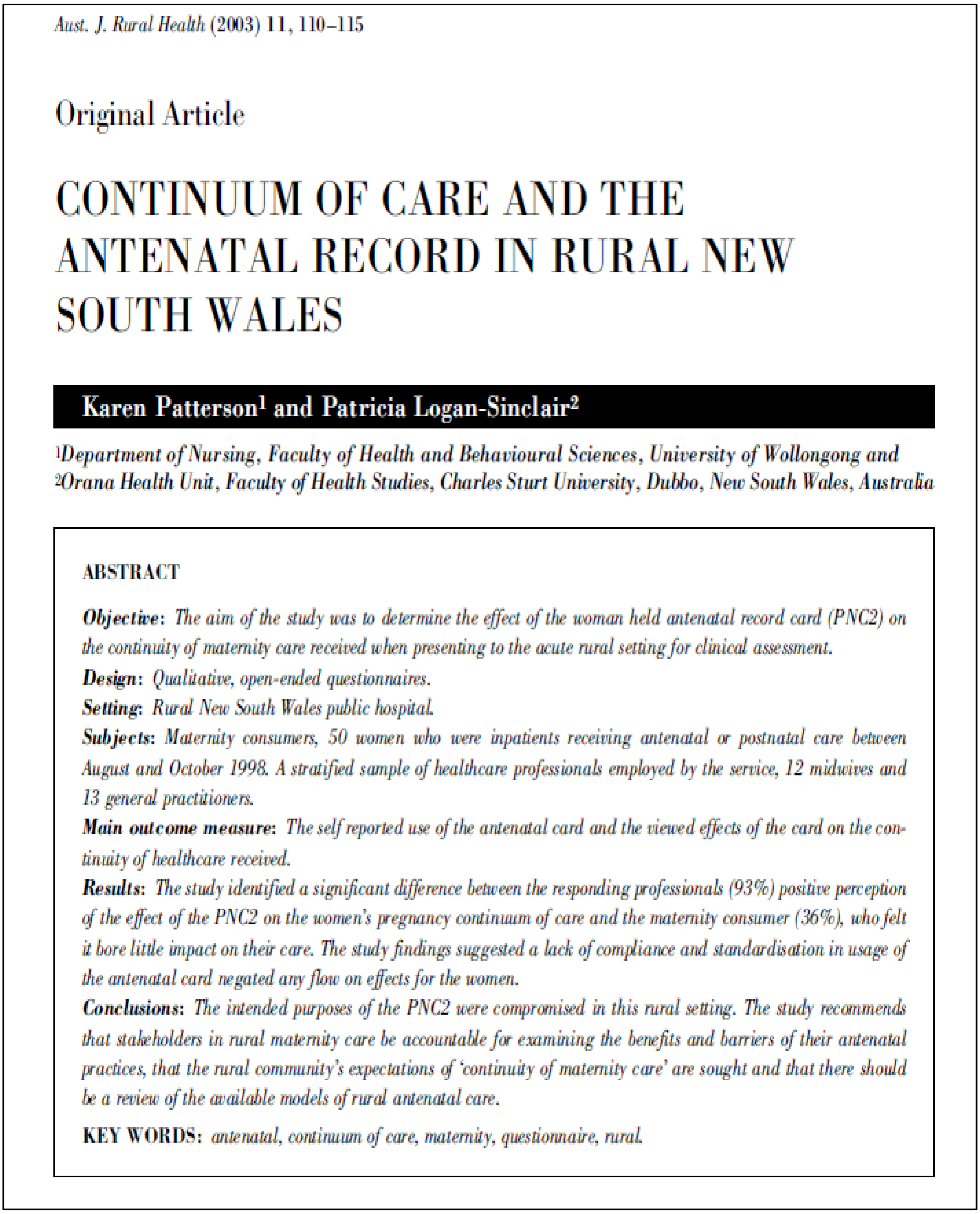
I recognised that I value and enjoy learning and feel a responsibility to share my insights and thinking with others. I do believe knowledge is power and empowering. The role of the educator provided an opportunity for me to engage with health providers in different ways, to ask questions of them and present data that would have been difficult for me to raise otherwise.

Setting up the antenatal classes, to me, was about distributing power. Providing women and their families with knowledge and practices that provided them with options. I witnessed how this changed the dynamics between the women and their healthcare team. Women were anticipating their needs and bringing to the labour room personal items.

Taking a research approach to demonstrate the case for change was a personal and professional risk. It enabled assumptions to be challenged. It gave the women a voice, where previously they had been spoken for. The survey approach although effective, had its limitation.

As a researcher, I need to be wary that I have blind spots, that I do tend to trust people and that their actions are with good intentions, until proven otherwise.

My love of learning, thinking critically and questioning out loud may not be received as the positive force for change that it is intended to be or an opportunity. I may be seen as a threat or an enforcer, people may just tell me what they think I want to hear or to please me. I need to be aware and reflect further, noting the dynamics between the oppressed and the oppressor, in particular the association with oppressed group behaviours and healthcare.



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Original Article

CONTINUUM OF CARE AND THE ANTENATAL RECORD IN RURAL NEW SOUTH WALES

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ABSTRACT

Objective: *The aim of the study was to determine the effect of the woman held antenatal record card (PNC2) on the continuity of maternity care received when presenting to the acute rural setting for clinical assessment.*
Design: *Qualitative, open-ended questionnaires.*
Setting: *Rural New South Wales public hospital.*
Subjects: *Maternity consumers, 50 women who were inpatients receiving antenatal or postnatal care between August and October 1998. A stratified sample of healthcare professionals employed by the service, 12 midwives and 13 general practitioners.*
Main outcome measure: *The self reported use of the antenatal card and the viewed effects of the card on the continuity of healthcare received.*
Results: *The study identified a significant difference between the responding professionals (93%) positive perception of the effect of the PNC2 on the women's pregnancy continuum of care and the maternity consumer (36%), who felt it bore little impact on their care. The study findings suggested a lack of compliance and standardisation in usage of the antenatal card negated any flow on effects for the women.*
Conclusions: *The intended purposes of the PNC2 were compromised in this rural setting. The study recommends that stakeholders in rural maternity care be accountable for examining the benefits and barriers of their antenatal practices, that the rural community's expectations of 'continuity of maternity care' are sought and that there should be a review of the available models of rural antenatal care.*

KEY WORDS: *antenatal, continuum of care, maternity, questionnaire, rural.*

In wanting to extend my research capabilities and being aware of the barriers to progressing my professional career in not holding formal University qualifications, I enrolled in the Masters of Midwifery (Research) program. My research "Determining the level of consumer involvement in healthcare" by Karen D. Patterson (uow.edu.au) sought to identify indicators of consumer participation at the individual level of healthcare, in the form of participation in decision making and information sharing related to an elective caesarean section. A multi-method approach was used, triangulating medical record audit, health care provider and consumer survey and interview data. The study found that the collection and aggregation of consumer satisfaction data to be an unreliable indicator of the quality of healthcare. The healthcare provider cohort held a range of views in relation to consumer involvement in their healthcare, with the dominant view being consumer involvement was not valued, which was reflected in the absence of evidence found in the medical record.

A relationship was demonstrated between the expectations of involvement in their healthcare held by women and their level of satisfaction. For example, women reported satisfaction in not being involved in their care as that was their expectation. The study cautioned satisfaction measures being used as indicators of healthcare quality or of service standards being met.

The research was related but separate to a larger Commonwealth study, Systematising care in Elective Caesarean Section – controlling costs or quality? (Sorensen et al., 2003).

I felt a significant sense of personal achievement in completing my Research Masters. My mother came to my graduation, as did my own family and friends, it meant a lot to me. I also wanted to set an example for my daughter and others that you can define who you are and what is important.

I believed my research findings spoke their truth, which was not necessarily reflective of the political and social rhetoric of the time re advancements in women-centered maternity care. I was cautious also that collecting satisfaction ratings was a beginning step for healthcare in contemplating the concepts of consumerism. I felt I was just scratching the surface of the women's experiences, with the questioning being targeted to assist the health service. I was hoping I was not contributing to the tokenism, I wanted to contribute something real. Being part of a larger study provided opportunity for the overall study findings to have broader impact and reach, however it did limit my capacity to influence the research design.

As a researcher, I have a better understanding now that my goal is to get a sense of what is really going on for people from their perspective, their reality. To privilege their perspective, not to use it to validate someone's else's view or practices.
I am feeling that the culture and presence of health care is so strong, understanding what really matters to the person is at the risk of getting lost or being misconstrued. I propose that in focusing on the person, the distraction of the healthcare provider and the healthcare setting can be minimized.

I believe people hold preconceived expectations of life, health, themselves, others, of something. These are connected to the person, their history, what's happening now and their goals. These influence how people interact and respond. Raising these to the surface, could be seen as exposing people, making peoples thoughts and actions vulnerable to being judged or criticized.

I need to be clear about my interests. That I am really interested in people, as people. That I appreciate that there may be layers of innate protective mechanisms that get in the way of telling things how they are. However, I will walk with them and follow their lead, we have a path to get us started, and let's see where we go. I am excited.

Determining the level of consumer involvement in healthcare

Karen D. Patterson, *University of Wollongong*

Year

2005

Degree Name

Master of Midwifery - Research

Department

Department of Nursing

Recommended Citation

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Abstract

Health and consumerism is a partnership featured in many Western developed countries. Nearly a decade ago, the National Quality Taskforce and Advisory Council recommended the adoption of a consumer oriented approach as being fundamental to providing safer services, minimising preventable adverse health outcomes, whist also improving healthcare quality. In accordance with this recommendation, it is now commonplace for healthcare organisations to incorporate the consumer oriented philosophy into their mission statements. In addition, healthcare recipients tend to be referred to as consumers in preference to the traditional term patient.

Despite organisational commitment for change and reports of consumer satisfaction with acute care services in Australia (AIHW 2000), the findings from the Bristol Inquiry (2001) and the King Edward Memorial Hospital Inquiry (2001) suggests that there is an absence of consensus as to the impact of these initiatives on the delivery or quality of frontline healthcare. This study aims to determine indicators of consumer participation in the planning and delivery of healthcare in an Australian context. The practice of consumer participation at the individual level of frontline healthcare is examined specifically for indicators of active participation in both decision making and information sharing. This study is complimentary to Phase Two of a Commonwealth funded project designed to explore clinical teams and the organisation of care related to the clinical condition, elective caesarean section. The study's participants have been determined by the Commonwealth project, with the study's samples being drawn from the recipients and providers of elective caesarean section healthcare, in three Queensland public hospitals over a three month time frame.

A multi-method approach is utilised to navigate the complex social and professional constructs that impact on the organisation and recording of elective caesarean section healthcare. Triangulation of the environmental, clinician, consumer and medical record data from the three study sites allows for a greater understanding of the relationships between and within the data sets. The medical record audits tendency to lack evidence of consumers actively participating in information sharing and decision making is shown to be a reliable representation of the environments inability to support participation, and the clinician and consumer samples passive view of participation at the frontline of healthcare. The triangulated data also clearly demonstrates the diversity of views and behaviours that clinicians hold in relation to the involvement of consumers in healthcare and that in the main consumer involvement is not valued. In relation to the quality and safety of healthcare, aside from the clinician's views on consumer participation, the absence of accountability to utilise standardised forms, function collaboratively or communicate clinical care effectively suggests that the study sites have numerous professional and governance issues that have yet to be effectively addressed.

In focusing on the individual aspects of the healthcare experience this study demonstrates that collection and aggregation of consumer satisfaction data to be an unreliable indictor of healthcare quality. This study demonstrates a potential relationship between expectations of healthcare and satisfaction with healthcare. Women who felt fully involved in decision making often claim to be dissatisfied with that level of involvement and women who felt uninvolved are often satisfied with not being involved. In order to satisfy consumers and secure a positive health outcome measure, the study findings suggest matching expectations with experience, and this would involve an active level of participation. However, meeting the consumer's expectations and generating satisfaction should not be interpreted as representative of meeting the technical quality or service delivery standards.

This study contributes to the limited body of research relating to consumer participation at the individual level of healthcare. The study demonstrates that overall the level of consumer involvement in healthcare is marginal. Inconsistency in beliefs and behaviours and an ad hoc approach to organising and communicating clinical care ensures the passivity of the healthcare recipients and brings into question the true quality and safety of Australian healthcare.

The feeling of achievement was somewhat short lived following my master's research, I was unsure where to next and was frustrated by some of my research findings, in particular with the healthcare providers indifference towards collaborating, lack of interest in communicating effectively or governance and limited sense of professional accountability.

I immersed myself in building leadership capabilities within the health workforce. I participated as program facilitator for the NSW Nursing and Midwifery Office (NaMO) pilot of the Royal College of Nursing United Kingdom (UK) Clinical Leadership Program; contributed as an advisor to the NSW Clinical Excellence Clinical Leadership Program; was commissioned to develop and deliver the Leadership Module of the NSW NaMO Take the Lead program; and lead the development of a university accredited program delivered within healthcare settings and on Australian and International campuses for post graduate health professionals.

Following the death of the young girl, Vanessa Anderson, that lead to the Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals. I took on senior policy officer role with the Ministry of Health, working on the report and recommendations, in particular the establishment of the NSW Health culture framework and setting up what is now known as the Health Education and Training Institute. I also took appointments with national taskforces and expert advisory groups related to Health Workforce strategy and development.

At this stage I contemplated my PhD studies and commenced drafting a proposal looking at the enablers and barriers to high performing multidisciplinary healthcare teams. In reviewing the empirical research and reports, I quickly became frustrated in the discussions about the historical, social, political, professional norms and cultural factors that were contributing to poor performance and harm to patients every day. I was disillusioned by the arguments as to why it was so hard for disciplines to established shared values. It was an ego-driven, inward looking and circular argument that I just could not engage with.

I was attracted to work with Justice Health and Forensic Mental Health Network, as I was interested in the experience of delivering and practicing health care in the context of a different dominant culture, that of NSW Corrections. The politics and the relationships both with Health and other government agencies were complex, with many levels of co-dependency and yet difference. Not surprising, health professionals and managers required support to transition into this context (Newman et al., 2015).

What was unexpected about this experience, maybe related to my naivety, was getting to know the people, commonly known as inmates or prisoners. People of all ages, genders, backgrounds and circumstances are required to navigate the ‘social hierarchies and prison etiquettes’, however with much higher stakes, their lives and their future (Patterson et al., 2014).

On reflection, I am wondering why I turned to focus on the workforce, building capability and workplace cultures at the organisational and system level. Was I focusing on what others thought was the best path for me? Was I being a polite pleaser again? With three children at school and a husband going through a career transition in studying to be a primary school teacher, maybe it was where I needed to be at that time, I was protecting myself.

In coming back to the micro-system level at Justice, connecting with people, I could not resist wanting to know more, to understand their experience and meaning, and how this could contribute and provide insights for thinking differently, break down barriers about how we traditionally think about health and health services.

As a researcher, the main hope I have is that I can bring to the surface the meaning people are making and what matters to them. Not because people are not capable, or they need help. Because I believe people are innovative within their own circumstances. Sharing or normalizing the resourcefulness of people will give other people options or ideas to build from. Perhaps it might enable or empower different ways of thinking and talking that will then lead to different behaviours.

Coming to a pause

Pausing here, this process of engaging with the researcher memo guided my early phases of the research, revealing insights from my experiences, assumptions, roles and how they might impact on how framed and designed the research. A summary of the insights I gained from this process, including practical considerations for the research that I planned to build into the research design can be found in the thesis Chapter 2 Table 2.1. Throughout the research I continued to maintain a journal that served to capture my reflections, and the questions and insights the process generated. I made it a practice of sharing my joys and struggles in making sense of my thinking with my critical companion, who would help me to hold a mirror up to see myself and the world around me in a different light.

Appendix B: “Why understanding what matters to the patient” (Patterson, 2017)

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Why understanding what matters to the patient matters

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Abstract

Purpose – The purpose of this paper is to explore the evolving of integrated care, focussing on developments in why what matters to the patient matters and how to better understand the value the patient brings to and anticipates from integrated care.

Design/methodology/approach – A descriptive piece that draws on relevant research findings, literature, reports and health policy.

Findings – Although integrated care is a contemporary policy agenda, it is bringing back to the forefront the benefits of a population health planning approach. The shift in the health systems focus from inward looking to outward looking is promising, albeit has taken 25 years and is still evolving. Leadership is being demonstrated, however, a shared vision is elusive and not all voices are being heard. The development of a narrative that defines integrated care from the patient's point of view is an important step. Next is better understanding the immediate and anticipatory public value integrated care offers.

Originality/value – This is a novel perspective of an enduring health reform policy concept. Currently the literature is thin.

Keywords Value, Integrated care, Narrative, Individual, Population health systems

Paper type Viewpoint

Introduction

Transitioning towards integrated care has been positioned in this journal and other publications as an approach that has the potential to offer value at the system, operational and individual level of health care. For integrated care to realise this value, it has been noted that a paradigm shift is required in the governance and management of public resources, away from the traditional bureaucratic model and towards a more responsive people-centred co-operative model (O'Flynn, 2007; Ferrer, 2015). Furthermore, this shift entails navigating an approach that values both systematisation and customisation, concepts which are conventionally in tension (Singer *et al.*, 2011). With coordination and patient centeredness as primary drivers for integrated care, the fast pace of change has been a catalyst for further exploring the evolving concept of public or social value, in particular how health systems have taken the opportunity to understand what constitutes value to the people they serve; in other words, what matters to the patient.

This paper aims to discuss the evolving nature of integrated care. Specifically, this paper will explore, discover and evaluate the issue of value and how it is constructed in the context of integrated care. The discussion draws on published research findings, literature, health policy and World Health Organisation Strategy publications.

Exploring value

Value in the for-profit and private business arena is often considered a quantifiable concept which is expressed as a return using an economic or exchange model, in contrast public value tends to be represented as a collective judgement of merit that may or may not be easy to articulate or measure (National Voices, 2015; O'Flynn, 2007). In the context of public health, being accountable for greater transparency in the investment of finite resources,

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integrated care has been put forward as the most appropriate and sustainable policy for ensuring public value; in that, the public receives safe, timely, appropriate health care that is responsive and cost effective (World Health Organisation (WHO), 2015). To maximise its public value, integrated care requires engagement and dialogue across organisational, professional and social boundaries (Moore and Khagram, 2004).

A feature of bureaucratic models, such as traditional public health, is hierarchical structures that are coordinated by rules, functionally departmentalised and largely impersonal (Uhl-Bien and Marion, 2009). In contrast the aspired people-centred model that underpins integrated care relies on structures that encourage informal interconnectedness and are supportive of dynamic interactions (Redding, 2013). This backdrop highlights a significant mismatch between the current operating model and the preferred model. Of relevance to exploring the concept of value, these conditions require a significant disruption to business as usual, including what is important and how to reasonably identify and measure the value produced.

Conceived in bureaucracy, it should not be surprising that public health organisations are primed to measure and monitor the value integrated care offers through focussing on system and operational measures (Redding, 2013). For example, from a system perspective, whereby integrated care means that a full range of health and social care services are joined together, value is represented through the designing of integrated care health pathways joining primary, secondary and tertiary services. This offers a traditional value in the forms of fiscal efficiencies and improvements in how services are planned, resourced and delivered (Birrell and Heenan, 2014). From an operational perspective, as an outcome of fostering co-operative relationships across organisational and professional boundaries, the value of integrated care is represented through enhanced staff engagement and opportunities for innovation and practice improvement (Wigens, 2016). It is estimated that integrated care health pathways, coordinating services from prevention, treatment and care, to recovery, rehabilitation and reablement that are approached within a co-operative relational ways of working, will improve both the process and outcomes of integrated care (Wistow, 2011).

In contrast, although improving the patient's experience continues to be widely referenced as both the driving issue and desired outcome for adopting the integrated care health pathway and co-operative approach, the value that this offers at the individual level remains poorly understood (Redding, 2013). It is common that integrated care outcome indicators comprehensively report on structures and processes, applying a balanced scorecard approach that illustrates how the services have improved their productivity and performance, rarely do they report on how the patients experience has been improved or how the individual has been benefited (Evans, 2014; Goodwin *et al.*, 2014).

The challenge for researchers and policy makers alike is to identify appropriate methods and outcome measures that are capable of capturing and analysing value at the individual level of integrated health care (Redding, 2013; McDonald *et al.*, 2015; Wodchis *et al.*, 2015). Left unaddressed, the inability to explore an individual's perspective of value alongside the organisations assessment of risk will see the bureaucratic drivers for integrated care strengthen (Brannelly and Matthews, 2010; Ferrer, 2015).

Discovering value

To support the shift towards a people-centred philosophy, where services are locally developed and contextually relevant, a population approach to the planning and delivery of integrated care has been widely promoted (WHO, 2015). Not a new concept, population health planning has played a significant role in understanding the interdependencies between the environmental, economic, political, social, cultural and behavioural factors that contribute to the health and wellbeing of communities and populations over the life course. The cornerstone of population health planning is effective and meaningful community, inter-sectoral and whole-of-government partnerships, which is closely aligned with the goals of integrated care (Public Health Agency of Canada, 2013; Huynh, 2014).

In acknowledging that integrated care is an evolving concept in itself, Evans *et al.* (2014) undertook an extensive review of over 25 years of international academic research and health sciences literature. Searching PubMed and EMBASE, a total of 114 articles were analysed. Evans *et al.* (2014) articulated a trajectory that illustrates six hallmark paradigm shifts. The authors proposed that the generative reframing of the value that integrated care offered has been a primary stimulus for the gradual refocussing of integration care strategies (Evans *et al.*, 2014). The six shifts in the evolution of integrated care were described by Evans *et al.* (2014, p. 125) as being:

1. from a focus on horizontal integration to an emphasis on vertical integration;
2. from acute care and institution-centred models of integration to a broader focus on Community-based health and social services;
3. from economic arguments for integration to an emphasis on improving quality of care and creating value;
4. from evaluations of integration using an organisational perspective to an emerging interest in patient-centred measures;
5. from a focus on modifying organisational and environmental structures to an emphasis on changing ways of working and influencing underlying cultural attitudes and norms; and
6. from integration for all patients within defined regions to a strategic focus on integrating care for specific populations.

In support of the gradual evolution of the focus of integrated care, the World Health Organisation summarised that no two health systems in the world, for good reasons, follow the same path or are exactly alike. Every population, and its respective health system, has a different starting point, with different challenges to overcome and needs to address (WHO, 2015). This approach calls for responsiveness, rather than prescriptiveness, as being the basis of the model of care. This means that the subjective (humanistic) features along with objective (system) features of health care are blended (integrated), valuing the harmonising of both people and systems (World Health Organisation, 2007).

Framing integrated care's value within a people-centred philosophy is about empowering and engaging individuals; however, it is also about accepting that prescribing the terms of these relationships is a contradiction (WHO, 2015). A critique of the international literature on how integrated care has been approached has identified that regardless of the type of integration being planned, the determinants for success were a shared vision that enabled clear expectations and accountabilities at all levels, called system integration, and shared meaning that enabled the coordinating of work and collaboration at all levels, called normative integration (McDonald *et al.*, 2015; Fulop *et al.*, 2005). The ultimate goal of integrated care is described as a joined-up system, connecting the health systems vision and purpose to ensuring an individual's care is coordinated, whilst also broadening the vision to ensure connection and responsiveness to the health needs and outcomes of benefit for the population (Alderwick *et al.*, 2015).

In 2007, the US-based Institute for Healthcare Improvement (IHI) invested in a campaign targeting both strategic and normative levels of integration. The Institute for Healthcare Improvement (IHI) (2016) Triple Aim goals represent the dynamic interplay between: a better care experience for clients and better care outcomes, improved population health and a more sustainable and cost-effective care system. The IHI Triple Aim framework, whose principals have been widely adopted, has been able to demonstrate and legitimise the value of working with individuals and communities to identify what they valued (IHI, 2016; McCarthy and Klein, 2010). With the initial key message being, drive with quality and costs will follow, health services were encouraged to review the evidence base and quality of their services, working with patients to redesign or remove practices which were ineffective or no longer of need (IHI, 2016). Lead by IHI President Emeritus, Don Berwick, the key message to the health system has been refined to:

> […] the more patients and families become empowered, shaping their care, the better that care becomes, and the lower the costs. Clinicians, and those who train them, should learn how to ask less, "What is the matter with you?" and more, "What matters to you?" (Berwick, 2016).

Evaluating value

Integrated care is topical, but not necessarily a new topic. A traditional method to conceptualise the value of something is to undertake an evaluation. Evolving within the population-based planning approach, integrated care ought to evaluate whether the plan is doing what needs to be done to meet the population's needs. Evaluation is a core element of health planning, and asks three questions: what should happen? what actually happened? and why did it happen? (The Health System Intelligence Project, 2006). The approach to evaluation, whether formative or summative, and the timing being prospective or retrospective, usually determines the tools and approaches used. A schema is often used to communicate the evaluation framework to a wider audience, as a means of generating a shared vision and meaning (Huynh, 2014; Porteous *et al.*, 2002).

Unlike most other interventions within health care, the empirical evidence base to advise how best to conceptualise the value, and therefore be responsive, to the needs of individuals within their integrated care experience has been described as weak (World Health Organisation, 2008). A 2006 Cochrane systematic review of integration within primary health services in middle- and low-income countries concluded that the focus of the research reviewed was on describing the supply of integrated care, from the system and operational perspective, with little attention to measuring the demand side (Briggs and Garner, 2007). The authors recommended that to influence the uptake of integration and its effectiveness for improving community health, future research needs to seek to better understand the individual patients view (Briggs and Garner, 2007). An update of the Cochrane review published in 2011 cautioned that integration may not always improve service delivery or an individual's health status and reiterated that policy makers and planners should monitor and evaluate integration strategies using rigorous study designs that equally values the experiences and benefits as viewed by the individual patient (Dudley and Garner, 2011). The authors advise that the individuals' views are highly influential on the operational effectiveness of integration strategies and on the community's uptake of integrated care services (Dudley and Garner, 2011).

In 2015, the lessons learnt from a cross-case synthesis of seven successful integrated care models in Australia, Canada, the Netherlands, New Zealand, Sweden, the UK and the USA supported that an effective model may look and operate differently in different programmes (Wodchis *et al.*, 2015). The authors reported that the integrated care programmes reviewed tended to lack rigorous or formal evaluations, making it difficult to differentiate the patient's perspective or learn from their experience. Wodchis *et al.* (2015) found that when integrated care adopted a responsive approach, customising the care experience to meet the needs of importance to a specific patient, meant that the process, outcomes and lessons learnt from one patient experience are unlikely to be comparable to another patient's evaluation of their experience. The authors recommend that in the context of there being no single best way to approach integrated care and that each patients experience is unique to their circumstances, it is critical for sustainability that programmes are continuously and robustly evaluated, monitoring the adaptions and changes to definitions that will eventuate over time when operating within a truly flexible, patient-centred model (Wodchis *et al.*, 2015).

An Australian study by McDonald *et al.* (2015) also examined the success of six different types of integrated primary health care centres (IPHCCs). Drawing on Kringos *et al.* (2010) systematic review of the core dimensions of integrated care, the study design focussed on examining the dimensions of access and coordination as they were closely associated with the Triple Aim of improved patient satisfaction, population health and the strength of primary care. Applying a mixed methods comparative case study design, McDonald *et al.* (2015) collected data through site visits, telephone and e-mail using semi-structured interviews, document analysis, non-participant observation and staff survey. The dimension of access was explored in terms of the five elements described by Levesque *et al.* (2013) including approachability, acceptability, availability and accommodation, affordability, and appropriateness. The dimension of coordination was explored as a feature of integration. For the purposes of this study, the descriptors for integration included organisational, professional, clinical, functional and normative integration (McDonald *et al.*, 2015).

McDonald *et al.* (2015) identified that across the study sites staff commonly made reference to the vision for "patient-centred practice" and the goal of "improved health outcomes" (p. 10). All sites had basic arrangements for access and there was a stronger explicit vision about access, including co-location of services and enhancing access for specific population groups, than there was a vision for integration. Integration was often referred to as a "one-stop shop" and "everything under one roof" that afforded opportunities for informal communication and information sharing, rather than having an explicit purpose or benefit (McDonald *et al.*, 2015, p. 10). The findings indicated that success for the IPHCCs was likely to focus on operational improvements, be it in the organisation's performance or the functioning of the multidisciplinary team. Limitations in the study design identified by McDonald *et al.* (2015) were that they failed to include investigating patterns of care at the individual patient level, excluding the patients perception of their experiences of access and integration or insights into the actual impact for the patients or their health care outcomes.

McDonald *et al.* (2015) findings were similar to that of the George Institute for Global Health (2014) who were commissioned by an Australian jurisdiction to undertake an independent evaluation of the implementation of their Integrated Primary and Community Health Policy, with particular focus on their flagship Chronic Disease Management Program (CDMP). The evaluation revealed that rather than responding as a coordinated, proactive model based on preventative principles, the policy was operationalised reactively, based on traditional crisis management principles (The George Institute for Global Health, 2014). The evaluation findings were found to be comparable to other international studies. The authors assessed that the integrated care model was in an emergent phase of development, with timely access to data and intelligence critical. A significant limitation to the study design was the difficulties in truly understanding the patient experience or capturing their voice within the data. The authors proposed that in better understanding the patient, as a central stakeholder and an active participant, would bring another dimension to understanding the data and perhaps contribute outcome measures of more relevance in evaluating the impact of the policy and the CDMP (The George Institute for Global Health, 2014).

One theory as to why research and evaluation design continues to focus on the system and operational perspectives of integrated care is the absence of a definition that is inclusive of, or exclusively represents, the patient's point of view (Redding, 2013). With the value that integrated care offers at the individual level unclear, determinates of progress and success towards realising this value will also remain unclear, unheard and therefore unexplored. A step forward in developing an integrated care narrative from the individual patient's perspective has been led by the National Voices, the coalition of health and social care charities working to strengthen patient and service user voice in policy in England, who have engaged widely over an extended period to develop a statement that offers a common frame of reference for what integrated care means (Redding, 2013). The statement offered is:

> I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together service to achieve the outcomes important to me (Redding, 2013, p. 322).

It is proposed by the National Voices (2015) that both the process taken to develop the statement and the statement itself will contribute to progressing the articulation of the value integrated care offers at the individual level of health care. To support a broader debate in conceptualising value and champion the development of new measures, in September 2015 the National Voices published a discussion paper inviting feedback as to "How should we think about value in health and care?"

The timeliness of this debate is supported by the Consumers Health Forum of Australia (2014) project, Real People, Real Data, which is focussed on how to use the patient experience and consumer evidence to drive improved health outcomes. The project has proposed that in gathering an individual's story about their health experience, known as a narrative, provides detailed data that draw attention towards what matters most to the individual patient (Consumers Health Forum of Australia, 2014). The project literature review found that it was uncommon for health services to gather and use patient story data in a systematic manner, preferring force choice survey questions that are retrospectively focussed on a specific intervention, unlikely to explore the immediate or anticipatory impact on their health experience and outcomes (Consumers Health Forum of Australia, 2014).

Insights and implications

It is apparent that although integrated care is a contemporary policy agenda, it is bringing back to the forefront the benefits of a population health planning approach. Practiced in fostering engagement and dialogue across boundaries, population health brings a range of established tools and strategies to enable and empower people and populations with the aim of improving health outcomes and wellbeing (Huynh, 2014).

The evolution of the focus of integrated care from inward looking to outward looking is promising, albeit has taken 25 years (Evans *et al.*, 2014). In acknowledging that there is no single model or best way for a health system to approach integrated care, the World Health Organisation has commissioned a resource that adopts a health systems perspective to illustrate the evidence and strategies available to support individual involvement and community participation in health policy and system design (WHO, 2015; Ferrer, 2015).

It is evident that the current mechanisms for evaluating system and operational performance have not yet evolved so as to meaningfully capture the elusive and dynamic elements of the individual's perception of their integrated care experience (McDonald *et al.*, 2015; The George Institute for Global Health, 2014; Wodchis *et al.*, 2015). Furthermore, in adopting people-centred and responsive approach it is likely that traditional approaches to evaluating and measuring health service performance and impact will be increasingly inadequate. However, if the value sought from integrated care continues to focus on supply, such as system and operational measures, the drive for change to invest in understanding the demand, such as individual level measures, will remain weak (Briggs and Garner, 2007; Dudley and Garner, 2011).

Leadership is being demonstrated and vision is needed. The refining of Don Berwick's (2016) IHI messaging for system reform from a focus on cost and quality shaping the health agenda, towards gaining a better understanding of "what matters to you"?, is significant. There has been international adoption of the IHI Triple Aim framework, placing inquiring what is important to the patient as the key driver for shaping the design of the health experience and understanding the impact or value of the health service, is likely to generate a variety of local innovations and improvements in health services.

The development of a narrative that defines integrated care from the patient's point of view is an important step in providing patient, carers and the community a voice. Importantly, this perspective offers a generic response to what may be of importance to an individual and of public value, and therefore provides the opportunity for further exploring and evaluating. The development of a shared narrative is also recommended as a way of supporting health policy makers and providers to be able to better articulate what their vision of people or patient-centred care looks and sounds like (Redding, 2013; Consumers Health Forum of Australia, 2014; National Voices, 2015).

Reform is inevitably slow. Within the complex and unprecedentedly fast changing environments of health care, where changes are both staged and emergent, provides a challenging and slippery backdrop for reform to take hold. Conversely, it could be argued that this also presents an environment ripe for change and disruption. Integrated care, perhaps reluctantly, is emerging as a change catalyst, holding the potential to support "co-ordinated efforts across population health systems" (Alderwick *et al.*, 2015, p. 2), moving beyond the stoic, risk avoidance and hierarchical approaches that have traditionally served them well, towards understanding what constitutes value to the people they serve; in other words, what matters to the patient.

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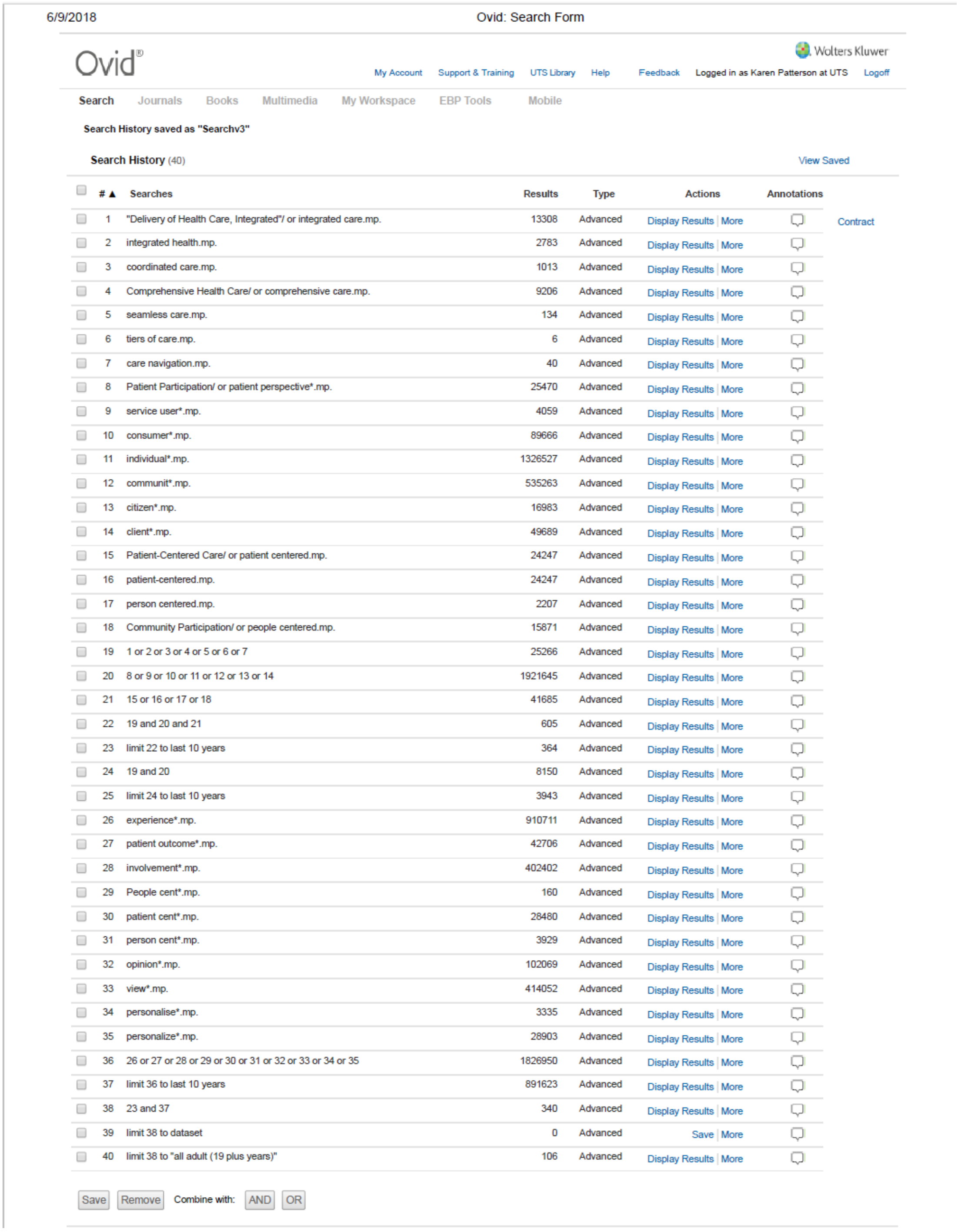
Appendix C: Ovid Medline Search Strategy



6/9/2018 Ovid: Search Form

Search History saved as "Searchv3"

Search History (40)

☐	# ▲	Searches	Results	Type	Actions	Annotations
☐	1	"Delivery of Health Care, Integrated"/ or integrated care.mp.	13308	Advanced	Display Results | More	
☐	2	integrated health.mp.	2783	Advanced	Display Results | More	
☐	3	coordinated care.mp.	1013	Advanced	Display Results | More	
☐	4	Comprehensive Health Care/ or comprehensive care.mp.	9206	Advanced	Display Results | More	
☐	5	seamless care.mp.	134	Advanced	Display Results | More	
☐	6	tiers of care.mp.	6	Advanced	Display Results | More	
☐	7	care navigation.mp.	40	Advanced	Display Results | More	
☐	8	Patient Participation/ or patient perspective*.mp.	25470	Advanced	Display Results | More	
☐	9	service user*.mp.	4059	Advanced	Display Results | More	
☐	10	consumer*.mp.	89666	Advanced	Display Results | More	
☐	11	individual*.mp.	1326527	Advanced	Display Results | More	
☐	12	communit*.mp.	535263	Advanced	Display Results | More	
☐	13	citizen*.mp.	16983	Advanced	Display Results | More	
☐	14	client*.mp.	49689	Advanced	Display Results | More	
☐	15	Patient-Centered Care/ or patient centered.mp.	24247	Advanced	Display Results | More	
☐	16	patient-centered.mp.	24247	Advanced	Display Results | More	
☐	17	person centered.mp.	2207	Advanced	Display Results | More	
☐	18	Community Participation/ or people centered.mp.	15871	Advanced	Display Results | More	
☐	19	1 or 2 or 3 or 4 or 5 or 6 or 7	25266	Advanced	Display Results | More	
☐	20	8 or 9 or 10 or 11 or 12 or 13 or 14	1921645	Advanced	Display Results | More	
☐	21	15 or 16 or 17 or 18	41685	Advanced	Display Results | More	
☐	22	19 and 20 and 21	605	Advanced	Display Results | More	
☐	23	limit 22 to last 10 years	364	Advanced	Display Results | More	
☐	24	19 and 20	8150	Advanced	Display Results | More	
☐	25	limit 24 to last 10 years	3943	Advanced	Display Results | More	
☐	26	experience*.mp.	910711	Advanced	Display Results | More	
☐	27	patient outcome*.mp.	42706	Advanced	Display Results | More	
☐	28	involvement*.mp.	402402	Advanced	Display Results | More	
☐	29	People cent*.mp.	160	Advanced	Display Results | More	
☐	30	patient cent*.mp.	28480	Advanced	Display Results | More	
☐	31	person cent*.mp.	3929	Advanced	Display Results | More	
☐	32	opinion*.mp.	102069	Advanced	Display Results | More	
☐	33	view*.mp.	414052	Advanced	Display Results | More	
☐	34	personalise*.mp.	3335	Advanced	Display Results | More	
☐	35	personalize*.mp.	28903	Advanced	Display Results | More	
☐	36	26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35	1826950	Advanced	Display Results | More	
☐	37	limit 36 to last 10 years	891623	Advanced	Display Results | More	
☐	38	23 and 37	340	Advanced	Display Results | More	
☐	39	limit 38 to dataset	0	Advanced	Save | More	
☐	40	limit 38 to "all adult (19 plus years)"	106	Advanced	Display Results | More	

Appendix D: CASP Checklist

	A. Are the results valid?						What are the results?			Will the results help locally	
	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Comments
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	
Burridge et al., 2016	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	researcher critical examine own role / bias/ influence - only explicit in data analysis
Petch et al., 2013	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	
Spiers et al., 2014	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	
Spoorenberg et al., 2015	Y	Y	Y	y	y	U	Y	Y	Y	Y	AA
Yarborough et al., 2015	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	

Critical Appraisal Skills Programme (2018). CASP Qualitative Studies Checklist [Online] https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-Checklist/CASP-Qualitative-Checklist-2018_fillable_form.pdf

Appendix E: Extracted findings and illustrations for each of the included studies

Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2016). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations, 19*(1), 74–86.	
Extracted findings (a verbatim extract of the authors analytical interpretation of the results/data)	Illustrations (direct quote of the participant voice, field work observation or other supporting data)
Sensibility of change (coherence) Self-awareness that change is necessary and sensible due to the health risks but experiencing dissonance between the rational view and the lived reality	Now you can't be, what shall I say, pig-headed about this. You can meet people who say, oh, to hell with this, I'm going to eat what I like. Well, you have to be reasonable, because you do have a longer life if you can measure and manage [P20(1), male, 71 years].
Diabetic life (cognitive participation) Personal challenges of managing what is viewed as an invasion of diabetes into all aspects of life and the incongruities between personal values and expectations and living with diabetes	Everything has to be value calls. It can't be absolute. So for me, [its] the muffin in the morning. I've tried to cut them down until it's just the ones that I really, really want; because I know my body doesn't like them. I also have very high insulin resistance in the morning, so it's just doubly bad, but when I'm doing other things elsewhere that are good, it's something I've got to make the call on [P12(1), male, 41 years].
Diabetes care alliance (collective action) The routines and partnerships in care have to be flexible and individualized to take account of personal contexts and expectations	My GP introduced insulin to me, but it didn't work because I didn't add the tablets that are [now] actually making insulin work in my body. But because it didn't work, I asked to see the specialist [P03(1), female, 58 years].

Spoorenberg, S. L., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS One, 10*(10), e0137803.	
Extracted finding (a verbatim extract of the authors analytical interpretation of the results/data)	Illustration (direct quote of the participant voice, field work observation or other supporting data)
Experiences with aging	
Struggling with health. We found clear differences between the participants from the three Embrace profiles with regard to their experiences with the consequences of aging. Robust participants felt in general healthy, but they feared the consequences of aging (e.g. progressive deterioration in health, increasing dependency, and loss of control). In	The robust participants were positive about their health, even if they were experiencing physical or mental symptoms. These symptoms did not affect their daily functioning, nor did they play an important role in their lives. The greatest wish of the robust participants was to stay healthy without impairments.

contrast, frail participants and those with complex care needs seemed to struggle with the consequences of aging, including deteriorating health, increasing dependency, decreasing social interaction, and loss of control.	The frail participants and those who had complex care needs were confronted with deteriorating health, describing their health as “not so good” or “poor.” “But to say “I feel fit,” no, I won’t ever be able to say that again.” (C15F)
Participants were ambivalent in accepting their health status. Most had resigned themselves to their physical and mental deterioration, stating that they had accepted their current health status and avoided thinking about future deterioration.	“No, what will be, will be. [. . .] Luckily, we don’t know what the future will bring.” (F3M)
Many participants (particularly those with complex care needs) expressed a desire for “better health”.	
Participants from all three profiles described specific fears related to their deteriorating health (e.g., continuous fear following a life-threatening condition or fear of a stroke).	“I feel. . . I’m generally more anxious, particularly in the dark and when driving, that sort of thing.” (F9F) Most of the participants also indicated that they feared falling due to loss of mobility, and that they had become more cautious when moving.
Participants rarely mentioned death during the interviews. When it was discussed, however, the participants differed in their attitudes toward death.	Some of the participants with multimorbidity spoke of death as a merciful release. Another participant with complex care needs said that he did not yet want to die, although he did think about the end of his life.
Increasing dependency. All participants expressed the wish to stay independent for as long as possible and to continue doing as much as possible without the help of others.	In general, dependency first concerned the need to use assistive devices in performing the activities of daily living. This was followed by dependency on others, including informal and professional care
Those who were not yet dependent on others expressed the fear of future dependency.	“You become so dependent if you require assistance with everything.” (C15F)
Most of the robust participants were still managing their daily lives without any help from others, although some feared becoming a burden to others.	“That you’re not dependent on someone else [. . .] because you see it here from close up: someone arrives in the morning to wash you, at lunch time to make you a hot meal and wash up again, and then in the evening to get you ready for bed. I hate the idea of that.” (R10F)

Most of the participants with complex care needs and some frail participants were dependent on others because of decreasing mobility or impaired cognitive functioning. Some found it difficult to accept the fact that they could not function as they had previously been able to do.	“Well I want to do [clean out] the cabinets; I really want to get it done. It all needs to be sorted out, but I can’t do that either. It makes me a bit angry with myself.” (F4F)
Dependency on assistive devices–Some participants felt reluctant to use assistive devices (e.g., canes or rollators), because they made them feel old or disabled. In fact, some participants did not use such devices at all, even if it put them at greater risk of falling.	“That’s what I need to get over [. . .] Then you really do feel disabled.” (F8F)
Most of the participants who did use assistance devices had complex care needs or were frail, although some robust participants used walking aids. Almost a third of these participants reported problems with their devices (e.g., rollator wheels getting stuck or wheelchairs that were difficult to get into an elevator). The participants saw these as reasons for not using the devices, despite their dependence on them.	“But this housing isn’t really suited to people with disabilities. You can’t get through the front door with a rollator, and they’ve got those high-speed bumps at the back of the house. They’re so high that you can’t go there at all with your mobility scooter.” (C5M)
Dependency on informal care–Most participants expressed reluctance to ask their children for help. Nevertheless, almost all of the frail participants and those with complex care needs were receiving such assistance (e.g., with domestic chores, gardening, finances) from their children, neighbours, or other informal caregivers. Most of the robust participants were not dependent on informal caregivers, although one participant had recently started asking her daughter to help with paperwork.	“Just my daughter [. . .]. She often comes on a Wednesday afternoon. [. . .] If any forms need filling out, she does all that for me. [. . .] Because you can’t always figure it out by yourself. Although I’ve only just recently started doing this. I used to do it all myself.” (R10F)
Independent living–Most participants wanted to continue living at home rather than moving into a facility, due to negative associations with loss of independence and freedom.	“Then I’ll have lost my freedom. I don’t want to leave here. I desperately want to stay here until the bitter end.” (C7F) Participants compensated for their decreasing mobility by adapting their homes (e.g., installing grab bars or replacing furniture) or by wearing personal alarms.

	Some participants found it difficult to define what they needed to remain living at home, expressing hope that they would receive care and support if needed. Robust participants also reported preventive strategies for maintaining independence, including staying physically active in and around the house, following a healthy diet, taking on mental challenges (e.g., puzzles and reading), and performing volunteer work.
Decreasing social interaction. Almost all of the participants stressed the importance of social contact, although there were differences in the number and quality of social relationships.	"Look, we do have social contact [. . .] it's very, very important [. . .] you can't cope without it. That's what we've found." (C1F) The robust participants retained social contacts by participating in clubs, volunteering, or sharing hobbies and activities, thereby stimulating a sense of usefulness.
Frail participants and, even more so, those with complex care needs, experienced changes in their relationships due to their physical impairments or illness, or due to the death of friends.	"And then someone else is gone, and then you have even more to cope with. And it hits you hard; it's hit me hard [. . .]. The companionship that was gone. [. . .] You can't go and enjoy that person's company anymore, however much you would like to." (F3M)
Frail participants and those with complex care needs also expressed a desire for more company and fun.	They wanted to "get out," (e.g. going on outings with their partners, visiting the garden centre, or taking vacations).
Social interaction also differed between participants who were living alone and those who were living with partners. The latter reported less need for social contact, new or otherwise, because they still had their spouses and spent most of the day together.	"We are still able to manage. We like to go out together, we do everything together." (R14M) Participants whose partners were deceased felt a great sense of loss and found it difficult to get out to meet others.
Loss of control.	All of the participants reported a desire to stay in control, and they considered it important to determine their own daily living schedules.
Participants who received care and support from multiple and frequently changing caregivers felt a loss of control.	"I've seen so many faces [. . .]. If you happen to be the first in line, then it's early, but if you're the last, then you're last in line. It changes a lot." (C6M)
Loss of control was also reflected in the themes mentioned above. For example, one participant's fear of becoming dependent stemmed from the assumption that dependency	"To be in control, because once you become dependent on someone else, your life isn't the better for it." (F3M)

would lead to the loss of freedom and the ability to control what one does and when one does it.	
Participants who became housebound because of problems with using their assistive devices (e.g., rollators, wheelchairs) experienced a profound loss of control.	"Because I can't get away from here at all. I can't get in the elevator with the rollator. And I can't get back up if I go downstairs [. . .] I've already managed to get the elevator really stuck [with the wheelchair]. My caregiver told me, "Don't do it again". It makes you nervous. So I'm literally a bit shut in here." (C7F)
Fears. Participants experienced a variety of fears related to the expected and emerging consequences of aging. These fears were intertwined throughout the aforementioned themes.	Frequently mentioned fears were largely related to deteriorating health and mobility problems (e.g., fear of falling). Furthermore, some participants postponed the use of assistive devices, as they feared feeling old and disabled. Others often mentioned fears related to becoming dependent on others, with the associated fear of becoming a burden to others and losing their freedom. The interviews also revealed that all of the participants feared losing control and freedom upon moving into an institutional setting, and they therefore wanted to age in place.
Experiences with Embrace	
We found clear differences in the experiences of Embrace care and support between the participants from the three different profiles. These differences corresponded to the different care intensity levels corresponding to the three different profiles.	For the frail participants and those with complex care needs, the case manager embodied Embrace: the case managers supported, monitored, informed, and encouraged them. In contrast, robust participants reported being informed and encouraged by the Embrace group approach.
Relationship with the case manager.	The relationships between participants and their case managers were based on equality and confidentiality; both aspects were seen as conditional for achieving productive interactions.
Equality The participants perceived their relationships with their case managers as being based on mutual equality. Their opinions were important, and they felt in charge.	"I think she's a friendly woman, and she's on a level with you rather than looking down at you, and that alone is worth a lot. And she talks like we do [in dialect], and she's very down to earth. We say she's a good one, and, as my husband says, we wouldn't want to be without her." (C1F)

The participants reported that their case managers took their personal preferences into account (e.g., in scheduling visits). In contrast, the participants reported that other healthcare professionals tended to visit when it suited their own schedules.	“Well she always asks, “What time can I come?” or “Does that suit you?”” (F4F)
Confidentiality Participants attached considerable importance to confidentiality in their relationships with their case managers, which had become even more confidential over time. They trusted that their case managers would not pass on information and that they could tell them anything.	“I don’t tell my children everything either. In that respect, I’m quite closed. But I’ve taken her [the case manager] into my confidence and I tell her everything. Then you’ve got someone you can tell it to, haven’t you? And it doesn’t go any further.” (C5M) In fact, some participants were more likely to confide in their case managers than they were to confide in their own children or general practitioners.
Interactions. Participants perceived their interactions with Embrace professionals in several ways.	They felt that they were supported, monitored, informed, and encouraged by Embrace, although the content of these interactions depended upon their profiles.
Being supported Frail participants and those with complex care needs felt supported by their case managers.	“It’s as if you’ve got some support [. . .] I don’t want to put her [the case manager] on a pedestal, but she’s a real pillar of strength for us.” (C1F) They found them highly supportive in many ways. They discussed problems with the case managers, talked about the future, and formulated plans for healthcare and other issues. Participants found it comforting that their case managers provided advice, “always knew what to do,” and were “always ready to help.” Almost all of the participants reported that they could contact their case managers if needed.
Emotional support. They felt reassured by the words of their case managers.	“As far as empathy is concerned, she’s fantastic. And the emotional support that she gives. . . Her words are such a help. “We’ll never, ever turn our backs on you,” she says.” (C2M)
Social support Case managers provided social support as their visits were enjoyable.	One participant even said that it would be like “missing a friend” (C7F) if the case manager were to stop visiting her.
Practical support Participants received practical support from the case managers	Case managers arranged various solutions (e.g., wheelchairs or volunteers for help with computers).

Being monitored Frail participants and those with complex care needs were monitored by their case managers.	“Anything we tell her she brings up again the next time. [. . .] Without being prompted, but she’s aware of it. [. . .] And it’s the small things, but she takes good note of them.” (C1M) They found it comforting that the same person visited regularly. They were able to discuss their situations with their case managers, who visited them once a month, to the participants” satisfaction.
Participants with complex care needs found it reassuring that their case managers were in close contact with their general practitioners and that they had regular meetings.	“Yes, she then says, “I’ve spoken to the doctor, and he thought this or he thought that”. Yes, we’re being looked after, I do have that feeling.” (C2M)
Being informed Participants felt that they were being informed in various ways.	The case managers played a crucial role in providing information to the frail participants and those with complex care needs. In contrast, robust participants received information on care and support options primarily during the Embrace community meetings, along with the other participants.
Participants with case managers regarded these professionals as “walking encyclopedias”, and they were able to discuss all kinds of issues with them.	“The [case manager] is a real source of information for us. We regularly have questions about one thing or the other, and she tries to find answers for us. And she follows up on it too.” (C1F) Most conversations tended to centre on such ordinary practical matters as current health, diet, medication, care and support, assistive devices, family, and social support.
The robust participants who attended the Embrace community meetings said that the information fair had provided them with useful information on care and support possibilities in their communities, as well as on clubs, volunteering, and the consequences of aging. The majority were unaware that they could receive care and support from the Elderly Care Team, and that their general practitioners also belonged to this team.	“You try to prevent things as much as possible, but I think that if something. . . if something were to happen to us, we’d know where we could get help. [. . .] A booklet containing all the information, I hang onto that. [. . .] I got it that morning [Embrace community meeting].” (R18F) At the start of the intervention, the robust participants received cards containing information on how to contact their Elderly Care Teams, if necessary, although none of them could remember receiving such a card.
Being encouraged– Participants received encouragement largely from their personal case managers and during the community meetings. Frail participants and those with complex care needs received suggestions from their case managers to	“For example, she [the case manager] brought me a leaflet. Because there are computer lessons for seniors here in Stadskanaal, “And that’s just what you need,” she said.” (C2M)

participate in social activities (e.g. courses or the Embrace community meetings).	
Some who attended the Embrace community meetings became inspired to participate in social activities.	“A dietician was there and [told us about] all that they do for the elderly. And we were all given leaflets to take home. They also take trips every now and then. [. . .] I went with someone I know.” (F4F)
The robust participants were also encouraged to engage in activities during the Embrace community meetings. For some participants, the community meetings offered a good opportunity to meet other people.	“I’d like them [Embrace community meetings] to be held more often. [. . .] Just getting to know people makes them worthwhile.” (R10F)
Feeling in control, safe, and secure. The support, monitoring, information, and encouragement that the participants received helped them to feel in control and provided them with a feeling of safety and security. This was especially the case regarding the participants with a case manager.	“I find it a great reassurance that she [case manager] says “We’re here if you need us.” (C2M) The participants made decisions in cooperation with their case managers, which increased their sense of being in control. Participants were encouraged to participate in society, which also added to their sense of being in control.
The participants also indicated that regular visits by a trustworthy case manager gave them the feeling that they were being monitored. The participants, including the robust participants, also knew what to do in case of emergency, which provided a sense of safety and security.	“If there’s anything I don’t know, I always talk about it with her.” (F12M)
Yarborough, B. J. H., Yarborough, M. T., Janoff, S. L., & Green, C. A. (2016). Getting by, getting back, and getting on: Matching mental health services to consumers’ recovery goals. *Psychiatric Rehabilitation Journal, 39*(2), 97–104.	
Extracted finding (a verbatim extract of the authors analytical interpretation of the results/data)	Illustration (direct quote of the participant voice, field work observation or other supporting data)
Theme 1: Recovery Means “Getting By”	
Participants who described “getting by” had low expectations for recovery. These individuals gave rich descriptions of experiences of living with overwhelming anxiety.	“The longer I’m sick and the more medications that don’t work I start feeling more and more defective too. It’s hard to keep hopeful that something will work, but I have no idea what it’s going to take, to be honest” (Female, 46).

	This participant then reported that certain medications and therapies had been helpful, but none so far had been able “to really remove that underlying sense of overwhelming dread.”
For these participants and others expressing similar ideas, recovery meant effective coping that offered relief from paranoia or persistent and unrelenting fear	Recovery means that I’m able to cope. Most people don’t live like I do; they don’t work in total isolation, afraid of people. I don’t think many people think that they’re causing outside disturbances, bothering people all the time . . . I don’t even like to talk to the neighbours, I always think they’re up to something, they have ulterior motives. God, just to be mentally able to cope with things . . . just to be able to go to church, to a meeting with people, a theatre and not freak out, or listen to somebody give a lecture or something, I just can’t do it very well (Male, 48).
Episodes of illness were contrasted with times when they were better able to take care of their basic needs. Adequate nutrition and sleep and the ability to maintain personal hygiene indicated some basis of self-control; thus, they were seen as sufficient indicators of coping and recovery.	“Bottom line, I guess recovery means to me . . . focusing on the things I can do to stay as healthy as possible. In other words, eating, getting some sleep, so real basic survival sorts of things” (Female, 58).
Theme 2: Recovery Means “Getting Back”	
For others, coping and meeting needs for self-care were only the foundation that allowed a focus on higher-order goals that represented recovery.	Individuals getting back tended to describe lists of daily goals, responsibilities, and tasks, such as getting along better with family and friends, maintaining employment, getting out in the community, and reengaging in hobbies and interests.
Many defined recovery as returning to the way they were before they experienced mental health problems whereas others likened it to feeling back to “normal”—like someone without a mental illness must feel.	I think recovery means . . . being able to do the things that anybody else can do. It means going to work, it means driving a car, it means being able to take care of your kids . . . it just means living a normal life similar to everybody else that doesn’t have bipolar disorder. (Female, 37).
Many described “getting back” as a gradual process of coming to know your illness and its effects and how to best control or manage it to live a personally meaningful and satisfying life.	“It’s being able to know your illness well enough to gauge what you can and can’t do” (Female, 33). “a continuous level of surveillance, attention and focus . . .” (Male, 55).

Typically, this level of self-awareness came after many episodes of symptom exacerbation; much trial and error; and sometimes significant losses of dignity, relationships, or work. This was a deep, hard-earned, personal understanding of illness.	. . . it's learning how to manage what my particular form of bipolar disorder is . . . it means not being afraid of it, and it means there's things to understand . . . understanding what it is, what all the pieces are, understanding what my own . . . strategies are . . . (Female, 46).
For some individuals, greater understanding of their illness and its course meant learning to recognize when assistance, particularly professional care, could be helpful.	"It means taking responsibility for yourself and seeking help when you need help" (Female, 49). Individuals talked about keeping appointments with mental health providers who were now seen as a valuable lifeline.
Medications were also seen as a resource. Although opinions on the role of medication in recovery varied, for many, part of learning to live with a diagnosis meant making peace with a choice to use medications.	"It means to keep my appointments regularly, taking my medication, that's one of the most important things" (Female, 63).
Some individuals described going on and off their medications multiple times before realizing that medications were beneficial, if not essential, to "getting back."	. . . every so often I would just go through this, this time, or phase, or something, where I'd say "what, I don't have this, I don't have anything wrong with me," because I'd been going along taking my medication, and then I'd just "I'm not going to take this anymore", and . . . it would be a cycle of a few days or a week, and I would just be out of my mind again (Female, 61).
Theme 3: Recovery Means "Getting On"	
Most participants believed in recovery and conceived of it as reaching a point where they could get on with their lives, where illness and symptoms were no longer the dominant aspect of their identity or a primary strain on their resources.	Where descriptions of getting back focused on the process of moving toward recovery, descriptions of "getting on" focused on the intended outcome of that process—moving forward.
Recovery for individuals who described moving on meant reaching a point where they felt satisfied with how they were feeling and felt that significant others could see evidence of their ability to manage their symptoms. This allowed opportunities for independence and self-reliance that were desperately longed for.	Recovery means overcoming your limitations . . . showing that you can have autonomy and take care of your bills and your lifestyle, and all the things you need to take care of, and you're in control of your life (Male, 33).

Among individuals who defined recovery as getting on with life, symptoms were typically described as improved or reduced. Individuals talked about stability and described a sense of freedom to be themselves	"Recovery would be remembering a couple of times a month to come and pick-up my prescription, then going on with the rest of my life worrying about more important things" (Male, 23).
Cross-Cutting Themes: Sense of Self-Control	
These recovery themes shared in common a need for a sense of self-control. As symptoms revealed themselves, mental health problems felt unpredictable.	For those "getting by," recovery was signalled by having just enough control that the illness no longer overwhelmed their sense of themselves or their lives. Those "getting back" found control through learning from and enduring episodes of illness; coming out on the other side; and being able, over time, to recognize personal triggers and vulnerabilities They came to realize that what they had first recognized as constraints of the illness that were to be rejected could come to be understood as limitations to be accepted; managed; and, in some cases, overcome. Control was then defined in terms of benchmarks met as they made their way back to a sense of personal normalcy. For those "getting on," mental illness and illness management were seen as insignificant, and individuals described their illnesses as "in control."
Cross-Cutting Themes: Recouping Losses	
Also common across themes where the significant losses participants had experienced—losses of identity, relationships, work, self-esteem.	Recovery was defined by many as the process of regaining what had been lost, although this differed across participants. For some it meant redefining a new self, for others it meant repairing old relationships, and for still others it meant needing to move on to build new ones.
A loss and then recovery of a unique identity apart from the diagnosis and symptoms.	Participants described their histories and the consequences and costs of illness that shaped how they came to understand their diagnosis and recovery. Over time, an illness identity was either adopted or imposed, and then substantial energy was spent managing the illness. This sometimes included, with difficulty, managing others" perceptions while at the same time managing their own personal sense of identity.
Difficulty of asking for help from family or friends when loss of autonomy and self-determination were costs.	Participants recalled how relationships changed as family and significant others began to define and treat them according to behaviours that were associated with diagnoses.

Repeated losses of self-esteem.	When symptoms made it temporarily difficult to manage responsibilities, participants described feeling as though others were disappointed in them, consequently lowering their expectations or taking responsibility for things participants had formerly done for themselves.
Recovery was measured as demonstrating competence and repossessing dignity	"Recovery would mean you could go to work and stay there, you could maintain a relationship without work, you could do something successful to make yourself proud, to get your self-esteem back, that would be recovery" (Male, 64).
An important marker of recouping losses was being able to establish an identity apart from illness	"Recovery means to me being able to say I have a mental illness, but it's not me, it's not who I am, it's not all me, I'm [person] over here and I have this mental illness, instead of it taking over my whole life" (Female, 42).
Petch, A., Cook, A., & Miller, E. (2013). Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health and Social Care in the Community, 21*(6). 623-633	
Extracted finding (a verbatim extract of the authors analytical interpretation of the results/data)	Illustration (direct quote of the participant voice, field work observation or other supporting data)
Data from the focus groups were analysed thematically and confirmed the validity of the SPRU outcomes framework.	Analysis of the interview data wholeheartedly reinforced the salience of the outcome's framework in Table 1. (Outcomes Users want). The research team worked with the service user research partners to distil the outcomes into a core framework of 15 outcomes reflecting those most important to all service user groups, and to reframe them in terms understandable to both the research interviewers and service users.
Quality of life outcomes: Feeling safe	Physical safety – feeling safe in neighbourhood, getting out and about, managing tasks of daily living, avoiding falls (for older people) Emotional safety – knowing help is on hand, being safe from intimidation, abuse and stigma.
Quality of life outcomes: Having things to do.	Opportunities for meaningful activity and employment during the day and evening promoted self-esteem, well-being and mental health, and supported people to live a "normal" life.

Quality of life outcomes: Contact with other people.	Relationships with staff and other users vital for combating isolation for those most excluded. Others needed support to sustain relationships with family and friends; Relationships between users and wider community often more challenging to establish.
Quality of life outcomes: Staying as well as you can be.	Users wanted support with all aspects of well-being, often emphasising links between quality of life and physical and mental health. Support from regular staff was valued in accessing mainstream and specialist services.
Process outcomes: Being listened to.	Important to users to have a say over their day-to-day life and service use; Very important to users who were fearful or distressed.
Process outcomes: Feeling valued and treated with respect.	Key issues for users were being treated as an adult, and an individual, and not being stereotyped; There were strong links with being listened to.
Process outcomes: Having choices.	Users wanted choice and control over where they lived and how they lived their life, and particularly over their daily routine. Only one carer reported wanting a choice of service provider.
Process Outcomes: Having people to rely on.	Users and carers wanted the security of knowing that staff would adhere to arrangements, and that if unavoidable delays occurred, that someone would contact them.
Process Outcomes: Knowing someone will respond.	Knowing services would respond at times of need was very important; easy access to services was highly valued. Out of hours support was viewed as vital in an emergency and its availability was associated with feeling safe.
Change outcomes Improving skills and confidence.	Following episodes of ill-health, users (especially older people) wanted services to support restoring confidence and skills. People also wanted to remain independent and stay out of hospital.
Change Outcomes: Improving mobility.	Following episodes of ill health, users (especially older people) wanted services to improve mobility where possible, and/or provide adaptations where required.

Change Outcomes: Reducing symptoms.	Service users with serious mental health and/or physical health problems wanted support to alleviate symptoms.
Differences reflected the diverse perspectives, circumstances and aspirations of the people interviewed.	When talking about safety, service users raised a wide range of issues including fear of falling, stigma, abuse, road safety and safety in the home to self-harm.
It was important to respondents from all groups to have meaningful activity in their lives and to have contact with other people.	How people were treated by staff was at least as important as what services were achieved with regard to quality of life and change outcomes.
Differences between groups were more evident in respect of the nature of contact with other people.	Many individuals using mental health services identified that they enjoyed opportunities to mix with people whom they believed would be less likely to judge or stigmatise them. People with intellectual disabilities, there was more emphasis on relationships with trusted members of staff. In contrast to the other two groups, older people tended not to express preferences over whom they wanted to have contact with. Of the three groups, older service users more frequently experienced significant social isolation.
Service users and carers identified limitations and barriers to effective services	Including staffing levels and lack of continuity of staffing; limited resources; access to transport – especially in rural areas; and time-limited services.
Co-location was viewed as important because it enabled service users to access different staff from one central place, and it facilitated improved communication between staff about their needs.	‘I think it’s a good idea because I don’t have to phone different agencies. I think – one phone call to that number up there, and I will get whoever I need … I’ve got one number and that’s good. I’m pleased”. (service user, East Renfrew)
The responsiveness of services was enhanced by co-location – process outcomes, or how the service was delivered, were facilitated by co-location.	Referring to difficulties in accessing support – “I was shunted from pillar to post. I felt like a carrier pigeon to be honest. “(service user, Goldenhill)
Multidisciplinary team Users and carers valued services that simultaneously met their health and social needs.	The meeting of these needs is not necessarily dependent on partnership, but the availability of multidisciplinary staff in one setting did seem to successfully deliver health and social care outcomes for users.

Availability of both health and social care was valued by users in achieving both change outcomes and quality of life outcomes.	‘I think it’s a nice thing, you feel as if you’re in a little net and they’re all working together to make sure that you are fine. “(service user, Knowsley)
Interventions clearly have the potential to support service users in improving well-being, as well as in achieving the goal of independence.	Many of the older users we spoke to had entered services following a health crisis. Some of the changes included assistance to recover confidence and skills after a stroke or fall, and modifying the environment to improve mobility.
Importance of social and emotional care was also emphasised by users	‘The other thing is that they have two [goals] at the ARC. One is the caring of the person and the other one is the looking into the person’s disabilities”. (service user, Blackpool) When people with intellectual disabilities talked about health, many users spoke in holistic terms about how they were supported to stay healthy, demonstrating knowledge of the relationship between health, exercise and diet.
The mental health service users who were most satisfied with the support they received were accessing holistic support.	If your health suffers, your social suffers, and if your social suffers, your health suffers. So it’s better to be all working together if you know what I mean? (service user. Goldenhill)
Specialist Partnerships: Users identified that staff in partnerships were less likely to treat them in a discriminatory manner, often contrasting their experience of the partnership with experiences of the acute sector in particular.	Several individuals made comments to the effect that staff were able to “see beyond labels”. This relates to a process outcome, being treated with respect.
Users of mental health partnerships valued not feeling stigmatised.	I don’t know how to put this. Just the general treatment. You’re treated, not on the same level, but at the same time you’re spoke to as a person, as a human and not as a diagnosis. (service user, Camden)
Several older individuals valued being listened to, rather than being “patronised”.	There’s an awful tendency in social work with old people, many social workers approach the over-65s as if they newly appeared at the age of 65 and they have no knowledge, no experience and they have to be patted on the head for them to talk, what to do. This group talk to you as adults, listen

	to you and they're obviously working together, it's a service, it's not a patronising. (service user, East Renfrew)
Extended Partnership: broader partnership working improved communication with other agencies to the benefit of service users, and often increased the options and opportunities available to users.	'Oh yes. This is like a steppingstone. They help you contact other services and let you know, enlighten you to other services that are available". (service user, Camden)
Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015). What outcomes are important to people with long-term neurological conditions using integrated health and social care? *Health and Social Care in the Community, 23*(5), 559-568.	
Extracted finding (a verbatim extract of the authors analytical interpretation of the results/data)	Illustration (direct quote of the participant voice, field work observation or other supporting data)
While the outcomes we identified from participants' accounts largely reflected those of Harris et al. (2005), key differences were evident.	Minor revisions were made to some existing outcomes to reflect nuances in participants" accounts, new outcomes were added across domains, and conflated the economic participation and social participation domains into one. This resulted in 20 "key" outcomes across three domains: personal comfort, autonomy, and social and economic participation.
Domain 1: personal comfort outcomes Personal hygiene – Its importance was reflected in language such as it being "top of the list", or, regarding showering, some- thing that "ought to be a human right".	I want to take showers and things like that, I want it to be easy . . . its part of your independence, isn't it, simple things like that? But yeah, it is important for your own well-being and your own confidence as well. (SU31, MS)
'personal hygiene" was revised to include "personal care".	Participants" accounts went beyond issues of cleanliness and hygiene. They emphasised the importance of personal care activities, such as choosing clothes to wear, dressing, haircare and shaving.
The importance participants placed on household maintenance as well as cleanliness warranted the revision of the "household cleanliness" outcome to include this. There were contrasting views about whether assistance was acceptable for achieving it. Assistance could be frustrating, but others felt it was acceptable, or even a socially "normal" thing to do.	There are enough people who get cleaners in who, you know, just because they can't be bothered to do it themselves. (SU23, MS)

Both physical health and functioning (e.g. walking) played a key role in participants” lives, hence the revision of this outcome to include the latter.	Poor physical health and functioning affected participants” social activities and outcomes, autonomy outcomes, employment and emotional well-being.
Emotional well-being permeated most other outcomes and issues.	Often, it was linked to the achievement of other things, such as being able to get out of the house. It was described in a number of ways, ranging from issues of self-esteem, confidence and resilience, to having, and addressing, feelings of anxiety and depression.
Personal safety, both in and outdoors, was a critical issue for participants, and was underlined by the strategies and adapted routines that were used to counteract risks. For some, however, taking risks with personal safety outdoors offered a sense of independence and control.	I want to get there on me own . . . If the day comes and I fall, I fall. I’ll live with it. (SU13, Stroke)
Maintaining and improving cognitive skills was identified as a new outcome in this domain.	Cognitive skills included memory, concentration and attention – reflected the importance of this for those with cognitive difficulties resulting from their condition.
Domain 2: social and economic participation outcomes Participants” accounts often revealed social, as well as economic, motivations for economic participation/	‘coz when you work you meet different people. (SU27, MS) [work] gives you your own self-esteem and makes you [pause] – it makes you feel of value. (SU12, MS)
For the majority of participants, accessing training, new skills and further/higher education was neither important nor relevant (bias average age sample).	In cases where these were important, the personal satisfaction and sense of purpose gained from learning a new skill, or the associated social aspects, were highlighted. access to further or higher education was a source of personal fulfilment, keeping motivated after stopping work or a way of “just keeping the cogs going” (SU17, condition withheld).
They are not only recipients of “care” but that they also adopted supportive roles within the family,	The importance of maintaining and developing familial roles and relationships included aspects of parenting and grand-parenting. It also reflected having time with family that did not involve caring role. ‘I like quality time for them to take me out, whatever, instead of “em coming and spending hours cleaning for me,you know”. (SU6, BI) Other examples being able to babysit nieces or nephews.

Intimate and personal relationships reflected the importance of spousal and partner relationships, and being able to develop new sexual relationships in the face of disability.	I may be a broken and battered old man, but it doesn't stop the brain thinking about how nice it used to be to be sexual. (SU20, MS)
The importance of social relationships and roles.	The need to both maintain existing friendships and relationships so that one did not "lose touch and just fade away" (SU5, BI) and develop new ones. To maintain these relationships, activities and roles were adapted in response to their condition.
Environmental accessibility was an issue.	It's really quite hard to get into . . . a friend's house; I can never get into their house and even those that maybe I can get in, then they've got an upstairs toilet or something and it's impossible now. (SU3, MS)
Social participation such as accessing advocacy and peer support.	The nature of "peers" described by participants varied, and included those who shared similar life experiences, beliefs and/or social activities and could include friends, neighbours and people who were part of the same social groups.
Support and reassurance was seen as an integral element.	Therefore, we were careful to distinguish between the support provided via advocacy and peer relationships, and support achieved through social relationships.
'Establishing and maintaining social and recreational activities" replaced "access to mainstream leisure activities" in Harris et al.'s (2005) original list.	The revision acknowledges the importance that some participants placed on accessing specialist activities, such as "disabled" swimming groups and social meetings, not just mainstream activities. Participants also described a wide range of "mainstream" social activities that they enjoyed, such as going out for meals, watching and/or participating in sport and going to the "pub".
'Citizenship" was an ambiguous concept for participants, but many talked about the importance of being able to contribute to the wider community.	For example, voluntary work was identified as something that played an important role for participants and was linked to maintaining personal well-being. Some participants focused on the importance to them of political participation, such as voting and being an active member of pressure groups.

Domain 3: autonomy outcomes ‘Being able to communicate” replaced the original outcome “communication access”, and reflected how participants talked about, for example, the importance of regaining speech skills following experiencing a stroke and communicating one’s wants and needs.	I wanted to get back to being OK and saying what I wanted to say. (SU16, BI)
‘Personal decision-making” was added as an outcome to this domain because of the importance participants placed on this for maintaining choice and control in their decision-making and in being informed	I’ve never had to, to rely on somebody else to make a choice for me. I mean I might have to, I mean who knows? I’m fortunate that, OK, I’m physically disabled now, but I’m not mentally disabled, you know. (SU29, MS)
The importance of being able to access all areas of the home as independently as possible.	This was underlined by the fact that adaptations were used to facilitate access, and that some chose to self-fund adaptation rather than to wait long periods for services to fund these.
Being able to get out to the wider environment was a dominant theme in participants” accounts; Two discourses of environmental accessibility were evident in the data – getting to places and getting in and around places. It was often implicated in other outcomes such as emotional well-being and personal safety.	I’m sick to death of these four walls, I want to go into [town], get myself something nice for tea, prepare it properly how I want to do it. It’s a big thing for me. (SU6, BI)
Getting to places was the most dominant discourse – It was often implicated in other outcomes such as emotional well-being and personal safety.	For example, one participant described difficulties accessing the local area due to safety concerns. This, in turn, had affected his ability to participate in social activities, and subsequently, his emotional well-being. Because of this inaccessibility of the local environment, outings could not be spontaneous, required planning ahead and dependence on family, meaning that he felt “limited” in what he was able to do independently.
Financial security was linked with a sense of emotional ease and relief (e.g. being happier or avoiding anxiety).	Financial security facilitated social activities, funded assistance to ease pressure on family carers, enabled retention of one’s home and facilitating a sense of independence.

Appendix F: Literature Review Synthesised Findings

Statement (1) People may have common needs, wants and fears; however, what matters most is knowing and respecting the person and their right to self-determination.

Extracted Findings	Categories	Synthesised Findings
Experiences with aging – *Struggling with health* – Clear differences were found between the participants from the three Embrace profiles with regard to their experiences with the consequences of aging. Robust participants in general felt healthy, but they feared the consequences of aging (e.g. progressive deterioration in health, increasing dependency, and loss of control). In contrast, frail participants and those with complex care needs seemed to struggle with the consequences of aging, including deteriorating health, increasing dependency, decreasing social interaction, and loss of control. (Spoorenberg et al., 2015)	Individual differences in perspectives, what was important, what was a priority, what they were afraid of, motivated by, what support they had and what was needed, what support looked like	Patients may have common needs and wants; however, what matters is knowing and respecting the person. It's not about better questions or more sophisticated frameworks, it's about deeply listening to understand the person's response. It is important that each person's perspective is respected, that they have their say and feel heard. That their goals, expectations, fears, context, and situation are taken into consideration in the design and delivery of services and interventions. To evaluate the effectiveness of supports and services received, it is important to first know the person and what is important to them. Every person, their perspective and circumstances are both unique and contextual.
Experiences with aging – *Decreasing social interaction* – Almost all of the participants stressed the importance of social contact, although there were differences in the number and quality of social relationships. (Spoorenberg et al., 2015)		
Experiences with aging – *Decreasing social interaction* – Social interaction also differed between participants who were living alone and those living with partners. The latter reported less need for social contact, new or otherwise, because they still had their spouses and spent most of the day together. (Spoorenberg et al., 2015)		
Experiences with aging – *Struggling with health* – Participants from all three profiles described specific fears related to their deteriorating health (e.g., continuous fear following a life-threatening condition or fear of a stroke). (Spoorenberg et al., 2015)		
Experiences with Embrace – *Interactions* – Participants perceived their interactions with Embrace professionals in several ways. (Spoorenberg et al., 2015)		

D1 The importance participants placed on household maintenance as well as cleanliness warranted the revision of the "household cleanliness" outcome to include this. There were contrasting views about whether assistance was acceptable for achieving it. Assistance could be frustrating, but others felt it was acceptable, or even a socially "normal" thing to do (Spiers et al., 2015)		People want to be seen, heard, and valued as an individual. Respect is important, respecting self and respect from others.
D2 For the majority of participants, accessing training, new skills and further/higher education was neither important nor relevant (bias average age sample). (Spiers et al., 2015)		
Differences between groups were more evident in respect of the nature of contact with other people. (Petch et al., 2013)		
Experiences with aging – *Struggling with health* – Participants rarely mentioned death during the interviews. However, when it was discussed, the participants differed in their attitudes toward death. (Spoorenberg et al., 2015)		
Process outcomes: Being listened to. (Petch et al., 2013)	Maintain sense of self respect, personhood respected, reclaiming sense of self, rights of a human	
Process outcomes: Feeling valued and treated with respect (Petch et al., 2013)		
Users of mental health partnerships valued not feeling stigmatised (Petch et al., 2013)		
Several older individuals valued being listened to, rather than being "patronised" (Petch et al., 2013)		
Cross-cutting themes: Recouping losses (Yarborough et al., 2016) Repeated losses of self-esteem. (Yarborough et al., 2016)		

Statement (2) –Social contact with other people is highly valued; experiencing the giving and receiving of support and companionship that is meaningful for that person, at that time.

Extracted Findings	Categories	Synthesised Finding
Quality of life outcomes: Contact with other people (Petch et al., 2013)		

It was important to respondents from all groups to have meaningful activity in their lives and to have contact with other people. (Petch et al., 2013)	Being in contact with people. Access to, or receiving support from, others. Company – relationships with people – meaningful, fun, reassuring and contribute directly or indirectly to achieving individual goals.	Patients want social contact with others. The frequency and type of social interactions sought differs for different people. The social contact being meaningful, generating a sense of fun or enjoyment, and being voluntary was described as rewarding for most. Reciprocity, the experience of both giving and receiving of support, was important.
D2 Social participation such as accessing advocacy and peer support. (Spiers et al., 2015)		
D2 Support and reassurance was seen as an integral element. (Spiers et al., 2015)		
D2 "Establishing and maintaining social and recreational activities" replaced "access to mainstream leisure activities" in Harris et al.'s (2005) original list. (Spiers et al., 2015)		
D2 The importance of social relationships and roles (Spiers et al., 2015)		
Frail participants and those with complex care needs also expressed a desire for more company and fun (Spoorenberg et al., 2015)		
Quality of life outcomes: Having things to do (Petch et al., 2013)	Play an active role in contributing to, or supporting, others – giving to others – meaningful activities	
D2 "Citizenship" was an ambiguous concept for participants, but many talked about the importance of being able to contribute to the wider community. (Spiers et al., 2015)		
D2 They are not only recipients of "care", but that they also adopted supportive roles within the family (Spiers et al., 2015)		

Statement (3) – It is important that the cognitive, physical, and emotional effort of change is recognised and that it is understood that a person's perception, acceptance, and engagement with change is personal and may vary over time.

Extracted Findings	Categories	Synthesised Findings
D2 Intimate and personal relationships reflected the importance of spousal and partner relationships, and being able to develop new sexual relationships in the face of disability (Spiers et al., 2015)		It is important that the cognitive, physical, and emotional effort of change is recognised. There are

Experiences with aging – *Decreasing social interaction* – Frail participants and, even more so, those with complex care needs, experienced changes in their relationships due to their physical impairments or illness, or due to the death of friends. (Spoorenberg et al., 2015)	Changing relationships and roles within relationships – adapting, new, letting go	many interdependent losses and adaptions experienced when a person faces changes in their health and related abilities. How people respond, react, reject, or accept change is personal, it takes its own time. Maintaining a sense of self-worth and dignity, when having to give up or take on new roles, behaviours or mindsets is important.
Experiences with aging – *Struggling with health* – Participants were ambivalent in accepting their health status. Most had resigned themselves to their physical and mental deterioration, stating that they had accepted their current health status and avoided thinking about future deterioration (Spoorenberg et al., 2015)	Accepting current state and acknowledging change, recognising change is going to keep happening, taking an active role/ participating in change, developing new ways of thinking about and integrating changes into their life	
Experiences with aging – *Increasing dependency* – Most participants with complex care needs and some frail participants were dependent on others because of decreasing mobility or impaired cognitive functioning. Some found it difficult to accept the fact that they could not function as they had previously been able to do. (Spoorenberg et al., 2015)		
Diabetic life (cognitive participation) – Personal challenges of managing what is viewed as an invasion of diabetes into all aspects of life and the incongruities between personal values and expectations and living with diabetes (Burridge et al., 2016)		
Cross-cutting themes: Recouping losses – A loss and then recovery of a unique identity apart from the diagnosis and symptoms. (Yarborough et al., 2016)	Self-awareness – understanding of self, sense of self, sense making processes, what makes up your identity, how does it play out over time, in your life and different relationships, who or what influences you and why – discovering and rediscovering as things change over time.	
Theme 2: Recovery Means "Getting Back" – Typically, this level of self-awareness came after many episodes of symptom exacerbation, much trial and error, and sometimes significant losses of dignity, relationships, or work. This was a deep, hard-earned, personal understanding of illness. (Yarborough et al., 2016)		
Sensibility of change (coherence) Self-awareness that change is necessary and sensible due to the health risks, but experiencing dissonance between the rational view and the lived reality (Burridge et al., 2016)		

Statement (4) Having basic daily living needs met is consistently the first priority. A person is unlikely to feel motivated or able to engage until basic needs are met.

Extracted Findings	Category	Synthesised Findings
Theme 1: Recovery Means “Getting By” – Episodes of illness were contrasted with times when they were better able to take care of their basic needs. Adequate nutrition, sleep, and the ability to maintain personal hygiene indicated some basis of self-control; thus, they were seen as sufficient indicators of coping and recovery. (Yarborough et al., 2016)	Ability to meet daily living – basic living needs being met – personal hygiene, nutrition, sleep, and safety – is a priority, the baseline indicator	Being able to meet basic daily living needs is the priority. They are the foundations of personal safety, comfort, dignity, sense of self control – progress /improvement will be limited/unsustainable if not met.
Quality of life outcomes: Feeling safe (Petch et al., 2013)		
Domain 1: Personal comfort outcomes– *Personal hygiene* – Its importance was reflected in language such as it being “top of the list”, or, regarding showering, something that “ought to be a human right”. (Spiers et al., 2015)		
D1 “Personal hygiene” was revised to include “personal care”. (Spiers et al., 2015)		

Statement (5) Mobility and accessibility are highly valued, they are associated with a person’s sense of independence, autonomy, and freedom.

Extracted Findings	Categories	Synthesised Findings
D2 Environmental accessibility was an issue (Spiers et al., 2015)	Being able to get to places – in the home and outside. The places going to need to be accessible.	Sense of self – independence, autonomy, and freedom – are associated with mobility – ability to move/get places – and accessibility – able to enter or use. Highly valued – people willing to risk personal safety to attain. The reliability and utility of assistance devices important Foundations of a sense of choice and control
D3 The importance of being able to access all areas of the home as independently as possible (Spiers et al., 2015)		
D3 Being able to get out to the wider environment was a dominant theme in participants” accounts. (Spiers et al., 2015)		
Experiences with aging – *Loss of control* – Participants who became housebound because of problems with using their assistive devices (e.g., rollators, wheelchairs) experienced a profound loss of control. (Spoorenberg et al., 2015)	Assistance devices need to be reliable and usable – made easier – rather than restrictive. Feeling dependent on device	

Experiences with aging – *Increasing dependency* – Most participants who used assistance devices had complex care needs or were frail, although some robust participants used walking aids. Almost a third of these participants reported problems with their devices (e.g., rollator wheels getting stuck or wheelchairs that were difficult to get into an elevator). The participants saw these as reasons for not using the devices, despite their dependence on them. (Spoorenberg et al., 2015)	increases sense of frustration and reduces feeling of control. Taking away sense of control; made them feel disabled or old – they were willing to take risk and not use or avoid device rather than feel this way.	
Experiences with aging – *Increasing dependency* – Dependency on assistive devices. Some participants felt reluctant to use assistive devices (e.g., canes or rollators), because they made them feel old or disabled. Some participants did not use such devices at all, even if it put them at greater risk of falling. (Spoorenberg et al., 2015)		

Statement (6) A person's perspective on their independence influences their sense of self and their social value.

Extracted Findings	Categories	Synthesised Findings
Experiences with aging – *Increasing dependency* – Dependency on informal care – Most participants expressed reluctance to ask their children for help. Nevertheless, almost all of the frail participants and those with complex care needs were receiving such assistance (e.g., with domestic chores, gardening, finances) from their children, neighbours, or other informal caregivers. Most of the robust participants were not dependent on informal caregivers, although one participant had recently started asking her daughter to help with paperwork. (Spoorenberg et al., 2015)	Fear of dependency, being dependent on others, reluctance/fear of asking for help, feeling like asking for help undermined sense of self-worth/autonomy – learning to accept/receive help/not feel helpless – lose sense of choice/control – feel self-determining	Independence is a cognitive, physical, and emotional state – it is a barrier and facilitator of a sense of choice and control. It is a primal need and want. A person's perspective on their independence influences their sense of self and their social value
Experiences with aging – *Increasing dependency* – Those who were not yet dependent on others expressed the fear of future dependency. (Spoorenberg et al., 2015)		
Experiences with aging – *Increasing dependency* – Most of the robust participants were still managing their daily lives without any help from others, although some feared becoming a burden to others. (Spoorenberg et al., 2015)		
Cross-cutting themes: Recouping losses – Difficulty asking for help from family or friends when loss of autonomy and self-determination were costs. (Yarborough et al., 2016)		

Experiences with aging – *Increasing dependency – Independent living* – Most participants wanted to continue living at home rather than moving into a facility due to negative associations with loss of independence and freedom. (Spoorenberg et al., 2015)	Sense of independence, able to get on, and freedom to be themselves	
Experiences with aging – *Loss of control* – Loss of control was also reflected in the themes mentioned above. For example, one participant's fear of becoming dependent stemmed from the assumption that dependency would lead to the loss of freedom and the ability to control what one does and when one does it. (Spoorenberg et al., 2015)		
Theme 3: Recovery Means "Getting On" – Among individuals who defined recovery as getting on with life, symptoms were typically described as improved or reduced. Individuals talked about stability and described a sense of freedom to be themselves. (Yarborough et al., 2016)		
Process outcomes: Having choices (Petch et al., 2013)	Having choice and maintain independence, autonomy, being able to communicate needs and wants	
Domain 3: Autonomy outcomes "Being able to communicate" replaced the original outcome "communication access", and reflected how participants talked about, for example, the importance of regaining speech skills following experiencing a stroke and communicating one's wants and needs (Spiers et al., 2015)		
Experiences with aging– *Increasing dependency* – Dependency on professionals– The frail participants and those with complex care needs were often dependent on professional assistance. (Spoorenberg et al., 2015).		

Statement (7) You cannot predict with confidence what matters most to a person or what their focus should be. Every interaction or intervention may result in intended or unintended consequences. Developing skills and techniques that enable a person to actively engage in iterative processes of planning, implementing, and evaluating change is empowering.

Extracted Findings	Categories	Synthesised Findings
Experiences with aging– Fears – Participants experienced a variety of fears related to the expected and emerging consequences of aging. These fears were intertwined throughout the aforementioned themes. (Spoorenberg et al., 2015)	What is important to a person, how they perceive and evaluate their experience and outcomes – cuts across each	Development of skills and approaches that enable a person to clarify their goals, plan, monitor and measure are important – sense of enablement.
Domain 2: Social and economic participation outcomes – Participants' accounts often revealed social, as well as economic, motivations for economic participation. (Spiers et al., 2015)		

D3 Two discourses of environmental accessibility were evident in the data – getting to places and getting in and around places. It was often implicated in other outcomes such as emotional well-being and personal safety. (Spiers et al., 2015)	of the findings – there are interdependencies/links across themes and domains identified in the studies – there is a knock-on effect – amplify – complexity – no consistent order of priority or importance	Expressing the characteristics of a complex adaptive system – what is important to people is dynamic, non-linear and contextual – every change/disruption has intended and unintended consequences – unpredictability. Understanding of the processes of assessing risks, the science of iterative improvement cycles, and how to measure and communicate any change or improvements to others – is associated with a sense of control/personal satisfaction – sense of empowerment.
D1 Emotional well-being permeated most other outcomes and issues. (Spiers et al., 2015)		
D3 Getting to places was the most dominant discourse – It was often implicated in other outcomes such as emotional well-being and personal safety. (Spiers et al., 2015)		
Availability of both health and social care was valued by users in achieving both change outcomes and quality of life outcomes. (Petch et al., 2013)		
Cross-cutting themes: Recouping losses – The significant losses participants had experienced were common across themes —losses of identity, relationships, work, self-esteem. (Yarborough et al., 2016)		
Theme 3: Recovery Means “Getting On” – Most participants believed in recovery and conceived of it as reaching a point where they could get on with their lives, where illness and symptoms were no longer the dominant aspect of their identity or a primary strain on their resources. (Yarborough et al., 2016)	Regaining and getting on/moving forward with life – a milestone – promotes a sense of self control and dignity.	
Cross-cutting themes: Sense of self-control – These recovery themes shared in common a need for a sense of self-control. As symptoms revealed themselves, mental health problems felt unpredictable. (Yarborough et al., 2016)		
Cross-cutting themes: Recouping losses – Recovery was measured as demonstrating competence and repossessing dignity. (Yarborough et al., 2016)		
Theme 3: Recovery Means “Getting On” – Recovery for individuals who described moving on meant reaching a point where they felt satisfied with how they were feeling and felt that significant others could see evidence of their ability to manage their symptoms. This allowed opportunities for independence and self-reliance that were desperately longed for. (Yarborough et al., 2016)	Sense of movement/progress, sense of achievement/ satisfaction/personal meaning.	

Theme 2: Recovery Means "Getting Back"– Some individuals described going on and off their medications multiple times before realising that the medications were beneficial, if not essential, to "getting back." (Yarborough et al., 2016)	Trial and error – followed by realisation. Risk taking – independence and control – show others that they are OK	
Theme 2: Recovery Means "Getting Back" – Many described "getting back" as a gradual process of coming to know your illness and its effects and how to best control or manage it to live a personally meaningful and satisfying life. (Yarborough et al., 2016)		
D1 Personal safety, both in and outdoors, was a critical issue for participants, and was underlined by the strategies and adapted routines that were used to counteract risks. However, for some, taking risks with personal safety outdoors offered a sense of independence and control. (Spiers et al., 2015)		
Change outcomes: Reducing symptoms. (Petch et al., 2013)	Realistic goals – balancing – achieving a baseline – self managing – accepting limits	
Quality of life outcomes: Staying as well as you can be (Petch et al., 2013)		
Theme 2: Recovery Means "Getting Back"– Many defined recovery as returning to the way they were before they experienced mental health problems whereas others likened it to feeling back to "normal" – like someone without a mental illness must feel. (Yarborough et al., 2016)		

Statement (8) – Self-development and learning new skills are important for preserving and achieving a sense of control, choice, confidence, and well-being.

Extracts Findings	Categories	Synthesised Findings
Experiences with aging– *Loss of control* – All participants reported a desire to stay in control, and they considered it important to determine their own daily living schedules. (Spoorenberg et al., 2015)	Able to determine daily living schedule, build capacity, skills and effective coping strategies – meet needs and challenges – living with illness	Self-development and learning new skills, in particular, preserving and strengthening cognitive capabilities that enable a sense of control and choice in the decisions made about and within
Theme 1: Recovery Means "Getting By"– For these participants and others expressing similar ideas, recovery meant effective coping that offered relief from paranoia or persistent and unrelenting fear. (Yarborough et al., 2016)		

Theme 1: Recovery Means "Getting By" – Participants who described "getting by" had low expectations for recovery. These individuals gave rich descriptions of experiences of living with overwhelming anxiety. (Yarborough et al., 2016)		their life and any changes that need to be considered. Most patients want to develop skills and strategies that will assist with keeping informed, making decisions, and building emotional resilience, these are associated with a greater sense of self confidence and well-being.
D3 "Personal decision-making" was added as an outcome to this domain because of the importance participants placed on this for maintaining choice and control in their decision-making and in being informed (Spiers et al., 2015)	Maintain and improve cognitive skills and decision making – underpins keeping informed, being able to learn and recognise, living with change – feel a sense of control and choice	
D1 Maintaining and improving cognitive skills was identified as a new outcome in this domain (Spiers et al., 2015)		
Theme 2: Recovery Means "Getting Back"– For some individuals, greater understanding of their illness and its course meant learning to recognise when assistance, particularly professional care, could be helpful. (Yarborough et al., 2016)		
Theme 2: Recovery Means "Getting Back" (Yarborough et al., 2016) – Medications were also seen as a resource. Although opinions on the role of medication in recovery varied, for many, part of learning to live with a diagnosis meant making peace with a choice to use medications. (Yarborough et al., 2016)		
Change outcomes – Improving skills and confidence (Petch et al., 2013)	Desire/motivation – high order goals – build and improve skills, functioning, reclaiming/enhancing confidence, achieve sense of well-being/happiness	
Change Outcomes – Improving mobility (Petch et al., 2013)		
Interventions clearly have the potential to support service users in improving well-being, as well as in achieving the goal of independence. (Petch et al., 2013)		
D3 Financial security was linked with a sense of emotional ease and relief (e.g. being happier or avoiding anxiety)		
Cross-cutting themes: Recouping losses– An important marker of recouping losses was being able to establish an identity apart from illness. (Yarborough et al., 2016)		

Theme 2: Recovery Means “Getting Back”– For others, coping and meeting needs for self-care were only the foundation that allowed a focus on higher-order goals that represented recovery. (Yarborough et al., 2016)		
Experiences with aging – *Struggling with health* – Many participants (particularly those with complex care needs) expressed a desire for “better health”. (Spoorenberg et al., 2015)		

Statement (9) – Regular contact with a trusted professional is important.

Extracted Findings	Categories	Synthesised Findings
Experiences with Embrace – *Feeling in control, safe, and secure* – The participants indicated that regular visits by a trustworthy case manager gave them the feeling that they were being monitored. The participants, including the robust participants, also knew what to do in case of emergency, which provided a sense of safety and security. (Spoorenberg et al., 2015)	Regular contact with a trusted person, who proves themselves to be trustworthy over time (keeps confidentiality), takes notice of what is happening and any changes, asks my perspective and takes into consideration what is important to me and my resources, and is practical, responsive, accessible, and reliable.	Patients who have experienced an integrated model of health care delivery describe a sense of safety and security and associate positive outcomes when they have regular contact with a trusted health &/or social care professional. This person knows the patient as a person, their limitations and strengths, they listen, they provide practical advice, they are reliable, they are knowledgeable, they invite free and open dialogue, they are trustworthy and a confidante.
Experiences with Embrace – *Relationship with the case manager – Confidentiality* Participants attached considerable importance to confidentiality in their relationships with their case managers, which had become even more confidential over time. They trusted that their case managers would not pass on information and that they could tell them anything. (Spoorenberg et al., 2015)		
Experiences with Embrace – *Relationship with the case manager* – The relationships between participants and their case managers were based on equality and confidentiality; both aspects were seen as conditional for achieving productive interactions. (Spoorenberg et al., 2015)		

Experiences with Embrace – *Interactions – Being supported* – Frail participants and those with complex care needs felt supported by their case managers. (Spoorenberg et al., 2015)		
Experiences with Embrace – Relationship with the case manager. *Equality* – The participants reported that their case managers took their personal preferences into account (e.g., in scheduling visits). In contrast, the participants reported that other healthcare professionals tended to visit when it suited their own schedules. (Spoorenberg et al., 2015)		
Process Outcomes: Knowing someone will respond (Petch et al., 2013)		
Process Outcomes: Having people to rely on (Petch et al., 2013)		
Experiences with Embrace – *Interactions – Social support* – Case managers provided social support as their visits were enjoyable. (Spoorenberg et al., 2015)		
Experiences with Embrace – *Interactions – Practical support* – Participants received practical support from the case managers (Spoorenberg et al., 2015)		
Experiences with Embrace – *Interactions – Being monitored*- Frail participants and those with complex care needs were monitored by their case managers. (Spoorenberg et al., 2015)		
Experiences with Embrace – *Interactions – Being informed* – Participants felt that they were being informed in various ways. (Spoorenberg et al., 2015)	Ready and timely access to information in varied forms, opportunity to talk things through with a trusted person, hear how others make sense and to consider options.	
Experiences with Embrace – *Interactions – Being informed* – Participants with case managers regarded these professionals as “walking encyclopedias”, and they were able to discuss all kinds of issues with them. (Spoorenberg et al., 2015)		
Experiences with Embrace – *Interactions – Emotional support*. They felt reassured by the words of their case managers. (Spoorenberg et al., 2015)		

Experiences with Embrace – *Interactions – Being informed* – The robust participants who attended the Embrace community meetings said that the information fair had provided them with useful information on care and support possibilities in their communities, as well as on clubs, volunteering, and the consequences of aging. The majority were unaware that they could receive care and support from the Elderly Care Team, and that their general practitioners also belonged to this team. (Spoorenberg et al., 2015)		

Statement (10) – There are core elements of an integrated model of health care delivery that matter from the patient's perspective.

Extracted Findings	Categories	Synthesised findings
Experiences with Embrace- Interactions – Being encouraged – Participants received encouragement largely from their personal case managers and during the community meetings. Frail participants and those with complex care needs received suggestions from their case managers to participate in social activities (e.g. courses or the Embrace community meetings). (Spoorenberg et al., 2015)	Facilitate social interactions within service design – being encouraged – building sense of community – we are in this together	Patients who have experienced an integrated model of health care delivery describe the following elements as important: respect for the person, their lived experiences, their situation and their perspective; value the persons health and social care needs equally; commitment to working as partners in multidisciplinary teams and fostering collegiate working relationships across the
Experiences with Embrace – Interactions – Being encouraged – The robust participants were also encouraged to engage in activities during the Embrace community meetings. For some participants, the community meetings offered a good opportunity to meet other people. (Spoorenberg et al., 2015)		
Experiences with Embrace– Interactions – Being encouraged – Some who attended the Embrace community meetings became inspired to participate in social activities. (Spoorenberg et al., 2015)		

		health and social care systems; genuine engagement with the community as partners and assets, inviting collaboration through codesign and seeking input and feedback in the co-production, delivery and continuous improvement of health services
Specialist Partnerships: Users identified that staff in partnerships were less likely to treat them in a discriminatory manner, often contrasting their experience of the partnership with experiences of the acute sector in particular. (Petch et al., 2013)	Professionals working in partnership on all levels – primary, acute, specialist and other agencies- minimise them and us –	
Extended Partnership: Broader partnership working improved communication with other agencies to the benefit of service users, and often increased the options and opportunities available to users (Petch et al., 2013)		
Experiences with Embrace– Interactions – Participants with complex care needs found it reassuring that their case managers were in close contact with their general practitioners and that they had regular meetings. (Spoorenberg et al., 2015)		
Service users and carers identified limitations and barriers to effective services (Petch et al., 2013)	The service should be designed to facilitate easy and timely interaction and communication between providers, enabling the MDT to value and consider the health and social needs of the person equally and be open to input and feedback from multiple perspectives (service users and carers) to inform continuous improvement	
Co-location: was viewed as important because it enabled service users to access different staff from one central place, and it facilitated improved communication between staff about their needs. (Petch et al., 2013)		
The responsiveness of services was enhanced by co-location – process outcomes or how the service was delivered were facilitated by co-location. (Petch et al., 2013)		
Multidisciplinary team – Users and carers valued services that simultaneously met their health and social needs. (Petch et al., 2013)		
Experiences with aging– Loss of control – Participants who received care and support from multiple and frequently changing caregivers felt a loss of control. (Spoorenberg et al., 2015)		
Diabetes care alliance (collective action) – The routines and partnerships in care have to be flexible and individualised to take account of personal contexts and expectations (Burridge et al., 2016)	Ensuring services and interventions are genuinely	

Experiences with Embrace – Clear differences were found in the experiences of Embrace care and support between the participants from the three different profiles. These differences corresponded to the different care intensity levels corresponding to the three different profiles. (Spoorenberg et al., 2015)	designed and delivered in partnership with the service user and carer, considering their changing individual health and social needs, expectations, and context. Be inclusive and talk with the person to understand what it feels or looks like for them to feel safe and in control, to be involved in decisions and to have a say in what does or does not happen next.	
Experiences with Embrace– Feeling in control, safe, and secure. – The support, monitoring, information, and encouragement that the participants received helped them to feel in control and provided them with a feeling of safety and security. This was especially the case regarding the participants with a case manager. (Spoorenberg et al., 2015)		
Experiences with Embrace– Relationship with the case manager – Equality – The participants perceived their relationships with their case managers as being based on mutual equality. Their opinions were important, and they felt in charge. (Spoorenberg et al., 2015)		
Importance of social and emotional care was also emphasised by users. (Petch et al., 2013)	Holistic view of the person, their lives and their situation and then customising how support and services are organised and delivered.	
The mental health service users who were most satisfied with the support they received were accessing holistic support. (Petch et al., 2013)		
D1 Both physical health and functioning (e.g. walking) played a key role in participants' lives; hence, the revision of this outcome to include the latter. (Spiers et al., 2015)		

Appendix G: Research Interview Guide (HREC Approved)

Thank you for making the time to talk with me …

Your health care experience

Tell me about how you came to be a patient of this clinic (Integrated care service)?
What is it like to be a patient at this clinic?
How has this experience been different to your other health care experiences?
What does 'being involved in your health care' mean to you?
When thinking about your clinic visits, what would be an example of being involved?
Walk me through how you go about preparing for, and getting to, your clinic visit
What matters the most (is most important) to you from your visit to the clinic?

What happens at home - Now?

From the clinic visit what (e.g. information/ knowledge/ skills / resources) was of benefit /useful when you were at home (self-caring for your health)?
Since being a patient at the clinic, have you had to make any additional / unexpected visits to the clinic or had to seek help from other services because you were worried about your health?
No – go to next question.
Yes - Tell me about this experience?
Was there anything that you remembered from your visits to the clinic that was helpful (of benefit) at this time? Thinking back, what would have been helpful for you?

What might happen at home – Later on?

What do you think /see as likely to be most important for you, in staying healthy at home in the future?
What actions have you taken related to staying healthy at home in the future?
How have the visits to the clinic, helped prepare you for the future?
What else would be helpful / of benefit to you?

Other thoughts

Thank you for taking the time to talk with me … now that we have talked about your health care experiences and the integrated care clinic … is there anything else you would like to share?

Appendix H: Conference Poster – Outcome Measures That Matter

Outcome Measures That Matter

A SYSTEMATIC REVIEW OF THE LITERATURE

19th International Conference
of Integrated Care, April 2019,
Sans Sebastian, Basque Country

ABSTRACT 653

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Academic Supervisors:
Professor Jo Travalgia PhD;
Professor Debra Jackson, PhD, RN, FACN;
Professor John Daly, PhD, RN, FACN, FAAN;
Professor Patricia M. Davidson, PhD, RN, FACN, FAAN;

RESEARCH QUESTION

The literature review aims to better understand person level outcomes associated with an integrated model of health care delivery as perceived by adults living in the community.

The review focuses on studies that investigate the perspectives of adults living in the community whose health needs were suitable for, or they had accessed, an integrated model of health care delivery.

The phenomena of interest was to understand how these individuals constructed their needs and wants (what was important to them) and/or their experience of the model of care, focusing on issues and outcomes important to them.

This literature review systematically identified published, empirical research between 2008 and 2018.

RESEARCH METHOD

Five eligible studies included in literature review

1 Burridge, L.H. Foster, M.M. Donald, M. Zhang, J. Russell, A.W. Jackson, C.L. (2015), *Making sense of change: patients' views of diabetes and GP-led integrated diabetes care*, Health Expectations, 19, pp.74–86 John Wiley & Sons Ltd

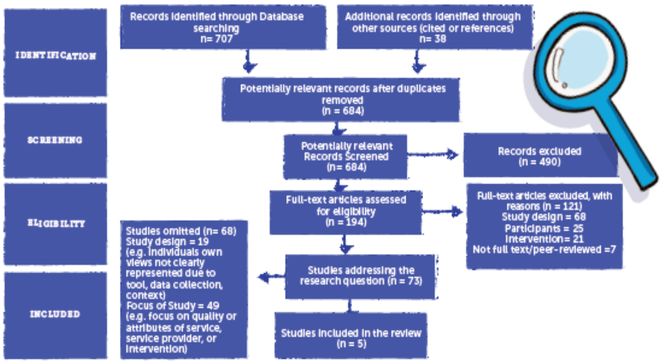
2 Petch, A. Cook, A. Miller, E. (2013), *Partnership working and outcomes: do health and social care partnerships deliver for users and carers?* Health and Social Care in the Community, 21(6), 623–633, Wiley & Sons LTD

3 Spiers, G. Aspinal, F. Bernard, S. Parker, G. (2015), *What outcomes are important to people with long-term neurological conditions using integrated health and social care?* Health and Social Care in the Community 23(5), 559–568, Wiley & Sons LTD UK

4 Spoorenberg, S.L.W. Wynia, K. Fokkens, A.S. Slotman, K. Kremer, H.P.H. Reijneveld, S.A. (2015), *Experiences of Community-Living Older Adults Receiving Integrated Care Based on the Chronic Care Model: A Qualitative Study.* PLoS ONE 10(10)

5 Yarborough, B. J. H. Yarborough, M.T. Janoff, S.L. Green, C. A. (2016), *Getting By, Getting Back, and Getting On: Matching Mental Health Services to Consumers' Recovery Goals*, Psychiatric Rehabilitation Journal, Vol. 39, No. 2, 97–104 American Psychological Association

PRISMA Flow Diagram



RESULTS

Literature Review Objective 1

To provide insights into how to pragmatically approach and organise a research project within a practice setting to ensure the patient's perspective is the primary source of data.

Findings

SUMMARY OF THE RESEARCH DESIGN CHARACTERISTICS OF THE STUDIES INCLUDED IN THE LITERATURE REVIEW:

Design
Qualitative research (1,2,3,4,5)

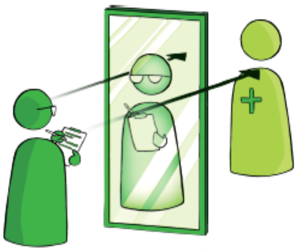
Sampling
Purposive sample (1,2,3)
Maximum-variation sampling (4)
Stratified sampling (5)

Methodology
Deductive approach applying Normalisation Process Theory (NPT) followed by inductive processes and constant comparison (1)
Outcomes important to service user's framework (2)
Modified Framework approach(3)
Modified grounded theory approach and constant comparative method (4,5)

Method
In-depth semi structured interview guided by purposively designed questions (1,2,3,4,5)
Face to face interviews in home (1,2,3,4,5) within 3 months initial appt (1); eight to ten months after initial (4); 24-month follow-up visit

Data Management systems
NVivo (2)
Kwalitan 6.0 software (4)
Atlas.ti (5)

None of the included studies could demonstrate a level of certainty that the researchers had critically examined their own role, potential bias and influence as an iterative process from commencement to completion of the study (CASP 2018).



Literature Review Objective 2

To appreciate how the studies constructed a social environment and sense of safety that enabled participants to share their experiences, thoughts and sensemaking.

Findings

All the included papers explored with the individual, in person, their views about their health and related health care experiences.

Interviews took place in person in a familiar setting, ranging from 20-90 minutes.

Questions were framed from a co-design approach to applying an existing outcome framework.

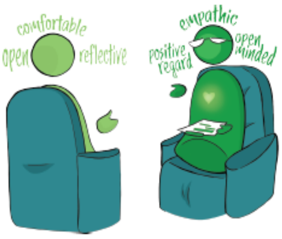
Study participants were guided to describe in their own words their experience, the benefits and what would be better or an ideal model.

Other questions included what the individual expected and what was important to them, not health specific.

Others encouraged reflection, exploring how participants made sense of their experiences over time.

An interest in the **interdependent relationship** between an **individual's sense of agency and their social conditions** was a theme in the synthesis of the study findings.

The importance of **enabling a safe environment**, whereby the researcher adopts an **open mind, listens with empathy, positive regard and suspends judgement**, emerged as fundamental.



Literature Review Objective 3

To propose recommendations on the benefits and insights that person-level outcomes offer integrated model of health care delivery across a range of settings

Findings

The meta-aggregative review approach resulted in **27 categories**, synthesisesd and framed into **10 indicatory statements**. Each study provided unique insights as to the value integrated care offered study participants across a range of settings.

The outcomes that mattered most to people included:

Respect for person's lived experience, situation and perspective

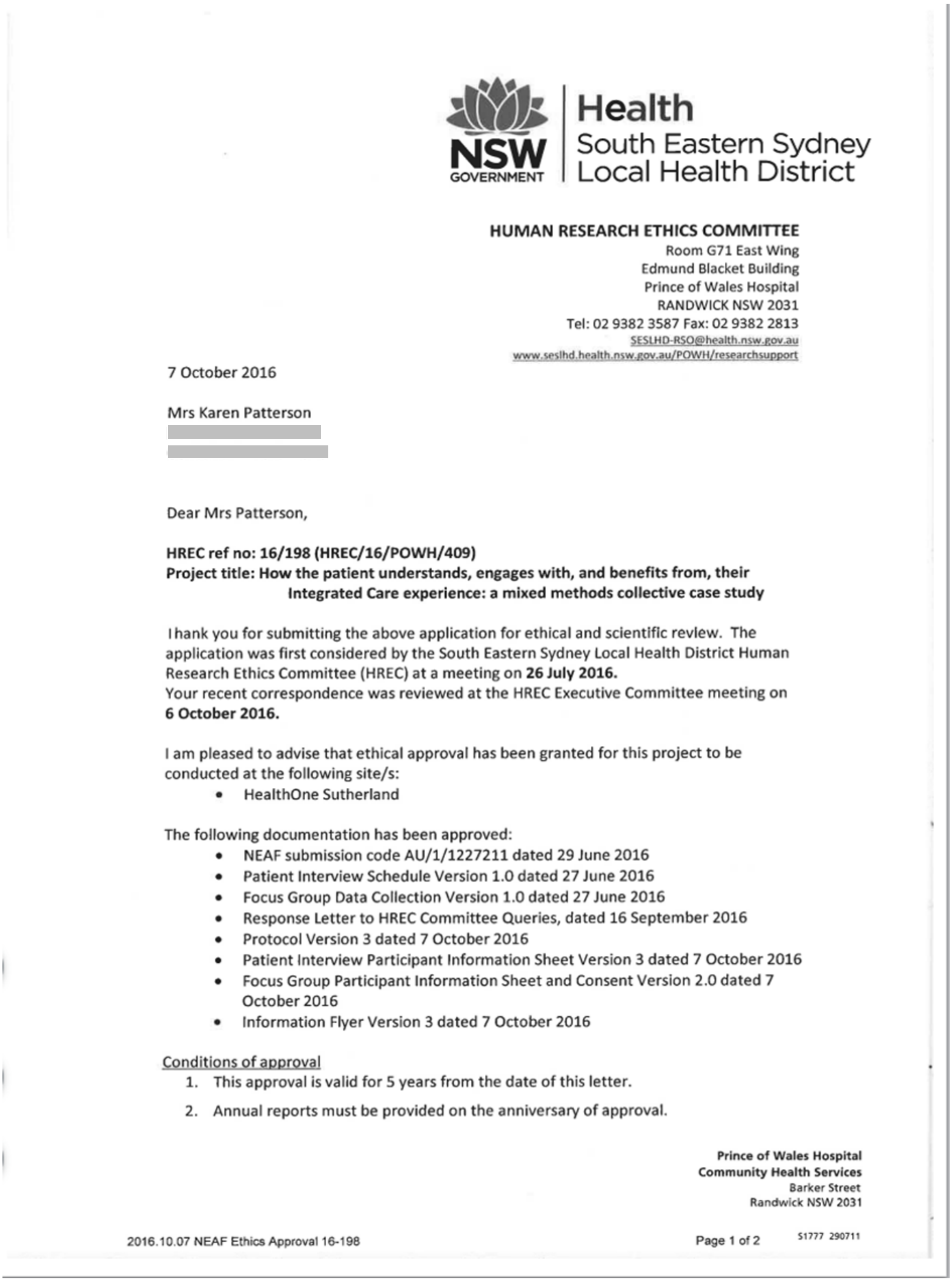
Value person's health and social care needs equally

Shared commitment to working in partnership across health and social care

Genuine engagement with community as partners and assets, facilitated through co-design and co-production

Appendix I: HREC Ethics Approval Letters

I1: Local Health District HREC Approval Letter



NSW GOVERNMENT | Health
South Eastern Sydney
Local Health District

HUMAN RESEARCH ETHICS COMMITTEE
Room G71 East Wing
Edmund Blacket Building
Prince of Wales Hospital
RANDWICK NSW 2031
Tel: 02 9382 3587 Fax: 02 9382 2813
SESLHD-RSO@health.nsw.gov.au
www.seslhd.health.nsw.gov.au/POWH/researchsupport

7 October 2016

Mrs Karen Patterson
[redacted]

Dear Mrs Patterson,

HREC ref no: 16/198 (HREC/16/POWH/409)
Project title: How the patient understands, engages with, and benefits from, their Integrated Care experience: a mixed methods collective case study

Thank you for submitting the above application for ethical and scientific review. The application was first considered by the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC) at a meeting on **26 July 2016.**
Your recent correspondence was reviewed at the HREC Executive Committee meeting on **6 October 2016.**

I am pleased to advise that ethical approval has been granted for this project to be conducted at the following site/s:

- HealthOne Sutherland

The following documentation has been approved:

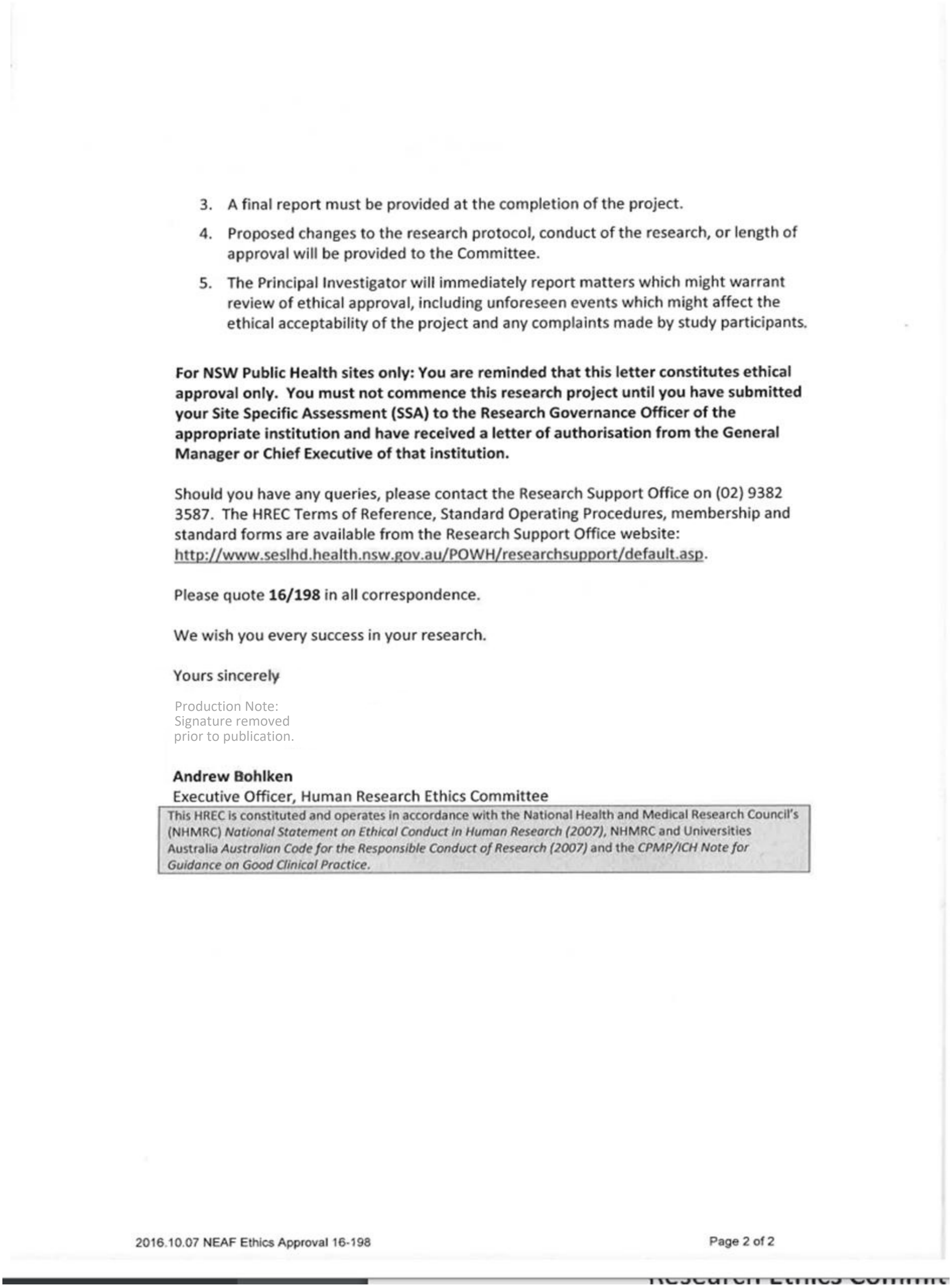
- NEAF submission code AU/1/1227211 dated 29 June 2016
- Patient Interview Schedule Version 1.0 dated 27 June 2016
- Focus Group Data Collection Version 1.0 dated 27 June 2016
- Response Letter to HREC Committee Queries, dated 16 September 2016
- Protocol Version 3 dated 7 October 2016
- Patient Interview Participant Information Sheet Version 3 dated 7 October 2016
- Focus Group Participant Information Sheet and Consent Version 2.0 dated 7 October 2016
- Information Flyer Version 3 dated 7 October 2016

Conditions of approval

1. This approval is valid for 5 years from the date of this letter.
2. Annual reports must be provided on the anniversary of approval.

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

2016.10.07 NEAF Ethics Approval 16-198 Page 1 of 2 S1777 290711



3. A final report must be provided at the completion of the project.
4. Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the Committee.
5. The Principal Investigator will immediately report matters which might warrant review of ethical approval, including unforeseen events which might affect the ethical acceptability of the project and any complaints made by study participants.

For NSW Public Health sites only: You are reminded that this letter constitutes ethical approval only. You must not commence this research project until you have submitted your Site Specific Assessment (SSA) to the Research Governance Officer of the appropriate institution and have received a letter of authorisation from the General Manager or Chief Executive of that institution.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp.

Please quote **16/198** in all correspondence.

We wish you every success in your research.

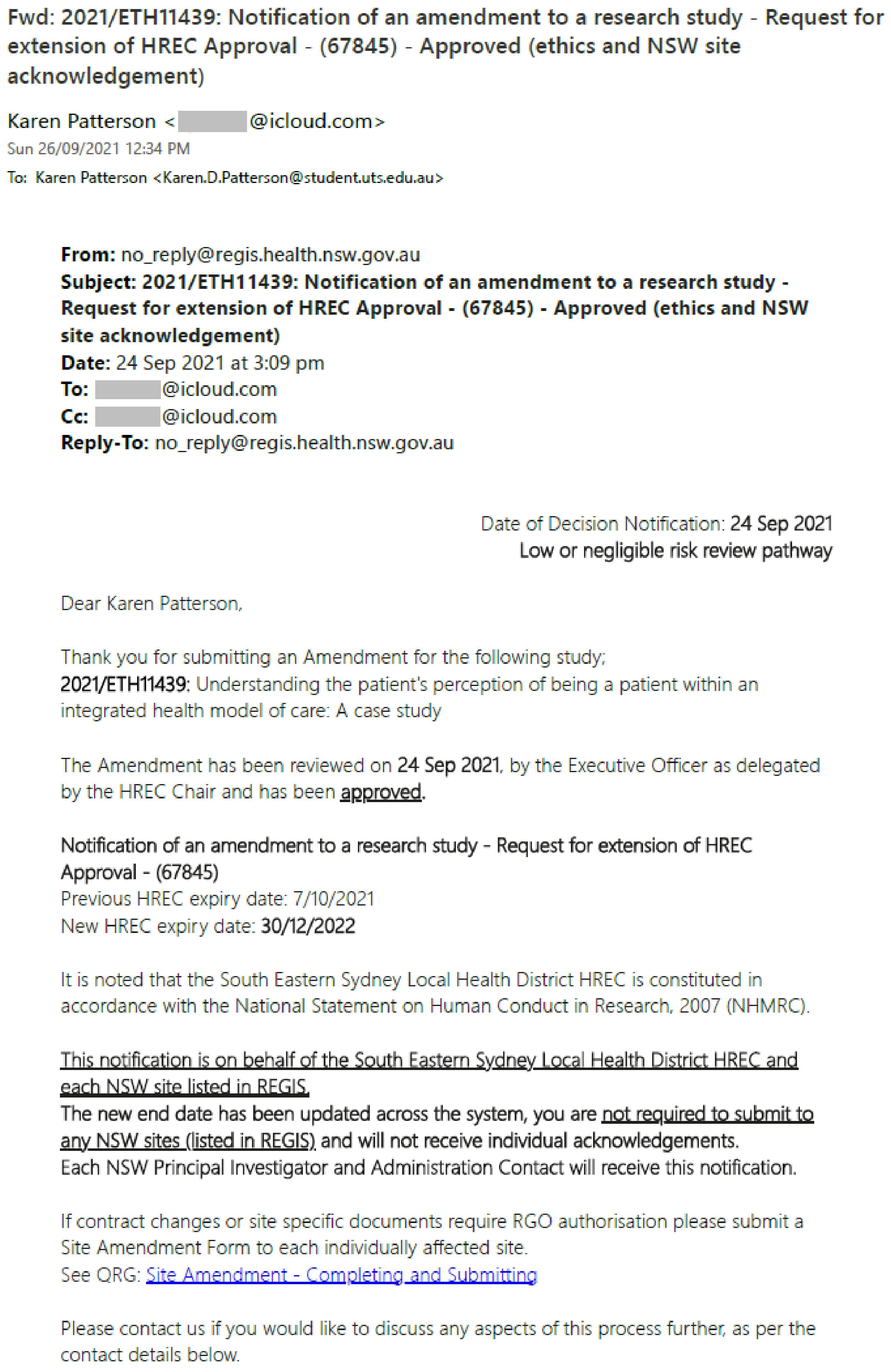
Yours sincerely

Production Note:
Signature removed
prior to publication.

Andrew Bohlken
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I2: Local Health District HREC Approval Request for Extension



Fwd: 2021/ETH11439: Notification of an amendment to a research study - Request for extension of HREC Approval - (67845) - Approved (ethics and NSW site acknowledgement)

Karen Patterson <[redacted]@icloud.com>
Sun 26/09/2021 12:34 PM
To: Karen Patterson <Karen.D.Patterson@student.uts.edu.au>

From: no_reply@regis.health.nsw.gov.au
Subject: 2021/ETH11439: Notification of an amendment to a research study - Request for extension of HREC Approval - (67845) - Approved (ethics and NSW site acknowledgement)
Date: 24 Sep 2021 at 3:09 pm
To: [redacted]@icloud.com
Cc: [redacted]@icloud.com
Reply-To: no_reply@regis.health.nsw.gov.au

Date of Decision Notification: 24 Sep 2021
Low or negligible risk review pathway

Dear Karen Patterson,

Thank you for submitting an Amendment for the following study;
2021/ETH11439: Understanding the patient's perception of being a patient within an integrated health model of care: A case study

The Amendment has been reviewed on 24 Sep 2021, by the Executive Officer as delegated by the HREC Chair and has been approved.

Notification of an amendment to a research study - Request for extension of HREC Approval - (67845)
Previous HREC expiry date: 7/10/2021
New HREC expiry date: 30/12/2022

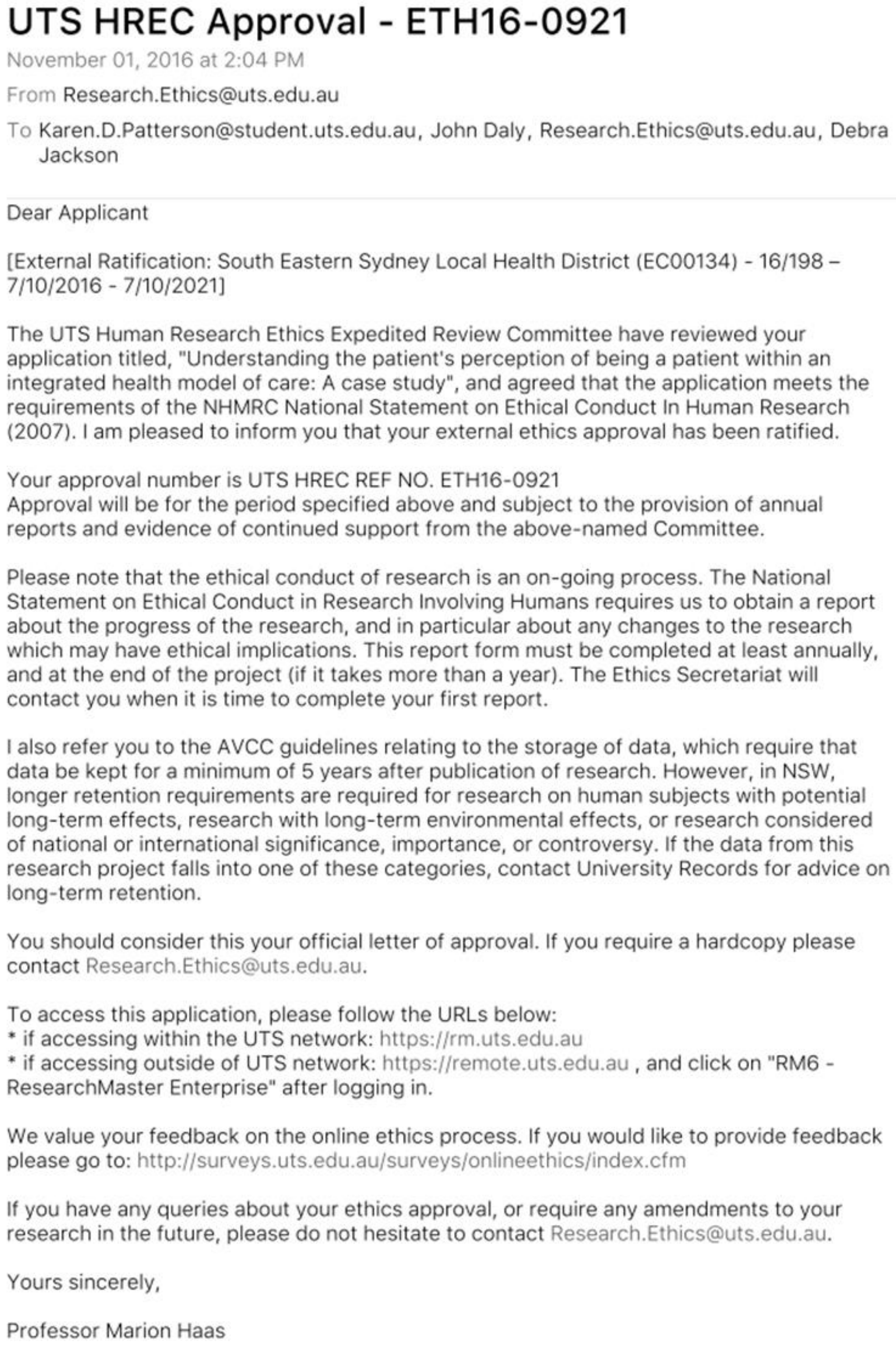
It is noted that the South Eastern Sydney Local Health District HREC is constituted in accordance with the National Statement on Human Conduct in Research, 2007 (NHMRC).

This notification is on behalf of the South Eastern Sydney Local Health District HREC and each NSW site listed in REGIS.
The new end date has been updated across the system, you are not required to submit to any NSW sites (listed in REGIS) and will not receive individual acknowledgements.
Each NSW Principal Investigator and Administration Contact will receive this notification.

If contract changes or site specific documents require RGO authorisation please submit a Site Amendment Form to each individually affected site.
See QRG: Site Amendment - Completing and Submitting

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

I3: UTS HREC Approval Letter



UTS HREC Approval - ETH16-0921

November 01, 2016 at 2:04 PM

From Research.Ethics@uts.edu.au

To Karen.D.Patterson@student.uts.edu.au, John Daly, Research.Ethics@uts.edu.au, Debra Jackson

Dear Applicant

[External Ratification: South Eastern Sydney Local Health District (EC00134) - 16/198 – 7/10/2016 - 7/10/2021]

The UTS Human Research Ethics Expedited Review Committee have reviewed your application titled, "Understanding the patient's perception of being a patient within an integrated health model of care: A case study", and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that your external ethics approval has been ratified.

Your approval number is UTS HREC REF NO. ETH16-0921
Approval will be for the period specified above and subject to the provision of annual reports and evidence of continued support from the above-named Committee.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://remote.uts.edu.au , and click on "RM6 - ResearchMaster Enterprise" after logging in.

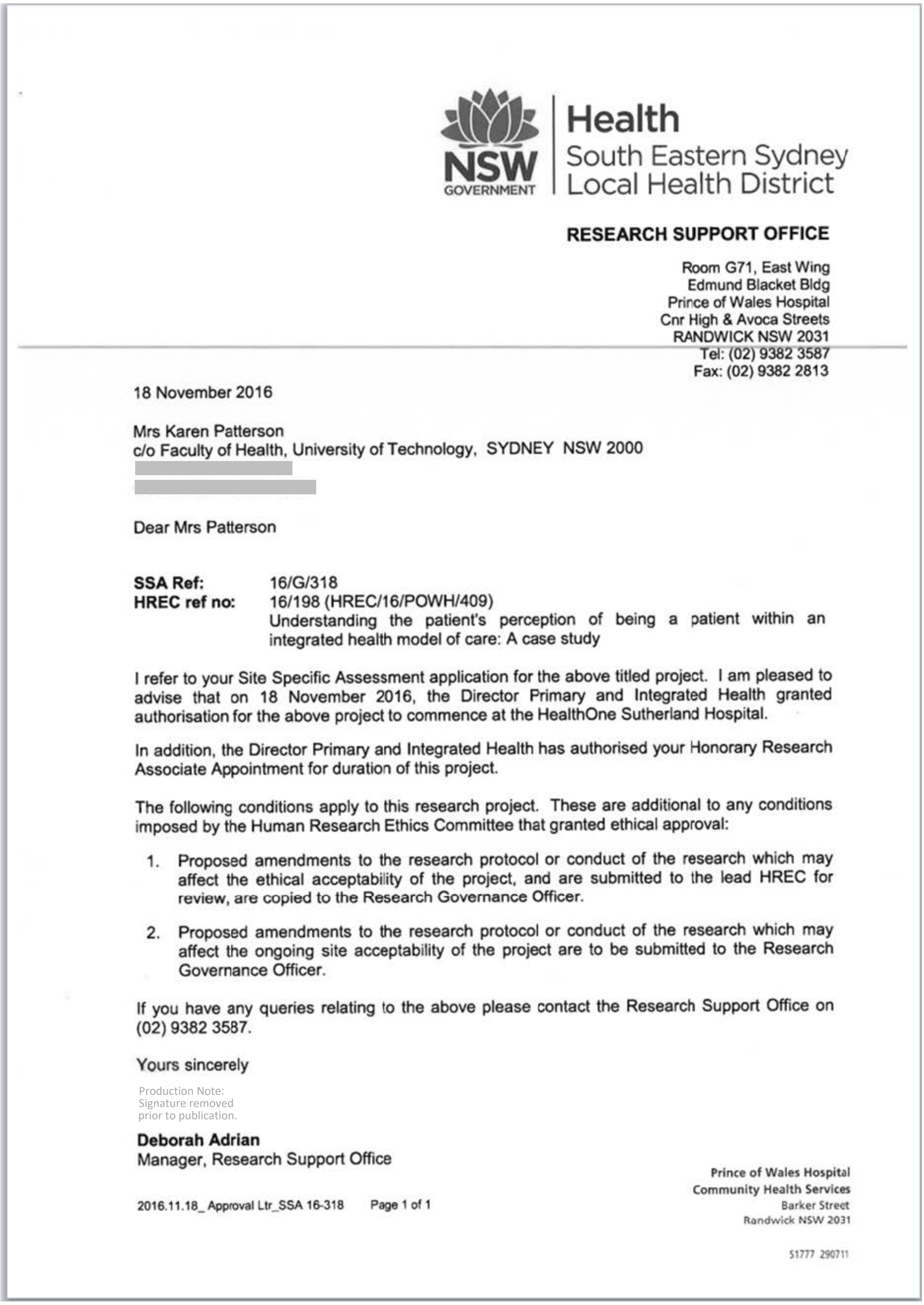
We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Professor Marion Haas

I4: Local Health District Approval Site Specific Assessment



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

18 November 2016

Mrs Karen Patterson
c/o Faculty of Health, University of Technology, SYDNEY NSW 2000
[redacted]

Dear Mrs Patterson

SSA Ref: 16/G/318
HREC ref no: 16/198 (HREC/16/POWH/409)
Understanding the patient's perception of being a patient within an integrated health model of care: A case study

I refer to your Site Specific Assessment application for the above titled project. I am pleased to advise that on 18 November 2016, the Director Primary and Integrated Health granted authorisation for the above project to commence at the HealthOne Sutherland Hospital.

In addition, the Director Primary and Integrated Health has authorised your Honorary Research Associate Appointment for duration of this project.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

If you have any queries relating to the above please contact the Research Support Office on (02) 9382 3587.

Yours sincerely

Production Note:
Signature removed
prior to publication.

Deborah Adrian
Manager, Research Support Office

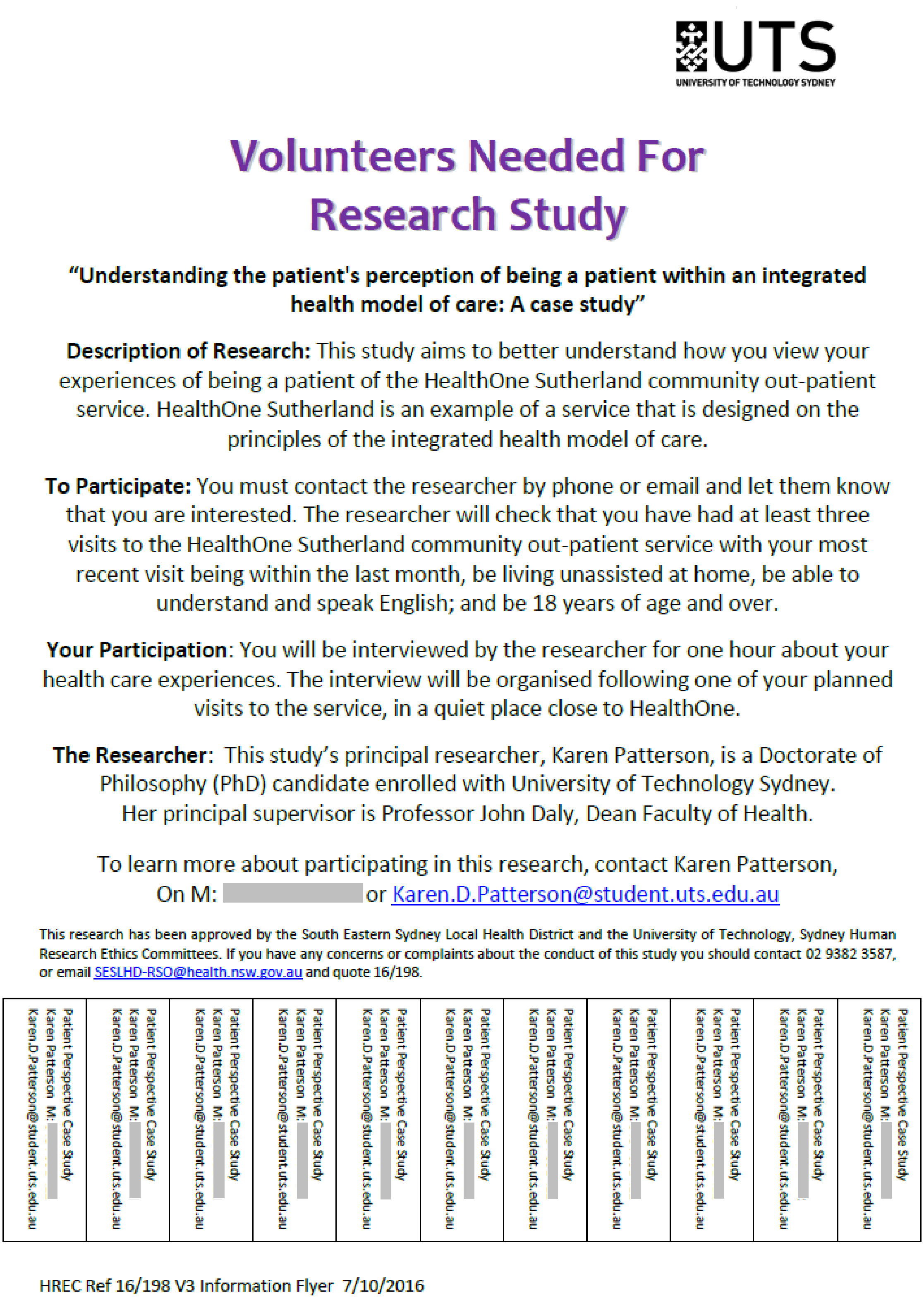
2016.11.18_ Approval Ltr_SSA 16-318 Page 1 of 1

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

S1777 290711

Appendix J: HREC Approved Supporting Documents

J1: Research Recruitment Flyer



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Volunteers Needed For Research Study

"Understanding the patient's perception of being a patient within an integrated health model of care: A case study"

Description of Research: This study aims to better understand how you view your experiences of being a patient of the HealthOne Sutherland community out-patient service. HealthOne Sutherland is an example of a service that is designed on the principles of the integrated health model of care.

To Participate: You must contact the researcher by phone or email and let them know that you are interested. The researcher will check that you have had at least three visits to the HealthOne Sutherland community out-patient service with your most recent visit being within the last month, be living unassisted at home, be able to understand and speak English; and be 18 years of age and over.

Your Participation: You will be interviewed by the researcher for one hour about your health care experiences. The interview will be organised following one of your planned visits to the service, in a quiet place close to HealthOne.

The Researcher: This study's principal researcher, Karen Patterson, is a Doctorate of Philosophy (PhD) candidate enrolled with University of Technology Sydney. Her principal supervisor is Professor John Daly, Dean Faculty of Health.

To learn more about participating in this research, contact Karen Patterson,
On M: [redacted] or Karen.D.Patterson@student.uts.edu.au

This research has been approved by the South Eastern Sydney Local Health District and the University of Technology, Sydney Human Research Ethics Committees. If you have any concerns or complaints about the conduct of this study you should contact 02 9382 3587, or email SESLHD-RSO@health.nsw.gov.au and quote 16/198.

Patient Perspective Case Study
Karen Patterson M: [redacted]
Karen.D.Patterson@student.uts.edu.au

Patient Perspective Case Study
Karen Patterson M: [redacted]
Karen.D.Patterson@student.uts.edu.au

Patient Perspective Case Study
Karen Patterson M: [redacted]
Karen.D.Patterson@student.uts.edu.au

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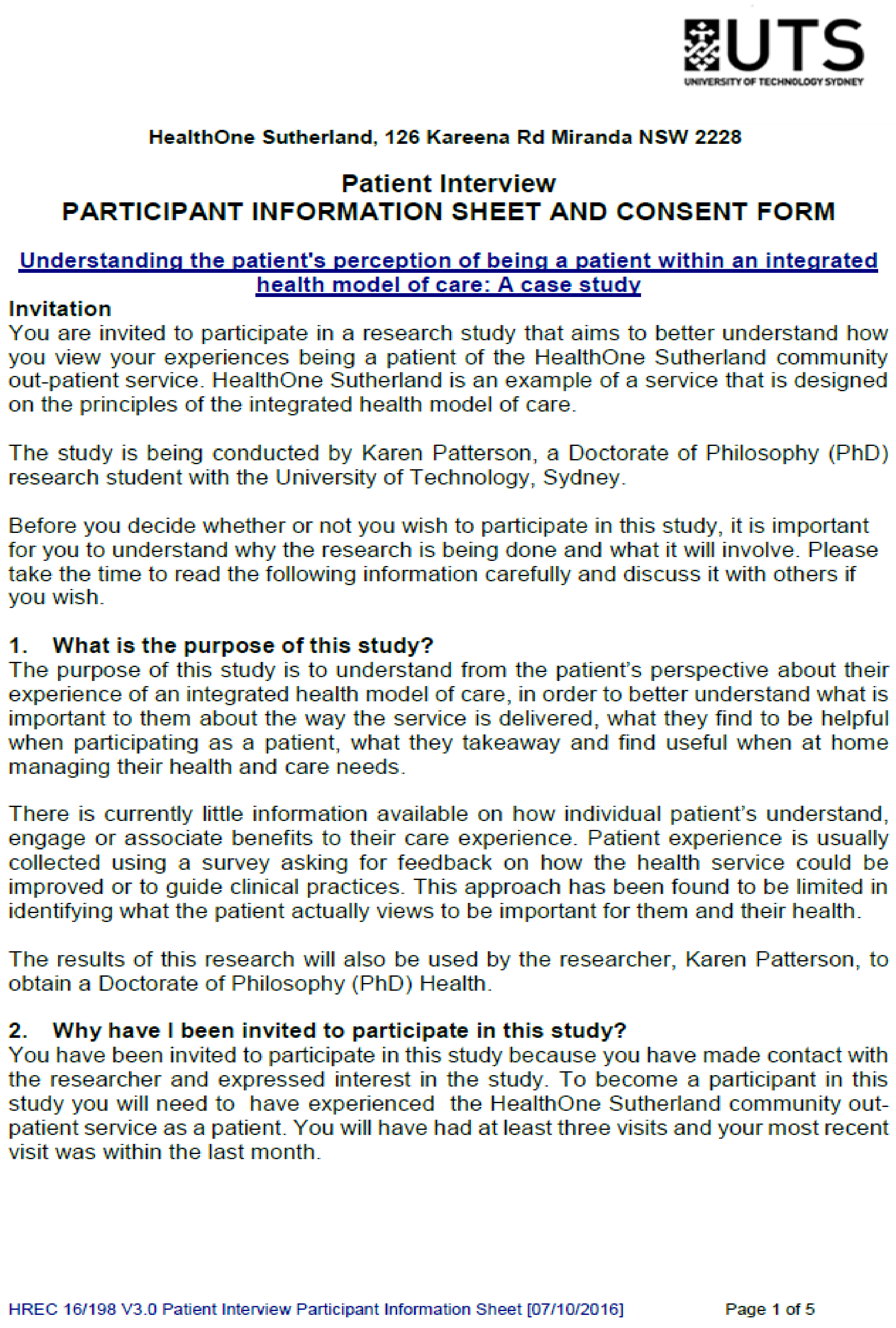
Karen.D.Patterson@student.uts.edu.au

Patient Perspective Case Study
Karen Patterson M: [redacted]
Karen.D.Patterson@student.uts.edu.au

HREC Ref 16/198 V3 Information Flyer 7/10/2016

J2: Participant Information Sheet, Consent and Withdrawal Forms



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HealthOne Sutherland, 126 Kareena Rd Miranda NSW 2228

Patient Interview
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Understanding the patient's perception of being a patient within an integrated health model of care: A case study

Invitation

You are invited to participate in a research study that aims to better understand how you view your experiences being a patient of the HealthOne Sutherland community out-patient service. HealthOne Sutherland is an example of a service that is designed on the principles of the integrated health model of care.

The study is being conducted by Karen Patterson, a Doctorate of Philosophy (PhD) research student with the University of Technology, Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. What is the purpose of this study?

The purpose of this study is to understand from the patient's perspective about their experience of an integrated health model of care, in order to better understand what is important to them about the way the service is delivered, what they find to be helpful when participating as a patient, what they takeaway and find useful when at home managing their health and care needs.

There is currently little information available on how individual patient's understand, engage or associate benefits to their care experience. Patient experience is usually collected using a survey asking for feedback on how the health service could be improved or to guide clinical practices. This approach has been found to be limited in identifying what the patient actually views to be important for them and their health.

The results of this research will also be used by the researcher, Karen Patterson, to obtain a Doctorate of Philosophy (PhD) Health.

2. Why have I been invited to participate in this study?

You have been invited to participate in this study because you have made contact with the researcher and expressed interest in the study. To become a participant in this study you will need to have experienced the HealthOne Sutherland community out-patient service as a patient. You will have had at least three visits and your most recent visit was within the last month.

You will have also indicated that you are: living at home in the community, meaning that you are not living in an aged care facility or receiving 24 hour supervision; you are able to understand and speak English; and you are 18 years of age or over.

3. What if I don't want to take part in this study, or if I want to withdraw later?

Before deciding to take part in this study the researcher will give you a copy to keep and discuss with you this Participant Information Sheet, including the Consent and Withdrawal forms.

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

If you do decide to take part, you will be asked to sign the Consent Form and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with HealthOne Sutherland, South Eastern Sydney Local Health District or the University of Technology, Sydney.

If you decide to withdraw from the project, please notify the researcher, Karen Patterson, who will provide you with the 'Withdrawal of Consent' form for you to complete and sign. You will be given a copy to keep.

4. What does this study involve?

Taking part in this study involves signing the Consent Form and agreeing to be interviewed by the researcher for one hour about your experiences and views related to your experience of the HealthOne Sutherland community out- patient service.

The interview will be organised following a planned visit to the service, in a quiet place close to HealthOne. The researcher will use a semi-structured interview guide allowing you the freedom to express your views in your own words. Throughout the interview the researcher will check-in with you or revisit areas to make sure they have understood and captured your meaning accurately. The interview will be digitally recorded and the researcher will take notes. Your information collected via the interview will be de-identified to protect your confidentiality.

5. Are there risks to me in taking part in this study?

There should be no discomfort for you in taking part in this study. If you did feel that some of the questions asked are upsetting or you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately.

If you become upset or distressed as a result of your participation in the research project, the researcher will stop immediately. An independent qualified health professional will be readily available and access to appropriate support services will be arranged. This will be available free of charge.

As a participant you may also withdraw from the research at any time.

6. Will I benefit from the study?

This study aims to further understand the patient's experiences of an integrated health model of care, using the HealthOne community out-patient clinic as an example. This study may influence how you approach your future health care experiences, however it may also not directly benefit you.

7. Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. Light refreshments will be made available during the study interviews.

8. How will my confidentiality be protected?

Of the people involved in your care, no-one will know whether or not you are participating in this study. Any information that is collected about you in connection with this study will be de-identified. Only the researcher, Karen Patterson, will have access to your details. The results that will be held securely for 5 years after the project has been finished at the University of Technology, Sydney (UTS). The data will then be destroyed. The study findings will not include your name, nor will any written reports about the case study.

9. What happens with the results?

If you give permission by signing the consent document, the researcher plans to discuss the results with her UTS PhD Research supervisors. The researcher may also be required to provide progress reports to the Human Research Ethics Committee (HREC) for monitoring purposes.

The researcher will publish the findings within her PhD Thesis. The researcher may also disseminate findings in peer reviewed journals, presentation at conferences or other professional forums. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

10. What should I do if I want to discuss this study further before I decide?

When you have read this information, the researcher, Karen Patterson, will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on her mobile [redacted] or email Karen.d.patterson@student.uts.edu.au with your contact details and Karen will contact you directly.

11. Who should I contact if I have concerns about the conduct of this study?

This study has been approved by the South Eastern Sydney Local Health District and the University of Technology, Sydney Human Research Ethics Committees. Any person with concerns or complaints about the conduct of this study should contact the South Eastern Sydney Local Health District Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email RSOseslhd@sesiahs.health.nsw.gov.au and quote 16/198.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

HealthOne Sutherland, 126 Kareena Rd Miranda NSW 2228

CONSENT FORM

[To be used in conjunction with a Participant Information Sheet]

Understanding the patient's perception of being a patient within an integrated health model of care: A case study

1. I,..
   of...
   agree to participate in the study described in the participant information statement set out above ***(or: attached to this form).***

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the HealthOne Sutherland, South Eastern Sydney Local Health District or the University of Technology, Sydney.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Karen Patterson on telephone [redacted], who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the Research Ethics Secretariat, South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email SESLHD-RSO@health.nsw.gov.au.

Signature of participant	**Please PRINT name**	**Date**
______________________	______________________	______________
Signature of witness	**Please PRINT name**	**Date**
______________________	______________________	______________
Signature of investigator	**Please PRINT name**	**Date**
______________________	______________________	______________

HealthOne Sutherland, 126 Kareena Rd Miranda NSW 2228

Understanding the patient's perception of being a patient within an integrated health model of care: A case study

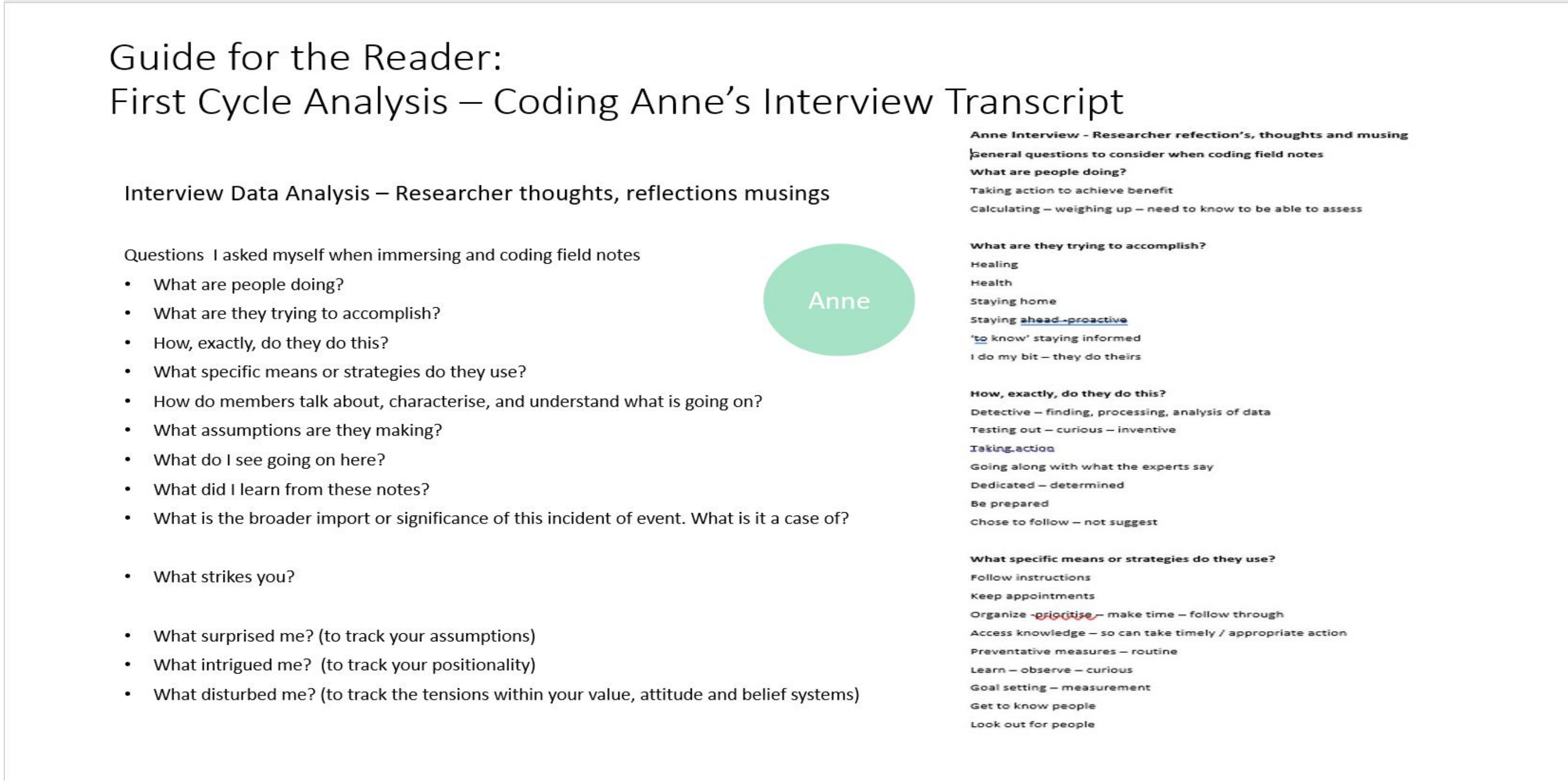
WITHDRAWAL OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any routine care, or my relationship with professional staff or my relationship with HealthOne Sutherland, South Eastern Sydney Local Health District or the University of Technology, Sydney.

Signature of participant **[*or person responsible*]**	**Please PRINT name** ***(insert or delete as necessary)***	**Date**
______________________	______________________	______________

The section for Revocation of Consent should be forwarded to **(INSERT name and address of Principal Investigator).**

Appendix K: First Cycle Analysis: Guide for the Reader - Coding Anne’s Interview Transcript



Guide for the Reader:
First Cycle Analysis – Coding Anne’s Interview Transcript

Interview Data Analysis – Researcher thoughts, reflections musings

Questions I asked myself when immersing and coding field notes

- What are people doing?
- What are they trying to accomplish?
- How, exactly, do they do this?
- What specific means or strategies do they use?
- How do members talk about, characterise, and understand what is going on?
- What assumptions are they making?
- What do I see going on here?
- What did I learn from these notes?
- What is the broader import or significance of this incident of event. What is it a case of?

- What strikes you?

- What surprised me? (to track your assumptions)
- What intrigued me? (to track your positionality)
- What disturbed me? (to track the tensions within your value, attitude and belief systems)

Anne Interview - Researcher refection’s, thoughts and musing

General questions to consider when coding field notes

What are people doing?

Taking action to achieve benefit

Calculating – weighing up – need to know to be able to assess

What are they trying to accomplish?

Healing

Health

Staying home

Staying ahead -proactive

‘to know’ staying informed

I do my bit – they do theirs

How, exactly, do they do this?

Detective – finding, processing, analysis of data

Testing out – curious – inventive

Taking action

Going along with what the experts say

Dedicated – determined

Be prepared

Chose to follow – not suggest

What specific means or strategies do they use?

Follow instructions

Keep appointments

Organize -prioritise – make time – follow through

Access knowledge – so can take timely / appropriate action

Preventative measures – routine

Learn – observe – curious

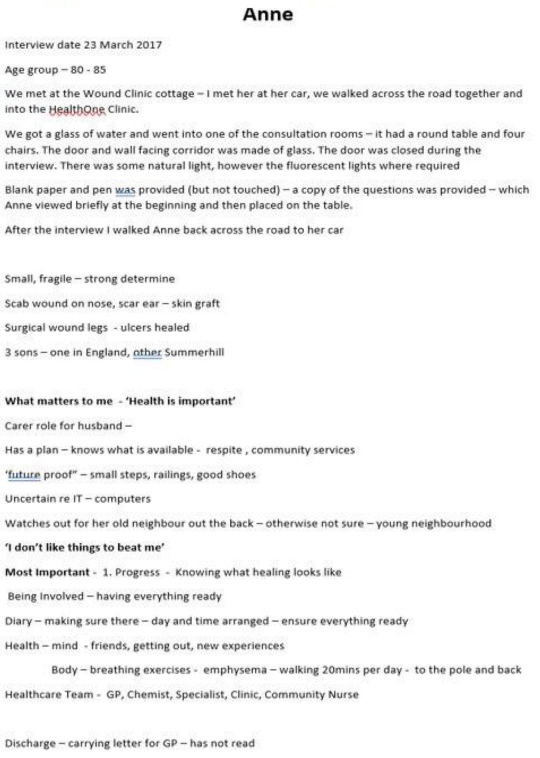
Goal setting – measurement

Get to know people

Look out for people

First Cycle Coding: Attribute & In Vivo

Anne



Anne

Interview date 23 March 2017

Age group – 80 - 85

We met at the Wound Clinic cottage – I met her at her car, we walked across the road together and into the HealthOne Clinic.

We got a glass of water and went into one of the consultation rooms – it had a round table and four chairs. The door and wall facing corridor was made of glass. The door was closed during the interview. There was some natural light, however the fluorescent lights where required

Blank paper and pen was provided (but not touched) – a copy of the questions was provided – which Anne viewed briefly at the beginning and then placed on the table.

After the interview I walked Anne back across the road to her car

Small, fragile – strong determine

Scab wound on nose, scar ear – skin graft

Surgical wound legs - ulcers healed

3 sons – one in England, other Summerhill

What matters to me - 'Health is important'

Carer role for husband –

Has a plan – knows what is available - respite , community services

'future proof" – small steps, railings, good shoes

Uncertain re IT – computers

Watches out for her old neighbour out the back – otherwise not sure – young neighbourhood

'I don't like things to beat me'

Most Important - 1. Progress - Knowing what healing looks like

Being Involved – having everything ready

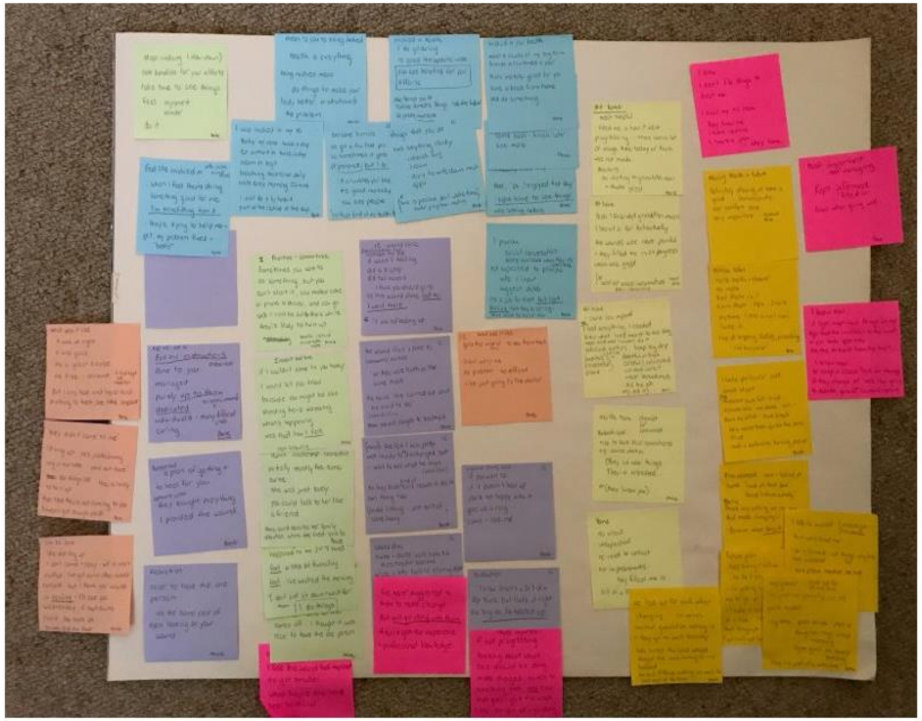
Diary – making sure there – day and time arranged – ensure everything ready

Health – mind - friends, getting out, new experiences

Body – breathing exercises - emphysema – walking 20mins per day - to the pole and back

Healthcare Team - GP, Chemist, Specialist, Clinic, Community Nurse

Discharge – carrying letter for GP – has not read



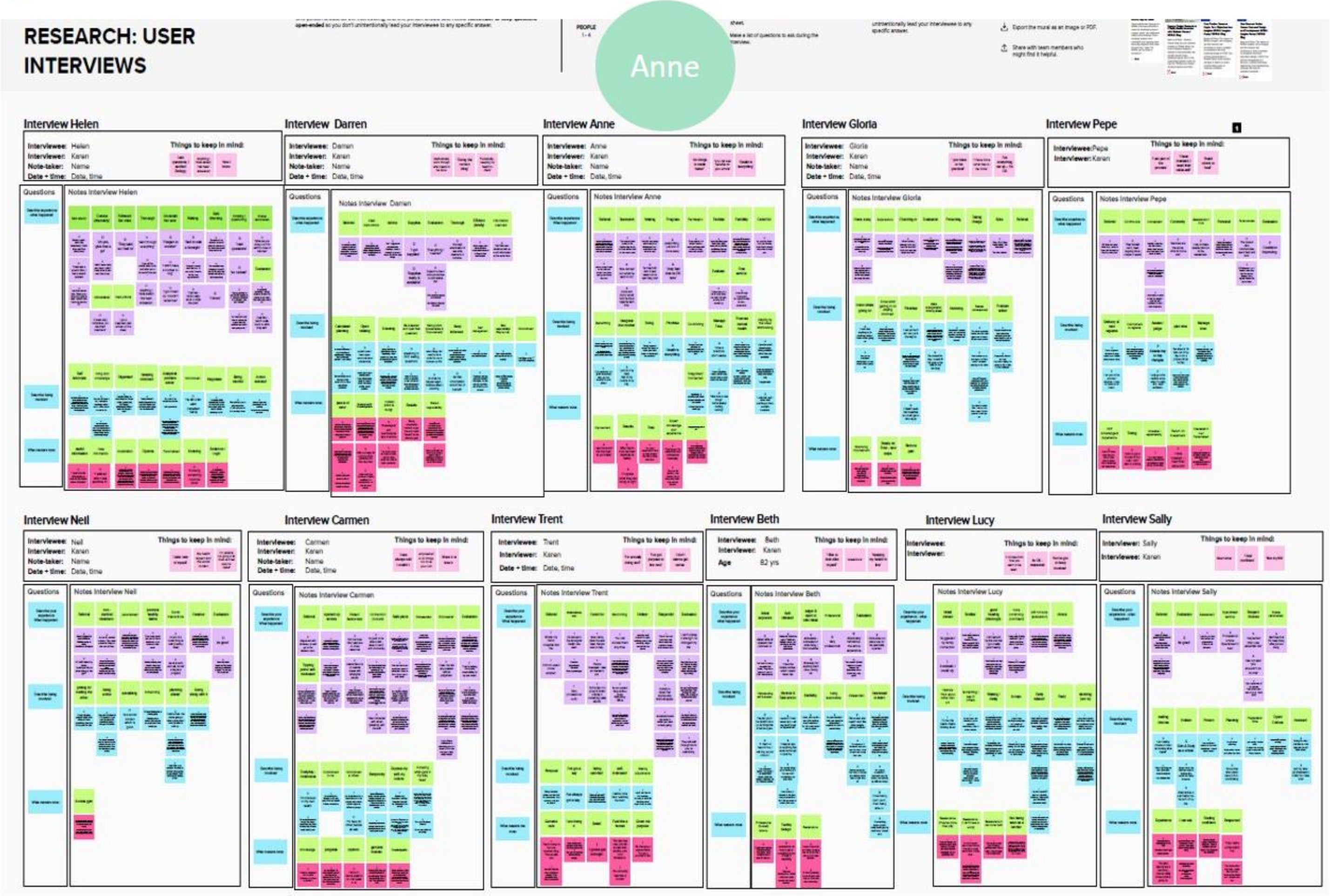
Attribute coding

In Vivo coding

First Cycle Coding: Focus on each person’s perceptions of their experiences of integrated care (Mural)

Exploring meaning

- What happened
- Describe being involved
- What matters most



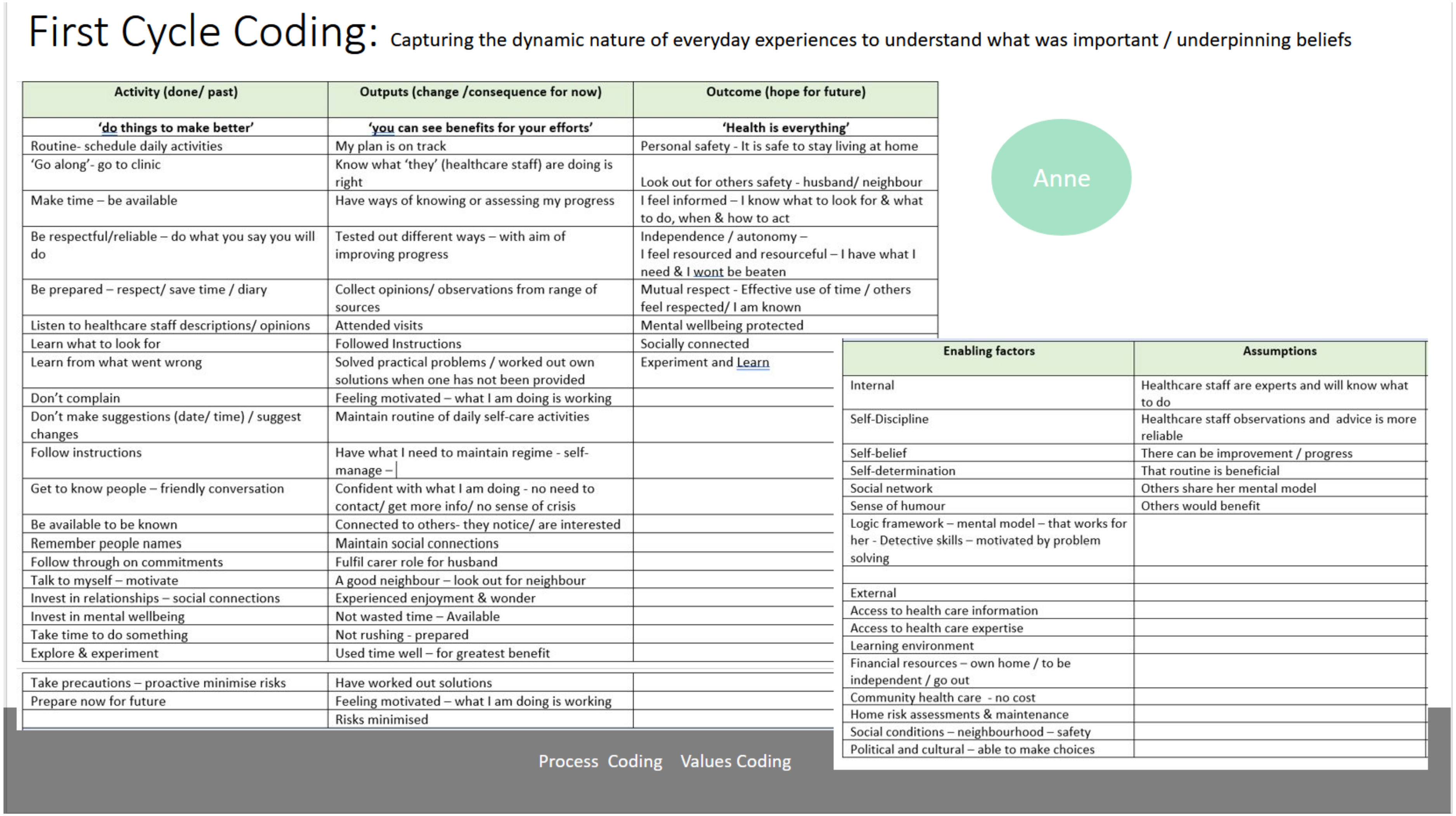
First Cycle Coding:

Focus on each person’s perceptions

of their experiences of integrated care

Exploring purpose / usefulness
- What was of value
- What was of benefit
- What actions
- How did you evaluate
- What's most important -takeaways

Question	Theme	Anne 80 - 85	KP - Comment
When self managing at home what has been most useful	clear description of progress	A – Being filled in on how it (healing) was progressing – describing – there was a lot of slough there today or there was not much – Its starting to granulate now , and	
	understanding	A -Yeah, I know what granulation means, I learnt a fair bit actually. The wounds were never painful & they filled me in on progress which was good	Anne could/ would not assess progress herself, needed data- will go along with them because they are the experts "I've never suggested to them to make
	Self initiated/ inventive / resourceful	A- I needed to keep the leg dry, they never said what I couldn't do. I was doubtful at first. Researched and carefully measured and applied. Was unsure if it would work. Never leaked once, did the job. 'I did it'	Anne was proud – they did not tell me not to – so was staying in the boundary of following instructions
What was of most value / benefit	I knew – prepared	A – I felt I had everything I needed, knew what I was meant to be doing.	
	I knew informed	A- most important is to keep informed, filled in, so know when going well	
Unexpected visit – What happened		A – No crisis or unexpected	
What was of most value / benefit		They kept me filled in , bit of a learning curve	
Anything that would have been helpful / improvements		No need to contact, no improvements	
Evaluation		A- I know now, "if I get suspicious things on my legs, that the circulation is the worst in your body apparently. It's the furtherst from the heart"	
		A – I know now ' to keep a close look on things, if they change or look like going to ulcerate, go to the GP, and he would organise, would do the referring'	
When anticipating the future			
Whats most important		A- Definitely staying at home is good, psychologically, your in your comfort zone.	
		A – Its very important, I'm a carer for my husband. 'I'm his carer'	
		A – I have a fear of tripping, falling, breaking	
Actions taken to protect or promote their health		A – I have put rails in the bath and shower, no mats, rail on the front step, the back steps have a slope with 2 rails.	
		A- Anytime I see a rail now , I use it.	
		A – I take particular care – small steps	
		A – in 98 my husband had a fall , wearing smooth sole old shoes, in the rain, down he went, it was a bad break. He's never been quiet the same since. Was a definitive turning point.	
		A – Been assessed – came and looked at	



First Cycle Coding: Capturing the dynamic nature of everyday experiences to understand what was important / underpinning beliefs

Activity (done/ past)	**Outputs (change /consequence for now)**	**Outcome (hope for future)**
'do things to make better'	**'you can see benefits for your efforts'**	**'Health is everything'**
Routine- schedule daily activities	My plan is on track	Personal safety - It is safe to stay living at home
'Go along'- go to clinic	Know what 'they' (healthcare staff) are doing is right	Look out for others safety - husband/ neighbour
Make time – be available	Have ways of knowing or assessing my progress	I feel informed – I know what to look for & what to do, when & how to act
Be respectful/reliable – do what you say you will do	Tested out different ways – with aim of improving progress	Independence / autonomy – I feel resourced and resourceful – I have what I need & I wont be beaten
Be prepared – respect/ save time / diary	Collect opinions/ observations from range of sources	Mutual respect - Effective use of time / others feel respected/ I am known
Listen to healthcare staff descriptions/ opinions	Attended visits	Mental wellbeing protected
Learn what to look for	Followed Instructions	Socially connected
Learn from what went wrong	Solved practical problems / worked out own solutions when one has not been provided	Experiment and Learn
Don't complain	Feeling motivated – what I am doing is working	
Don't make suggestions (date/ time) / suggest changes	Maintain routine of daily self-care activities	
Follow instructions	Have what I need to maintain regime - self-manage –	
Get to know people – friendly conversation	Confident with what I am doing - no need to contact/ get more info/ no sense of crisis	
Be available to be known	Connected to others- they notice/ are interested	
Remember people names	Maintain social connections	
Follow through on commitments	Fulfil carer role for husband	
Talk to myself – motivate	A good neighbour – look out for neighbour	
Invest in relationships – social connections	Experienced enjoyment & wonder	
Invest in mental wellbeing	Not wasted time – Available	
Take time to do something	Not rushing - prepared	
Explore & experiment	Used time well – for greatest benefit	
Take precautions – proactive minimise risks	Have worked out solutions	
Prepare now for future	Feeling motivated – what I am doing is working	
	Risks minimised	

Anne

Enabling factors	**Assumptions**
Internal	Healthcare staff are experts and will know what to do
Self-Discipline	Healthcare staff observations and advice is more reliable
Self-belief	There can be improvement / progress
Self-determination	That routine is beneficial
Social network	Others share her mental model
Sense of humour	Others would benefit
Logic framework – mental model – that works for her - Detective skills – motivated by problem solving	
External	
Access to health care information	
Access to health care expertise	
Learning environment	
Financial resources – own home / to be independent / go out	
Community health care - no cost	
Home risk assessments & maintenance	
Social conditions – neighbourhood – safety	
Political and cultural – able to make choices	

Process Coding Values Coding

Appendix L: First Cycle Analysis - 11 x Coding Participant Interview

Table L1: Anne's Experience of Integrated Care

Attribute Coding: Anne's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Anne	Date: March 2017 Location: Integrated Care Unit Arrived: drove own car Interview Length: 54 mins	75-80	Female	Own home, with Husband	Carer	Gardening Regular Exercise	Dermatologist referral (specialist)	~ 8 visits Since Dec 2016 attended every few weeks over 4-month period	Wound Clinic	General Practitioner Community Nurse Chemist Plastic Surgeon

Process, In Vivo and Values Coding

Sequence	Code	Anne's Datum supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Abiding by rules	"He said, I think you should go to the wound clinic, and so I went there" 'I don't complain, I don't make suggestions or suggest changes'. 'She (nurse) carried out what he said to do'. She (doctor) wrote a letter back to the referral doctor 'next time you go just hand him this'	In trying to understand what Anne's experiences of integrated care were like, the researcher was increasingly aware of contradictions whereby from one perspective Anne's words could be interpreted as being passive, deferring to the expert. Like a paternalistic relationship. Yet on the other hand what was emerging were insights into an active, intentional, thought through approach. Anne had critically undertaken a division of labour, allocating responsibilities to those who she assessed had the expertise and was fully committed to the responsibilities she gave herself. She carefully managed her time, feeling frustrated when the respect she showed to others was not reciprocated. Anne repeatedly stated that she's a doer - Doing whatever had to be done to achieve her desired outcome, healing.
	In sync	The wound clinic spoke to the community nurse 'so they were both on the same track'. 'The nurse and doctor would both be there together each time'. 'They (community nurse) brought everything; I provided the wound'	
	Waiting	'She felt I was pretty well ready to be discharged, but ... Wait, wait to see what he says'. 'so, they both kind of said leave it do its own thing now'	

		‘Sometimes you want to do something, but you can’t start it, say make a cake or something, or prune a shrub or something’. “I feel that was a little bit frustrating, because I feel I’ve wasted the morning”	Considering Anne’s demographic data, it may be that Anne has a pre-existing frame of reference, her own moral code, which she had honed over time. An embedded heuristic which implicitly & explicitly influenced her thoughts and behaviours. It would suggest this way of thinking and behaving has been effective in achieving other life goals. Gets the job done. In accepting Anne’s descriptions of how she followed instructions, and how she observed others following instructions and waiting for the advice of the senior person, who is male, could be understood that Anne may have experienced in her lifetime constructs such as patriarchal power imbalances or oppressive social systems like paternalism. What is interesting is that Anne comes across as quite influential and strategic in how she manages herself and her situation. In saying she that her experience of Integrated Care is familiar to other experiences. There is a sense that she knows what she has to do / how she needs to be – if she is to achieve her goals. It is interesting to consider the layered duplicity in Anne’s representation of what happened.
	Yes, but	“Oh, it was alright. Yeah. It was good. I mean, it’s a great service. It really is. And it’s free, which is a big thing. But I only had, and I never said anything to them, one little complaint.”	
	Just like	‘Pretty much like just going to the doctor’, ‘just lovely’ talk to her like a friend,	
	They’re helpful	‘They’re trying to help me & get my problem fixed & better ‘ ‘it’s a job for them, but I get a feeling that they’re caring, they want to help you’	
	Have choices	‘If you want to, if it doesn’t heal up, you’re not happy with it. Give us a ring, come and see me’	
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Doing things	“I feel involved when I feel they’re (Integrated Care) doing something good for me.” “Being involved means ‘to do things to make your body better or whatever’s the problem.” “I do things.”	
	Knowing my place	“I provide social conversation, being available when they are available. I am not expected to provide information or input (with wound care) I suggest dates”	
	Everything’s connected	“Health is everything” “(walking) - it circulates your blood, its good mentally, you see people”. “I do gardening, which is good therapeutic-wise, and you see benefits for your efforts”. ‘I meet a couple of my long-term friends a few times a year, that’s mentally good for you, have a break from home and do	Anne has a holistic view of her health, being involved extends beyond the boundary of the interaction with the Integrated care clinic, into her everyday living activities.

		something." "Take a break from ordinary" "Be tourist - curious - walk around different places, spontaneous, come back and finish later, see more"	Making something a habit, building into routine could be linked to Anne's valuing of time & of not wasting time. Anne's focused determination could be linked to her action-orientation. She feels involved, she is the driving force, she is leading. Anne was very clear about what was important, seeing improvements, that the assessment is reliable, that action is taken if not, that she has invested her trust (and time) wisely
	Establishing habits	I was involved in my HC, bathe my nose twice a day, put ointment on twice a day, cream on legs, breathing exercises daily, walk every morning 20 mins I just do it by habit. It's just part of the routine of the day	
	Not giving up	"I've got a few feet problems, so sometimes it gives me a bit of penance, but I do it." 'I talk to myself - motivate'	
	Managing my time	"I have everything ready, rubbish bag, cream, diary to write down the next appt." 'Take time to see things' 'we're always rushing, rushing'	
Significance -What mattered most to you about your integrated care experiences?	Seeing improvements	"I see most times the wound has improved. It's got smaller. And what they've done has been beneficial and its healing. And that what they're doing is right."	
	Taking action	"If not progressing, thinking about what else should be doing, make changes, switch to something else, see how that goes - give it a week"	
	Trusting expertise	"I say, "All right. Okay." And I go along with them. They are the experts." "I will go along with them because they've got the experience and professional knowledge"	
	Reliable assessment	"it's the same pair of eyes looking at your wound"	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Keeping informed	"The wounds I've had were never painful. And they filled me in on the progress, which was good."	

		“Yeah, well, they sort of filled me in how it was progressing like, “There was a lot of slough there today or there was not much.” “They certainly kept me informed. If I wanted to know something”	What was important / mattered to Anne about her integrated care experience were directly linked to what Anne needed to self-manage at home and guided her actions
	Learning	“I learnt a fair bit actually [laughter]. I did.” “It’s starting to granulate now, and that’s good” “making time to let heal”	
	Choice	I needed to keep the leg dry, they never said what I couldn’t do. I was really a bit doubtful at first. I was saying will this work? And do you know what, it never leaked once in two years.	
What was useful when something unexpected happened or you were worried about your health?		Nothing unexpected or concerning between visits. “I didn’t have to do anything like that. It all worked fairly good”	
Actionable - What actions have you initiated at home that will promote your health?	Monitoring for changes	I know now, “if I get suspicious things on my legs, that the circulation is the worst in your body apparently. It’s the furthest from the heart”	Anne has sought input from experts and has the knowledge that she needs to take action and make changes. Anne is both systematic in her approach to change, yet also values dedicating time to be curious and spontaneous. Time is important to Anne – taking, saving, focusing, investing, protecting, finding. Friendships and mate ships are important
	Not waiting	I know now ‘to keep a close look on things, if they change or look like going to ulcerate, go to the GP, and he would organise, would do the referring’	
	Taking precautions	I have put rails in the bath and shower, no mats, rail on the front step, the back steps have a slope with 2 rails. Anytime I see a rail now, I use it. I take particular care - small steps	
	Making changes	Been assessed - came and looked at the house ‘had all that done, twice I think actually’ They say, ‘there was nothing we can say that needs changing’. Because we’ve done it	
	Being neighbourly	“I have a neighbour I look out for as she is on her own. ‘it’s just neighbourly, we are good mates’	

	Finding joy - Positive experience	“I like to meet a couple of my long-term friends a few times a year. Three or four times a year we meet and go into town.” “We’ve tried to go somewhere or do something, like as if we’re tourists.” “So we’ve been to lots of places.” “Well, that’s mentally good for you, I think, to have a break from home and go and do something” “You just sort of feel, “Oh. I enjoyed that day.”	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Staying home	“To stay in your own home as long as you can is very important”. ‘Definitely staying at home is good, psychologically, you’re in your comfort zone”. “It’s very important, I’m a carer for my husband. ‘I’m his carer’”	The focus for the future is to ensure she has access to experts and the connections that will enable her to stay at home, and be a carer for her husband
	Avoiding injury	I have a fear of tripping, falling, breaking	
	Keeping up routine	“This won’t beat me”. Keep doing routine ‘to do as long as I can’. ‘It’s getting harder & harder for me to walk up that hill’ ‘I take it one telegraph pole at a time - I’m going to get to that telegraph pole’ ‘I will huff and I will puff until I get there’	
	Staying socially connected	“We look out for each other - the cul de sac is changing, another generation coming in & they go to work basically.” “It’s nice to have local connections, like the service station, ‘they can see things, they’re interested’”	
	Being known	“I know my Healthcare team and they know me. That the plans to stay home”	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?		“I’ve been informed. I had that assessment done. I’ve been informed all the things that I’m eligible to have, help in the home which	Integrated Care experience is clearly aligned to Anne achieving her future goals

		I would have to if I got ill or broke a bone or something”.	
		“I’ve got a phone number they gave me to ring if needed on anything. But I don’t need it”	
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** I now know - what to look for and what actions to take. Why? I have the understanding and information I need to make choices and take actions.	**Measure** Self-assessment Sense of confidence – self efficacy in my ability to self-manage – predict and prevent. I have a plan of action with points of reference and options. I have people’s names and contact details	
	Good use of time Why? avoided wasting time.	Reliability People do what they say they will do; Attendance as per agreed schedule / diary. Are knowledgeable and have expertise in the field. Are friendly and open to being known. Will help me learn / explain to me	
	Good value Why? its free and convenient	Self-assessment Comparison to previous experience Access to parking Phone contact	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Make sure respect other people’s time, If cannot turn up for appointment let the person know	2.Minimise the number of people, one set of eyes is better	

Table L2: Helen's Experience of Integrated Care

Attribute Coding: Helen's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Helen (H)	Date: April 2017 Location: Integrated Care Unit Arrived: 2 buses and walked Interview Length: 78 mins	75-80	Female	Own home, alone	Retired	Studied Biology Social activities Learning skills an languages. Two children	Self-referral via GP	~ 3 visits over 4-month period + Initially attended senior week	Wound Clinic	GP Practice with seven doctors Chemist

Process, In Vivo and Values Coding: Helen's Transcript

Sequence	Codes	Helen's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Giving it a go (self-initiating)	H- Senior's week – "open day advertised, I think they said free blood tests". H- There was a wound clinic, I had a wound problem. H- 'oh yes, give that a go'	Helen's experiences of integrated care were shared in an energetic yet pragmatic, matter-of-fact way. She described herself as sensible and no-nonsense. Helen's studies in Biology appeared to have given her a useful approach to making sense within her everyday life. In sharing her experience and meaning you get a sense that she is applying a scientific method, observing, asking questions, testing out her theories and then applying them in different contexts. Helen likes to see a clear logic, that her healthcare providers have considered her situation and are then intentional with their interventions and advice – rather than a 'fishing expedition' which I understood as being more about luck; let's see what bites approach. One thing that stood out about Helen is how she demonstrates proactive behaviours in her day-to-day
	Discovering	H- I didn't know what was there. I didn't know what it was, and I found out. H- I got their referral form, I filled it out, I rang up to make an appt- I couldn't form had to be faxed by GP.	
	Following the rules	H -'I just took it (referral form) home and rang up? And that wasn't good enough' 'I said, "Well, I can read it all out. It's written on the form," three lines and what was wrong with me.' 'They said the form had to be faxed by the GP…so I had to go up in the pouring rainy day, went back up the hill to the GP practice and said, "Oh, can you fax this thing through?" that was Thursday. And	

		so, I missed the next day's Clinic. So, I had to wait a fortnight for the next appointment. H - 'They said, so I had to'	activities, she is not afraid to create change, actively make alterations, if it gets her the results she is looking for. This could be described as Helens self-management approach, the more she knows about what is happening with her health the more prepared she can be to act, to speak up, to prevent further illness, and to protect her ongoing health and well-being. Helen self-initiated going to Senior's week at the integrated care clinic, motivated by the ability to get more data (blood test) and that it was a free service. In contrast to the 'no cost' service, she is happy to invest her time in going to see different providers at the same time for the same treatment. It is interesting that neither knew about the other. Self-efficacy or self-belief is something that comes to mind when listening to Helen's assessment of her abilities and actions and their contribution to achieving her health goals. It was interesting that in Helen's interview she was also at times forced into doing what she was told to do, e.g., with her referral form. In following the rules, it had consequences, delayed her progress. It is interesting that Helen said she 'didn't have a fax machine…' – I am curious that if she did have a fax machine whether she would have just faxed the form herself. I would not say that Helen was being compliant or deferring to authority – I get a sense that she 'had to do it' as she could not have the means to do another way. Waiting for Helen, although frustrating, was not a big concern. A sense of acceptance. This may be because she has weighed up the possible risks/ threats to her
	Taking charge Directing my self	H 'I felt like I hadn't really stuck to what they said'. H - Its gradually improving - mostly because of what I've chosen to do rather than what they said to do H so I rang and I said to them,' How to contact the nurse, what the problem was, what I was going to do'.	
	Explaining why	H 'went through everything'. H 'I got all the advice what to do and what not to do and all the rest ' H 'I got a treatment plan written on the sheet'	
	Missing (information) Not knowing	H 'I began to wonder'. H 'I didn't have a number to ring'. H 'I got mixed up. Couldn't remember' H 'I had to ask them to put the PBS number on it, because otherwise if it's not there, cost you a fortune' H The clinic sent me for a vascular ultrasound 'They said 'who's your GP? and I told them'. I thought it (results) should be coming back here (clinic). When I go to the clinic the results weren't there. They had to phone up – the results had gone to the GP – I didn't know. They don't give you the thing anymore - the report in an envelope – which was useful because you knew you had them.	
	Waiting	H 'had to wait a fortnight'. H 'thought I would wait and see; it was only 2 weeks till the next appointment'	

	Self-directing/managing	H ‘because of my common sense of what I’ve chosen to do rather than what they said to do’. H ‘I’ve actually been directing it myself, but all the help and advice and what to do& everything H ‘I know’	overall health were minimal – this may form part of her Health Belief Model (HBM) Helen noticed when things were missing, she picked up mistakes, she preferred to know e.g., what number to ring, or to have a copy of the report – rather than leaving to chance. It was important to Helen that her health professional considered her needs, her prior experiences with allergies etc may have heightened this. Thinking before acting. I am not sure why Helen did not disclose. She may have been running her own controlled experiment. Maybe if they did know she was seeing both, they would excerpt their power and take control from her. Or it could be, that you do whatever it takes to get the results – outcome focused. By personal agency I mean that Helen is communicating her needs to others, excerpting her influence, advocating for what she needs, taking responsibility for the consequences. Helen collects and archives observations, experiences and information – data – so easily retrievable when she needs it next or to compare. In theming what being involved means to Helen, it appears that everything is connected – it’s a web, a system – coming back to Helen’s biology studies, it is like she has embodied the philosophies of her studies and see’s the world through an ecosystem lens.
	Questioning why	H ‘I ask questions’ H ‘so I asked’ H- ‘Anything I have asked has been answered ‘	
	Encouraging	H-’What are you doing to it? Oh, we’ll do more of that then’	
	Individualised	H ‘it feels very individual, not standard treatment’	
	Familiar (Just like)	H The GP treatment is the same, it’s no different from what the clinic was doing I’ve been having this wound treated for over 12 months.	
	Concealing	H I’ve been going to the GP all the time anyway H ‘the GP thinks all I’m doing is putting on the steroid lotion’	
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Knowing why	H ‘Being involved, I would interpret that as you had choices, and you know what’s going on. You know why’	
	Self-advocating (personal agency)	H GP didn’t want to send me to the specialist as they specialised in that field. I said, ‘well look they have told me to go, and I have to go back, and I haven’t been?” GP said, ‘Oh all right then’. H I want to know why, particularly if it’s not working, I’ve got to do something you know	
	Applying prior learnings	H I’ve sort of learnt a lot. I recognise sensitivity when I see it. What not to do and to do	

		H I've had eczema umpteen years- since born. I am experienced in being allergic, sensitive to various things. I learnt about being allergic'	Everything she does, her involvement, is connected. She starts from what she knows, and then builds from there
	Thinking ahead (planning)	H 'I've got the trolley (to carry things in). I've got it all in a plastic bag (GP documents). I photocopied before I came, so I've got a copy'. H 'I've got the trolley because the bag's so heavy. And its late-night shopping tonight' H 'Plan route to walk from bus (front of hospital) to clinic, considering my legs are swollen, stairs, hill, cars, traffic, am I carrying anything 'The shortest route is the diagonal, it actually works out quicker to walk longer'	
	Weighing up risk/benefits	H 'And hospitals are where sick people are [laughter], and that's where--I know I get sicker when I'm visiting the doctor. The last year, I put off getting my flu injection, so I didn't have to sit amongst all the sick people'. 'I waited a while, a couple of months.' 'It's probably safer (at home) from infection'. 'I've been more mindful of it since I've been getting older'. H 'I'm a bit of an analytical person, I ask questions'	
	Committing	H 'It's still a fair walk' (repeated twice)	
	Managing my time	H 'I arranged my clinic appointment for 9am as I had to be in the city at noon, they had said 10 o'clock, that would be stretching it a bit'	
Significance -What mattered most to you about your integrated care experiences?	Knowing	H 'Knowing something could be done'	

	Systematic (intentional) approach – professional expertise	H The GP is not good at diagnosing.... It's just a fishing expedition, defensive medicine, whereas a good diagnosis and the right treatment is better.	
	Useful (applicable) information	H 'I could use this information to read all the labels, backs of bottles'	
	Explaining why	H 'I realise I am a bit of an analytical person. I ask questions. I want to know why, particularly if not working & I've got to do something else. They gave me the reason why I could not use canola oil instead of olive oil - they gave me samples to try myself'	
	Having choices and reasons	H 'the fact that they thought of different options. What I couldn't use and what I could… To know the rationale behind (not just treat surface symptoms)	
	Personalised for me	H Discussing and talking, my previous GP 'I had to ask, 'what was that for?' Try this try that, not personal, she (GP) wasn't that experienced with me'. H 'and I was asked'	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Testing options	H- the sample of creams - being able to test them to see if allergic	What was useful to Helen at home is aligned with her science logic, drawing on what she can observe and record, and learning from what does and does not work. This approach allows Helen to customise her treatment within the options. Good use of money continues to be important. This is the first time Helen mentions feeling safe related to 'knowing'.
	Saving money (not wasting)	H - saves money on wasting money on products that you may be sensitive to	
	Written plan	H – having a treatment plan with instructions written on it	
	Feeling safe	H -feel/ know what I am doing is safe	
What was useful when something unexpected happened or you were worried about your health?	Seeking reassurance 'What should I do'	H - First visit 'I got this allergy problem with this stuff, what should I do? I thought, 'it's not important'. I didn't ring as had an appointment in 2 weeks. It takes	This situation revealed Helen's vulnerability if her system fails to provide her with feedback – Helen appears confident in her theory and approach, to take self-initiated action – she also recognises the risks and

What happened		about 5 days & I waited to make sure that's what was happening (that was the cause, Yeah) H - after the second visit, I rang as I could not fill prescription, I needed to get an alternative from the chemist. I haven't heard back. They were either satisfied with what I said. The fact I don't know. I don't know if they got the message. My skin was improving, I thought 'what could I do?'. It was a five-week interval - if 2 or 4, but 5 weeks. I thought well I cannot not do the right thing for five weeks. I thought I better (still be) safe, I'm not using what you think I am using.	had calculated that an extended period of time without assurance was compromising her safety. Even though Helen did have a treatment plan, it did not provide a response for when the plans changed (e.g. could not fill prescription)
What was useful	Frustrating - Flying blind – (not useful) Helpful if I'd known	H - What would have been helpful, was if someone took my call. I told them what the problem was, discussed it and said 'well….'They just took my details & where they could contact me if I wasn't home. I provided my daughters details because she is home all day. It would have been helpful if I'd known that they knew 'got your message, you're doing the right thing'. H 'even an email, just send an email saying, 'Fine Helen, continue with what you're doing'. I don't know whether they know.	Helen expressed her frustration, that her plan did not work e.g. in providing her daughter's details, and that the system failed (e.g. they did not call back) – Helens analytical thinking pattern was being tested – she recognised the error, however was uncertain with what to do after that
	Giving *them* feedback (the irony)	H - I did get a follow-up call from seniors' day -asking was it a useful referral - I said yes, I've gone to the clinic. I thought, I've already been twice already'. I said it was useful & all this kind of thing. I told them (about not getting the call back), they said 'oh that's useful feedback'.	Helen thought it was quite humorous that the clinic called her for feedback, and found her feedback useful. She felt they should have known (had a system) that captured that she had been a couple of times. Helen's feedback to the service seems to be a socially acceptable response rather than reflecting her feelings or experiences
	Convincing myself I'm fine	H- she's now got posters for the clinic and it's got a direct number on it - helpful. It would have been reassuring to know that they knew what I was doing & it was OK to do what I was doing because it was all like	Helen reflected on the improvements made that she relates back to her feedback. There remains a level of uncertainty as to whether she should have taken different actions

		what I decided to do? 'Maybe I should have?... but the fact the skin is improving'. 'I thought well there's nothing more I can do. Its working fine. Its fine'.	
	Thinking of others – what if	H - but other people who haven't been used to these things (being sensitive), It would have been a bit disconcerting 'What do I do?' Go to the GP & the GP would have thought 'well it's not my treatment. What do I do?'	In expanding her thoughts into the ecosystem, Helen then started to think about the impact on others and the possible consequences
Actionable - What actions have you initiated at home that will promote your health?	Engaging (mind & body) in intentional activities	H- I do activities - directed at health, physical health, like exercise classes or brain type things. Not just wishy-washy things. Things that you've got to think and remember, learn, like dancing, complicated coordination activities. H- I've been going 4 - 5 years, you can see some people deteriorate over time, people who go there are obviously actively engaged & regard themselves & are mindful - it seems to work	Helen's beliefs and actions continue to be guided by thinking like a system, and being intentional. Every action has a consequence - there are reoccurring patterns – Helen recognises that independence, which has been a strength of hers as a young woman, is now a vulnerability / risk. Helen is also observing changes in others. Which is helpful data for her. Helen takes action to both avoid waste and to learn/ discover new things, that could help her avoid future waste
	Investing my time purposefully	H- I go to Wesley Mission Seniors four days a week. It (the Mission) began in the '60's, it's based on testing, realised what people needed, now expanding. It's all purposeful. Social engagement, using your brain, keep going, keep you informed (guest speaker)	
	Avoiding deterioration (being proactive)	H - I initially went because of the activities when I couldn't bush walk - movement for mobility. I was at home, and I was still in my sleepwear at lunch time, And I was eating too much, and I was just, I was just turning to mush.	
	Building social connections	H- I went monthly for the activities & to keep engaged. Then I discovered it was the people I like, so I got to know people, and now these are the people that I like. Even in holiday breaks we go out to lunch. It's	

		become a social connection thing as much as an activity thing	
	Discovery learning	H- Highly exciting experience - doing things you’ve never done, revelations. - you’ve got to be co-ordinated; you’ve got to remember; you’ve got to learn.	
	Volunteering	H - I volunteer with the council, propagation ministry, twice a month.	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Staying mobile	H- mobility definitely, especially now I know what the problem is with the legs. I think that I will gradually become less mobile.	Helen is actively thinking about the future, she knows change is coming, she is collecting data, ensuring she has backup data and thinking of strategies that could avoid or mitigate the likely impact.
	Thinking ahead	H- I don’t have a car, my daughters the only family apart from my son who’s not able to help. Always thinking as to how this is going to impact on my mobility.	
	Access to information	H- I have a regular chemist - been there for decades - not important to be a regular - I go there because they’ve got everything on a computer. You know what you got last time - you then have options to change or choose another.	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Knowing the facts (having a diagnosis)	H- The Fact that they thought I might have poor blood flow… and that was thinking … that was good.	To Helen, Integrated care has served her need for evidence and knowing what is available that is useful for her planning – now she knows it is there and trustworthy – that is reassuring for the future.
	Having options	H- I know the clinic is here, I know I have bad circulation, they have provided suggestions.	
	Putting plans in place	H- Has made me think a bit. Think around what plans to put in place, making changes, what is safe. I don’t think I am typical for my age group.	
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care?	**What matters** My thinking and actions will result in benefits for me.	**Measure** Test / compare against personal theory. Compare against data observed from others.	Helen is constantly evaluating against her theory in action - calculates consequences / scenarios -

Measuring **-** What did you use to judge effectiveness	Why - I am analytical. I like to calculate, I like data /evidence. I am being responsible. I am not wasting my money or time.	Feeling responsible – I have avoided possible consequences. I have kept safe	Compares against others - if others got benefit – that’s a form of validation- this feels responsible for Helen
	I have received a ‘Good’ diagnosis. Why? Decisions are more robust if they have followed a structured scientific approach. Need facts and data that is able to be stored and drawn on later	I can see evidence of a systematic approach. Data in storage – accessible / benchmark Self-assessment I feel confident. I have a level of certainty.	Helen feels more confident if she has evidence of structured problem-solving approach – gives a level of logic - certainty - so she can plan her next steps – store the data away to draw on later.
	I can trust what I know. Why? So, I know I am investing my efforts & resources appropriately. My calculations can be confirmed (its more than just being reassured)	Self- assessment Trust, Trustworthiness – people, information, processes – I have assessed the risk. Access to information – phone number/ documents/ data. I have been efficient – avoided waste.	Helen likes to know, it’s more than reassurance – she needs to trust the information given to her as she is going to build it into her planning. Avoid error, which is waste & risk to safety
	I know what I have to do for me going forward.	Relevance - My plan and options are personalised to me	Helen needs enough familiarity to feel like she can do it herself – do what is needed - take action & responsibility. Helen has a belief that she is not like others, ‘not typical’, important that any plan is customised or personalised options
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1. The need for initial referral form to be faxed by GP Surgery to be accepted	2.Clarity re contact details and reassurance that you will receive a call back	3.Recognition that everything has a cost, need to ensure PBS form completed, access to samples helpful when have allergies
	4.Uncertainty re test referral/ results process – results went to GP rather than Clinic		

Table L3: Gloria's Experience of Integrated Care

Attribute Coding: Gloria's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Gloria (G)	Date: May 2017 Location: Diabetic Clinic Arrived: drove own car Interview Length: 57 mins	70-75	Female	Own home, alone with dog	Retired Registered Nurse	Art (painting) Visiting friend in aged care facility Attending Art exhibitions	Orthopaedic (specialist). In-Patient referral extended to Out-patient	approx. 4 months as an out pt	Wound Clinic	GP Rheumatologist Orthopaedic

Process, In Vivo and Values Coding: Gloria's Transcript

Sequence	Codes	Glorias voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Doing what has to be done	G - "Well, they're kicking me out. I've got to go home or go to a nursing home." And he said, "You're not going to any nursing home." He said, "Will you go to xxx?" He said, "There's a nurse out there who is excellent at healing wounds, and I want to send you out to see him. Will you go out?" And I said, "Sure."	From the beginning of our interview at the Diabetic clinic, it was apparent that Gloria was at ease in the clinical environment and with clinicians and hospital staff. Gloria worked as a registered nurse in the emergency department up until her retirement, and had a well-connected clinical network, who she was happy to call on as required. There was a sense of an ethos of mutual respect. Intentional is a word that comes to mind. Gloria had done and was continuing to do everything within her control to orchestrate. people and services to achieve her end goal – that being hip surgery. I could imagine Gloria running a busy Emergency Department. She was drawing on her communication skills and ability to bring people from diverse backgrounds together to focus on a shared purpose/ goal – that being Gloria.
	Problem solving	G - I could come and see the Wound Clinic as an outpatient because there was a disabled spot right outside the rooms, and if not, the car park was opposite. They failed to tell me that I wouldn't be able to walk from the car park to here. So, we've had to address that problem of getting a spot, which has been a bit hard at times.	
	We have a thing – mutual respect	G - I chose to have him (nurse) do this, and we have a thing. Himself or me are the only people that touch this ulcer.	

		G - Not just slop things on & say 'that's going to be fine' he describes to me, explains, he asks me, I have a say	A tension was emerging about power and control and about feeling vulnerable and exposed. There was a sense that Gloria's actions and behaviours were being driven by her sense of vulnerability, rather than a need for power or control. The more vulnerable she felt, the greater her need to control. Her experiences of integrated care were providing Gloria with the data and information, she needed to stay informed, make changes, and act, to ensure the end goal remained achievable. Gloria gives the impression of being motivated and having self-belief in her ability. Her expectation that she will achieve her goal, is mostly high, with some brief periods of doubt, which she problem solves her way through, designing work arounds, being adaptive and innovative in the moment. Gloria's descriptions, create an image where she is placed at the centre of her health care experiences, at the clinic and at home. I was surprised by Gloria's confidence that her different healthcare providers 'knew' what was happening, even though they did not talk. I am uncertain if she was bridging that gap, or this was her related to her belief/ trust in the health system. 'If you think things out you can usually get around it …You know you've got to set things up'. Glorias comment, raises in me the relationship between Gloria's reasoning, behaviours and the specificity of her actions. It bought the Theory of Reasoned Action and its extension, the Theory of Planned Action, to mind.
	Explaining	G- (nurse) tells me how it is going because I cannot see, got to be my eyes, to tell me how it is going. Explained to me how it was	
	Co- Contributing	G - When making changes he'd say, 'how did that feel' He'd ask 'was that alright last time'	
	Protecting	G - Nurse wanted to take dressing down to check & swab when admitted to hospital by GP. 'You're not touching, I'll go home'. 'I managed to put them off. So, they rang the Clinic - they still stuffed it up'. G - There is no way I'm going home (from hospital) on Thursday, I'm going home Wednesday morning to see the Clinic, last day before his (nurse) holidays'	
	Taking Charge	G- The clinic was worried about what would happen when (nurse) on leave. I knew x (friend) would do it the right way (she is a trained nurse). She said, 'I'll just do whatever you say' She does what I say. She'll do what I tell her. I trust her to do it	
	Silos (bridging)	G- 'They (GP & Clinic) haven't talked, but they know'	
Meaning - What does 'being involved in your integrated care experience' mean to you	Knowing 'what's going on'	G - I won't take anything or do anything unless I know what's going on	
	Keeping informed	G - I don't think anyone should blindly go into healthcare. They should have it explained to you, so you know what you're saying yes to	
	Prioritising (time management)	G- I rest as much as I can, put it (my leg) up. G - If there is dust around (the home) I don't give a dam because it's more important for me to rest, to put my leg up, to get the ulcer healed	

		G - I might go back to bed with the paper. I'm lying around trying to get this healed. Putting it up as much as possible G - I haven't even had breakfast (so could get to clinic appt)	Gloria has confidence or trust in her theories, her meaning, and her involvement is both considered and creative.
	Thinking ahead (planning)	G - I have the paper delivered. People across the road put (paper & mail) up on the verhanda - so I don't have to go down 3 steps - I've only got to go to front door & pickup. G - I've trained the dog - to wait till I've gone to the toilet (in the morning)	
	Investing	G - I invested in an electric chair - so I can put leg up when I sit down, so I have a change from the bed.	
	Committing (whatever it takes)	G - I've got to walk on my bum to the front verhanda, get to the steps, there is a rail, so I can pull myself up G - Everybody thinks I am mad I've been saying I'm going to dig a hole in the backyard	
	Taking responsibility – Avoiding	G- The beds probably better, but the chair gives me a break - off pressure points. G- Took tablets to try and ease it off (the pain) - because coming to the clinic G - Takes me a long time. Everything is slow, I do it slowly too, so I don't fall. If you're going fast, you've got no chance of saving yourself at all. G- I go slow to make sure I stay on my feet, once I hit the ground, I can't get up	
Significance -What mattered most to you about your integrated care experiences?	Monitoring progress – healing	G - 'look and see how we're going' 'see how it's progressing' 'he takes it off & it's improving'	
	Expert knowledge	G - You get an educated explanation, so you know what's going on	

		G - The only one that's got it starting to heal. His (nurse) knowledge, knows what he is doing. Fantastic, because he is fabulous	It was important, and expected, that her experience of integrated care contributed to progressing her healing, to enable her surgery, which would reduce her pain, and allow her to engage in activities she enjoys. These connected milestones could be seen as Gloria's 'value chain' – system of connected consequences. Access to expertise and knowledge was an accelerator, as it complemented and refined her own efforts.
	Progressing – meeting deadlines	G- It's not just healing a leg ulcer. Its healing a leg ulcer so I can get this hip done. I have a tentative date to get my hip done. I know whether we are going to make the date. G - I got to get this hip done because the pain is horrendous. 'I yelled with pain'	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Finding comfort from pain	G -When the dressing is done well - Does it hurt? Of course, you can feel it - sometimes the treatment can sting for 24 hours. I know when the Integrated Care nurse puts it on, that it will settle and its comfortable. If it's done badly, can get very irritated and I need to rip it off. G- The more irritated the ulcer, the less sleep I get, it just impacts on everything G - the Integrated Care nurse or me are the only people that touch the ulcer	What was useful to Gloria at home was that she knew what 'a dressing done well' let like and who she could trust to achieve this. Gloria demonstrating her self-awareness or perhaps bias to expertise – in that she 'does not suffer fools gladly' –
What was useful when something unexpected happened or you were worried about your health? What happened	Nothing reported – had a plan if it did	G- Nobody touches it, I told you, if needed I would ring the Integrated Care clinic. I have their numbers. The GP is open Saturday morning and there is always the hospital, as a last resort.	Gloria has a plan and options.
Actionable - What actions have you initiated at home that will promote your health?	Setting up back-up plans 'fail-safes'	G- I have a mobile phone. I've got a little thing I can put it in if I'm going out the back. In the house I have five phones.	Glorias actions are linked to her belief in that if she plans well, including options, coordinating others and

		G- My neighbour puts out and brings in my garbage. If he hasn’t seen me, he comes in. If the back door is open, he knows I’ve got up & I’m ok. If not open, he will come looking for me. If I fell, I may have to lie for a couple of hours, but I know someone is going to come.	monitors vigilantly assisted by reliable data, she will likely be successful. I am imaging this approach has been successful for Gloria, and maybe rewarded before Gloria is highly motivated and intentional – I feel confident to say that Gloria is leading and managing her health. Health is everyday life, Gloria shares that she is aware that she cannot achieve her Health goals alone, she needs to strategically engage others. Gloria gives of an aura of self-determination – believe in self – she is also empathic about the needs of others. Gloria is methodical and thorough, thinking in the present and planning for the future – or example she makes choices, initiates changes, trains pet dog, organises neighbours, misses meals, invests in motorised chair, planning renovations, organised disable carpark, uses medical networks / relationships to secure access to care. Self-determination – believe in self.
	Managing risks	G - I have a message machine ‘if you ring and I’m home I will ring you back, but you’ve got to leave a message’. The message is a male friends voice. I deliberately did that, so people think a male is in the house.	
	Investing wisely (for the future)	G- I’m in a fortunate position, I haven’t got a lot. I’ve got a few dollars. G- Going to have renovations - renovate the bathroom. I want to get a carport, so when I open the doors to get out (of the car), I’ll be undercover all the way to the house. G- The other plan is I am going to change cars to an SUV. Its higher, easier to put things in the boot, to get in and I can get a ramp for loading electric chair	
	Maintaining social activities	G- I’ve bought an electric wheelchair. I know I am never going to run again. If I want to go to the shops, it might be easier. G - I like to go to the show, if I’ve got the wheelchair, I’ve got my seat, I don’t have to look for a seat.	
	Maintaining independence (practical)	G - they will put my washing on the line if I call, but I don’t call them. I drape the laundry on the back verhanda. G- I only like drive through when buying food, getting out of the car is not easy. G. The pharmacist, George, I still go to the same place. I ring him up so he can have ready. I park in front, toot the horn, he brings out to the car.	

	Keeping abreast of what's new & innovative	G - I'd like a wheel machine that I can stand up on, take me everywhere I want to go, so I don't have to walk at all. They haven't invented one that is safe enough. Doesn't take up much space. Would be good for me in the long term.	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Setting things up	G - You've got to set things up, G- I have to work out a plan that I can do it myself. G- It's not about being independent. I have to be independent because I haven't got anybody. Even without having a say (which is important) I don't have a family that are going to help me. I have to do it myself. G. When I was in hospital last time, I asked, 'at discharge what do I do?' The doctor replied, 'if you would like, you can come to my clinic'. 'Yes, I will'. Gives you a leg in, I don't hope to go there, but you have to be practical	Gloria has been consistent in what is important and her expectations of herself and others – Planning, relationships (people), information (data) 'I have done what has to be done'
	Knowing them - Maintaining relationships	G. I know them (clinical staff) all. G. My specialist doctor said, 'anything you want just call, I'll fix it for you'. I can check-in. He is knowledgeable, tells me options & impact.	
	Access to information	H- I have a regular chemist - been there for decades - not important to be a regular - I go there because they've got everything on a computer. You know what you got last time - you then have options to change or choose another.	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	'I can call on trusted people when needed'	G - What matters is getting the hip done. As the ulcer is getting better, the hip is getting worse.	For Gloria, her experiences of Integrated care have provided her with access to the expertise and knowledge she required to progress her plan for surgery, which is critical to her future health. It has

		G - Because I have a tentative date to get hip done. I know whether we are going to make the date.	also grown her network of trusted health professionals, which is integral to managing any future health threats
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** 'I've everything set up – I'm OK'. Why? 'I can do it myself'	**Measures** Self-assessment I can implement my plan effectively. I am confidence/ feel peace of mind. I can call on trusted people when needed. I have strategies in place that have or will prevent or avoid complications or inefficiencies. I am on track – progressing towards my timelines & goals. My pain is tolerable / level of comfort	'I have to work out a plan that I can do it myself'. I can access the medication/ supplies / support I need. Able to make choices/ accept consequences – I have managed my time. I have access to the information/ expertise required to get results. I can live a more productive and comfortable life. I cannot afford to get sick or have mishaps - not good use of my time or resources.
	'I know what's going on'. Why? I have access to knowledgeable explanation and reliable information that I can use to monitor my progress and adjust.	Self-assessment I have a say – I feel included. Proven reliability of information sources I feel a level of certainty that I understand what I need to do (knowledge has been transferred from the expert to Gloria) The data is useful for my timeline / plans. My level of pain/comfort experienced	Observation – be my eyes, information – provide knowledgeable explanation, Information is correct, trusted and can be taught to me - I can be educated/ instructed / coached – so then I know. I can add to / complement from other sources.
	'I have access to what I need'. Why? 'I have to be independent.' I am not a burden to others – put extra stress on others. 'I haven't got a lot. I've got a few dollars.'	Self-assessment Comparison to previous health experiences and experiences in healthcare Access to parking Able to access people/information. I have invested wisely. I can visit my friend and engage with social interests. Level of pain / comfort experienced	Previous medical treatment and support services received - did I have access to everything I need - information/ supplies/ support - Are the instructions clear - can I access/ ask questions when I need to
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	None offered		

Table L4: Lucy’s Experience of Integrated Care

Attribute Coding: Lucy’s Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Lucy (L)	Date: Oct 2017 Location: Integrated care unit Arrived: drove own car Interview Length: 69 mins	65-70	Female	Own home, with Husband	Retired Librarian	Reading Regular exercise Social activities Volunteering 2 Daughters	Self-Referral (recommended by family)	visited 3 times over a 4-month period	Skin cancer clinic	GP retired – now does not have regular GP

Process, In Vivo and Values Coding: Lucy’s Transcript

Sequence	Codes	Lucy’s voice supporting the code	Researchers’ interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Self-initiating	L - Suggested by family member L - It existed; I could try	Lucy description of her experience of integrated care was shared in a reflective manner, drawing from her previous experiences to situate what it was like for her. There was a sense of tentativeness, sense that Lucy was still processing her thinking, making sense of her experiences. Lucy’s description was both deferent to expertise whilst also being a self-confessed cynic. This was probably not what I had expected in the context of Lucy sharing that she was a retired Librarian. On reflection my bias was that I had expected that Lucy would have neatly categorised and shelved her experiences, providing a succinct synopsis. I interpreted that Lucy’s concern of not enough time being given before a decision was made, was related to comparing with her own mental processing, that includes a series of deductions, not ruling anything out
	Good hearing (thorough)	L - I did feel with my first visit that I got a really good hearing L - Previous HC exp always so quick, felt it was a little bit rushed. In & out in 5 minutes	
	Convincing	L - I went away feeling confident. I got a better deal than where I had been going. L - Previous HC -I needed more convincing every time I’ve been there that everything was fine	
	Negotiating treatment	L- I think I had choice - there where a few areas I thought were problematic. I asked if they might be able to check & remove. In the end we negotiated a bit & they did take it away.	
	Appraising	L - I had to learn that they know what they are looking for. I was slow to realise it (speed) comes from knowledge.	

		L -? but has that (confidence) come because they actually found something. They did take the time. They did find something. Or is that co-incidental?	unless it has been thoroughly examined, discarding irrelevant information (or as Lucy says ‘rubbish’) along the way. Lucy was particular about what she assessed as ‘authentic’ information, for example “very little use for the chemist, it’s not an information source for me, it’s more a business’. I found Lucy’s unpacking of what being involved in her integrated care experience meant to her to be insightful. That involved meant to her thinking about it - not thinking about and just doing, thinking and not doing. Combined with Lucy’s reference to her approach as ‘a bit crazy’, and laughter. Which is situated in the context of Lucy’s family and friends working in health care, having medical knowledge and her overall good health, which means she can take a ‘fairly relaxed’ approach. A pattern was emerging in Lucy’s unpacking of what involvement meant to her – the pattern went ‘wait for a problem’ ‘panic’ ‘accept or decline’. Some assumptions or maybe Lucy’s heuristic rules were emerging. • Speed (in diagnosis) comes from having expert knowledge. • Only significant/ major health problems require you to be ‘really out there, asking questions & getting second opinion’.
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Thinking & observing, not doing	L- To me, that means maybe thinking about the sort of things-- it’s not how I am involved, but it’s probably something I see in other people. Now, that’s a bit crazy [laughter].	
	Dwelling	L - Involved - in one way relaxed, in other ways aware of the possibilities of what can go wrong - maybe even dwell on them, but never do anything	
	Modelling others	L - I see other people, they anticipate things, they actively go and be checked. L - I like to look at other people & try & grasp what it is that keeps them good. I watch people, try & take on board - I can do that	
	Waiting	L - my involvement is that I’m slow off the mark. I wait till something happens rather than thinking ahead, sorting it out before a problem. L - I’m probably a bit accepting of whatever might be thrown at me. I’m perhaps not as questioning as I could be	
	Accepting Doing what they say	L – I don’t have medical knowledge, so I accept & basically do what I am told L - I haven’t had a lot go wrong. I’m a bit blasé or a bit cynical. It’s that sort of leaving it in their hands	
	Going with the flow	L - I don’t think I’m hugely positively involved in my health. Comes from being healthy - fairly relaxed. L - My preparation is more logistics, not physical or psychological. I’m a happy walker, I would incorporate that into my timing.	

		L - My health problems have been insignificant - if you're dealing with major health problem - I think you would be really out there, asking questions & 2nd opinion L - I am not a good GP goer as a general check-up - only would go if something concerned about. L - A bit of a sixth sense, not actively conscious. I'm probably just laid back & going with the flow. I don't think I'm thinking ahead or anticipating	• Accept and act on medical knowledge – they know best. • Only go to the GP if there is something you are concerned about – or you will be considered a worrier 'Worriers will turn up on the doorstep everyday'. • Other people are more together than me – they have the knowledge, anticipate, active – If I watch/learn/adopt what works for others, I will be able to avoid too.
	Panicking	L - my part of involvement is I will wait till a problem happens & then panic. Panic & go to someone, & then blindly accept what is thrown at me. L - I jot the date in my diary, then panicking the day before realising time to go there & then negotiating how	
	Deciding (not to)	L- I may visit a doctor with what I think may be a problem & then decide not to go with the advice. L - "(Doctor) I'll write you a prescription & I've gone away & not filled it? Is that involvement or not involvement. L - Reading, a huge part, love it, happily borrow, being a librarian. I'd peruse, glean information because it interests me in the first place. Well aware of authenticity, if its academic. I happily discard / dismiss what I think is rubbish	
Significance -What mattered most to you about your integrated care experiences?	Reassurance – Professional (They've done their job)	L - From the Doctors, for whatever you've been there for, that they have done their job thoroughly. You are (probably) safer.	For Lucy what mattered most was preserving her peace of mind and her desired reputation or social identity/ image (how she wants to be seen and perceives others to see her)
	Reassurance – Peace of mind (I don't have to worry)	L - So that I cannot play it over & worry that there's much worse than it really is. L - I can be easily made to feel that you're alright, you've had your time, we've looked at you. I need 'look we've really had a good	That she had access to expert information, there has been a thorough assessment, Lucy has permission to come back, and that she can manage her anxiety and take proportionate action.

		look. There's nothing there. Then I can relax & forget about it. I get anxious.	
	Reassurance (I can come back)	L - That's its ok to come back. If there's a problem or need. I like to know that if you might like to come back I can.	
	Permission to come back. (Saving face - avoiding being seen by others as a worrier)	L - Knowing that you can go back if you need to - is important because 'I don't want to be seen as one of those worriers who turn up on the doorstep everyday'. It comes from how you want to be seen. I know they probably don't remember you from a bar of soap.	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Being Proactive - protecting skin (self)	L Protecting skin - Probably the single most important thing that I am doing L Apply sunscreen L Wear a marvellous little hat L I got the message loud and clear that I will be visiting the clinic in the future [laughter] because of the fact that they could see that I've got plenty of sun damage, so that was brought home to me.	What Lucy has found useful at home suggests that she feels reassured and is adopting protective and proactive behaviours – this suggests that she has progressed through her wait, panic, accept / decline stages of change – and has accepted and is actively adopting a different mindset / behaviour.
	Taking preventative action Protecting family (others)	L I'm also yelling at my husband who rows- that's new L Before I didn't care, that was his business L But now I am saying you got to do it; you've got to	Lucy is also applying her mindset/ believes to protecting others – shifting from the free-flowing approach to an active (somewhat intense approach, which is aligned with her 'panic' stage of change)
What was useful when something unexpected happened or you were worried about your health? What happened	Initiated action	L Biopsy visit was unexpected. They gave me all clear - then went out and someone said, "what's that?". At home I looked and thought there is something there. The next appointment was six months. I'm feeling that I'm being over cautious, worrying about being silly about it.	This was significant for Lucy, in that she initiated action (after a brief waiting period) and felt assured that it was OK to come back to the clinic for assessment. Even though it was still a worry to Lucy as to how others 'saw her', she was able to act on her worries
	Anticipating - feeling OK to act on worry	L I'm feeling OK with it because it's that feeling that it is OK. She (I/C) has given me that in saying, "we don't expect to see you	

		but you're welcome". Anticipate that it could be something - go & do something about it. I've actually learned that it's OK	
Actionable - What actions have you initiated at home that will promote your health?	Protecting	L Wear hat, put on sunscreen	
	Maintaining Health	L Keeping fit generally - keep joints moving & exercising L Eating healthily	
	Keeping mind & body active	L Keeping involved in things, things that I read about, hear about, keeps you moving L Keeping involved psychologically - Relating to people	
	Socially connected	L Family & friends essential L Connections to other people L Social as well as physical - exercise then lunch with friends	
	Connecting to purpose	L Involved in something that matters to you L community is important L I volunteer - helping mothers & baby in crisis - much more excited than ever dreamed of	
	Staying up to date	L Important keeping up to date on current affairs / news L I attend training & in-services (volunteer role) L I have a cousin who is an RN & Husband a Dr - I have a hotline to her, they just have (health) knowledge 'I would never have thought of'	
	Open to learning & new ideas	L I speed read. Pull out things that are relevant - invited to a lecture - then I went to the library & read the book - case studies - had a range of ideas of what kept them going because they didn't want to just retire - I'm now thinking in that way	
Future – What might happen? What do you foresee or hope for your future health?			

Predicting What is likely to be important for your health, at home, in the future?	Anticipate – Pro-actively avoiding	L My vision is not having to spend hours visiting Doctor surgeries L I want to do everything I can to avoid that - hoping it's not part of my future L I am hoping not to be using Health services at all. L Keep away from mental health services or knee operations. L If I slacken off & put on a little weight - I can really feel the difference in my joints & general well-being.	Up to this point, Lucy had described herself mainly as an avoider - then panicker- which I had interpreted as a negative frame of reference. She looked mainly to others, watched, and copied what other people do – which I had interpreted as a passive approach. In our conversation re future, Lucy provided insights into what was most likely her motivation and influencing her experiences. I reflected on whether I was being bias in interpreting Lucy's worry, panic, avoidance as negative, if I reframed her worry & avoidance to being an anticipatory response, it then took a more positive frame. I reflected on & discussed at supervision, exploring my sense-making, and binary categorising into positive & negative. Lucy had helped me to deepen my awareness understanding of my own assumptions & heuristic rules
	Keeping moving	L my mother is 93… she's got a whole range of issues. And I think, "Well, why?" She's obviously got longevity… but she could have been physically much more able if she'd concentrated on keeping everything moving well. Yeah, so I'd like to look at other people and try and sort of grasp what it is that keeps them good.	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	It's OK	L Knowing you can go back if you need to is important L you can go back - feel you've got some sort of continuity with your history - they have some sort of background of who you are, why you are	Lucy's experience of integrated care has left her feeling Ok to come back If she is worried or wants to check, that that is Ok, indifference to her plan to avoid all health services or waiting till she has a major health concern. They know her, who she is and is not - avoiding being labelled as a worrier
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** I am avoiding further, future illness or going to Dr	**Measure** Self-assessment – 'I am doing what I see others are doing'. 'I am initiating preventative action for self & others'	'I see other people, they anticipate things, they actively go and be checked'. 'I watch people, try & take on board - I can do that'. 'Protecting my skin is probably the single most important thing that I am doing. I'm also yelling at my husband - that's new.'
	I have what I need to make considered decisions / choices about my health	Self- assessment – I feel confident in their (health professionals) assessment – 'good hearing'. I feel like I have determined or influenced decisions.	'I did feel with my first visit (I/C) that I got a really good hearing. I have had to learn that they know what they are looking for.' 'I may visit a doctor with what I think may be a problem & then decide not to go with the advice.' 'I happily discard / dismiss what I think is rubbish.'

		I have assessed (using librarian skills) quality of information (or if I think it is rubbish)	'I asked if they might be able to check & remove. In the end we negotiated a bit & they did take it away.'
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Finding another GP when yours retires 'I did have a GP - similar age, has now retired - you've got to click with someone. I still don't have one - if someone said who is your Dr? I would not have an answer. I think I would like a woman Dr'	2.Is the health system fit for purpose? 'My needs (health) may be totally different (to my mother's)' 'My generation is healthier, most of my circle are fit & healthy - not using the health system'. 'What will prompt change (for health services to be of use for her circle)?' 'Change takes time'	3.Acknowledging health & social inequities 'We are in a wealthy area, educated, resources, access to beach & bush.' 'I have heard about increases in obesity & diabetes – I see young people around here are active & healthy - seen them running with their prams & personal trainers.' 'I do go to shopping centres (in other suburbs) I'm aware I'm observing a different demographic all together'. 'I can see we're protected'

Table L5: Darren's Experience of Integrated Care

Attribute Coding: Darren's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Darren (D)	Date: Feb 2018 Location: Integrated care unit Arrived: drove own car (travelled 120km) Interview Length: 49 mins	35-40	Male	Lives with Father in family home	Part-time University qualified	Visits mother in aged care	Plastic Surgeon referral (specialist)	attending for six months	Wound Clinic	GP Pharmacist Specialist Gastroenterology

Process, In Vivo and Values Coding: Darren's Transcript

Sequence	Codes	Darren's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Covering all the bases	D - GP referred me to the plastic surgeon as the ulcer was not healing, I had an ultrasound & biopsy taken. No cancer & not surgical, so referred to the integrated care clinic. D 'I also spoke to my gastroenterologist about the treatment, and they suspended his treatment (medication he was already taking) so that it can be sort of weaned out of the systems, and hopefully, in that respect, it would start to heal a little bit quicker, which for all intents and purposes, it has. I find that my wound now is healing up quite well. So, I'm pretty happy about that, finally, after all this time since August last year to now. So, it's been six months.'	From our first contact Darren came across as being intentional, for example in how he was specific about the time and date for the interview, and openly sharing with me the logic behind his thinking. Darren was very interested in how I was approaching the interview and my research, sharing he was previously a university student, but did not share what he studied. He gave me the impression, from the way in which he quickly engaged with the interview questions, that he had spent some time reflecting and considering his responses. Darren mentioned several times the importance of being prepared, to 'ask questions'. He raised several times the benefits and preventative or avoidance properties of clear communication and having an open mind that is receptive to taking on board and applying new information. 'So does not happen again or minimise effect of returning ' What Darren expected, and believed to be important, were related to his ongoing self-management of his
	Pretty straight-forward	D – my initial phone call with the clinic I got the finer details. It was pretty straight-forward. It's very easy to understand. There was no ambiguity about it at all.	
	Setting up for the doctor	D- 'For my first clinic visit the doctor was not there, so the clinic nurse had a look and just suggested we do some compression	

		bandaging and just to make sure that we treat it, and manage it, and keep it clean, and do all the right things, and everything about that so that when I come back here for my second visit and seen the doctor they'll be able to do a little bit more of a thorough examination and see what type of treatment that we continue on with'	health and chronic conditions. He raised several times the importance of ease of access to expert knowledge, and to the information and supplies that he would need for healing his wounds. I interpreted this as reflecting his health belief model, which was underpinned by self-advocacy and self-management. 'What things do I need to do in order to improve'. Darren's involvement in his health care was strategic, focused on establishing relationships that would enable him to achieve his goal of healing. He mentioned his health care providers by name and several times referred to 'Information as key'. He described himself as methodical and gave many examples of how, in different aspects of his life, he researched and critically considered the information he had available and then calculated the risk, followed by taking planned action. Which he would 'follow to the 'T''. When talking about what was important to him, he tended to order and prioritize his thoughts, expressing his greatest need and then others in sequence. Darren referenced feelings of anxiety, of being overwhelmed and the importance of having peace of mind. He expressed a range of emotions from sadness to laughter during the interview. I interpreted this as being self-aware and emotionally intelligent.
	Receiving supplies	D '(the Clinic) provided me with some of the products that I needed in order to manage my condition for this kind of compression wound treatment, provided me with supplies and everything else that I needed, that was fantastic'	
	Establishing relationships	D 'Saw the doctor, her name was xxx' D 'The nurses name was xx'	
	Balancing support & service	D 'Took me about 45 minutes (clinic visit) which was a reasonable amount of time just to feel comfortable in the area, which I did feel overwhelmed with so much information, but at the same time, I felt like that I had received this much support and service about treating the wound and speaking to someone about it. So, the balance there I thought was quite good.'	
	Established processes	D 'And making appointments were pretty easy as well. I understand that this is a well-established institution, XX Hospital. I was born here so long ago'	
Meaning - What does 'being involved in your integrated care experience' mean to you	Being open minded & ready to communicate	D 'I think being involved in my healthcare would mean that I would have a really open, communicative relationship with the provider and myself, so that I've been coached or educated in what is happening, what the causes of it all are so that I can get a better understanding of how this may have occurred and why it's developed'. D 'the key thing is information.'	

	Asking questions and taking actions to prevent and improve	D ‘A typical example of being involved is just asking questions. Really. It’s pretty much all you can do because when someone has been diagnosed or having something, they would want to know as much information as they can’. D ‘speaking to a healthcare professional, asking questions about what things do I need to do in order for me to improve my life so that this sort of thing doesn’t happen again or minimise the effect of things returning.’	
	Accessing a qualified professional	D ‘it gives a little bit more peace of mind knowing that someone is there to help, and they know what they’re talking about. I think that’s a crucial element of it.’ ‘Making sure that someone is highly qualified in a special field such as this so that the best results can come from it. You just can’t have any person off the street saying, “Here’s your stuff. Go about it. Do whatever you want, and then come back and see me.” It just doesn’t work.	
	Making decisions	D ‘It’s just self-management of my own time. My own schedule’ D ‘It’s really calculating how much travelling time that I would need to require to get here.’ D ‘Due to this, my other medical conditions, my financial situation, I wasn’t being able to live up here, so I had to move back home with mum and dad’. D ‘But if one sits down and just methodically works through what needs to be done, I think it’s pretty straight-forward’.	
Significance -What mattered most to you about your integrated care experiences?	Getting results	D ‘what’s the most important is to get the end result, making sure that I’m healed’	

	Sharing responsibility- Given the correct information to act on	D ‘it’s worked both ways. Obviously, the healthcare professionals need to give me the correct information, so that I can undertake the correct methods of treating and managing my wound, so that the best possible outcome is achieved. So, 50% is on the clinic. The rest of it’s on me. So, if I do everything right by the book, from what they’re telling me and I can see the results at the end of the day, fine. That’s what I want. D ‘And it’s not going to be a matter of magic, or anything, or luck, or anything like that. It’s just a matter of them telling me what to do, making sure the information is correct. I follow that to a T, and if everything sorts out, perfect. It’s all I want.	
	Timely access to expert knowledge	More importantly, I think, is having someone there to talk to for a number of reasons. Number one, obviously, for the immediate treatment for it. Number two, where people can feel a little bit more rest assured, even more, peace of mind knowing that the people that they’re talking to know what they’re doing, having immediate access to them, and being able to answer all and any of the questions that they may have.	
	Access to experienced professional	D ’obviously, there’s a lot of anxiety. There’s a lot of thought going through your mind thinking, “Okay. Yeah. This is pretty serious what we need to do.” So being able to have a professional there who knows the job inside out, upside down, back to front is really important because, again, the key thing here is information.	
Now – What’s happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Knowing I am doing the correct thing	D- ‘being educated on what needs to be done and coached on how needs to be done’.	What was useful to Darren was related to his belief that the information exists that will assist him in healing, that he just needs to access it from the expert sources

		‘Doing the correct thing’ ‘trained in caring for the wound’	and diligently follow the instructions. This will ensure he is ‘on track’ and helps with his calculations of progress and any risks ‘I can’t afford this to happen on a frequent basis’, ‘I cannot afford to get sick’. Having key words or knowing reliable sources are also helpful for doing his own research. I have interpreted that Darren believes there is a right or correct way of caring for his wound, and that he ‘just’ needs to be trained how - ‘correct information’ ‘instruction manual’. If he has the knowledge and the tools, he can take responsibility (do his bit) to prevent and /or improve his situation. If he is unsure, he knows how to go about finding out
	Having instructions	D- ‘having a guide - in the event I can look through & make sure I haven’t skipped a step - my instruction manual - definitely useful - probably the most useful’	
	Feeling prepared	D- Organised, with ready access to supplies and information, ‘having the materials, like bandages’	
	Having access to information	D – ‘I have the resources, if I need further info I can jump online & find out all I need to know’. ‘Finding out myself’ D- ‘I know who to call’. ‘Someone is there to help & they know what they are talking about’	
What was useful when something unexpected happened or you were worried about your health? What happened	Unmet expectations Being let down (disappointed)	D- Yes, on the second visit we discussed pain management control. Endone was suggested and the Doctor wrote instructions on a letterhead. I went to pharmacist and found out that it was a narcotic, I needed a prescription. The pharmacist said, ‘I am not going to give you this’. D- ‘I went to the GP; he was not impressed. He said the Doctor prescribing should prescribe. That it was potentially highly addictive and risk of subsequent problems.’ D – ‘he was not happy (GP)’. D – ‘biggest issue that I had, quite disappointed to be honest. I have no problems giving (the integrated care service) feedback today.	Darren had previously mentioned his dislike of ambiguity and his preference for clear communication and expectations of qualified health professionals and their expert knowledge. For Darren it was unexpected, a disappointment and I imagine embarrassment that the information, or his understanding, was not correct. I interpreted that he felt exposed and put at risk. His trust in the integrated care team was likely threatened. This may cause him to feel less confident or question the ‘correctness’ of other aspects of his care. Darren did express confidence in providing feedback to the integrated care team, which suggested to me that he felt safe to do so, or as Darren expanded on later in the interview that he was working on adopting a mindset of acceptance. This is related to self-awareness, where he accepts his imperfections and practices mindfulness.
Actionable - What actions have you initiated at home that will promote your health?	Applying information	To take what I have learnt and apply, to take information and adapt, open to being taught/educated/ coached.	The actions Darren described as initiating at home were similar to his experiences of, and involvement in, his integrated care. However, in this scenario, he is

	Being methodical	Being organised and efficient, considering pros & cons - safely testing out options – accepting there will be consequences - do what needs to be done. Have a backup plan - know who to call, seek out expert advise	leading and being responsible for planning, applying and adapting what he had heard and learnt. All focused on progressing his wounds healing. Darren referenced several times the positive experiences, including information, support and supplies, in relation to his colostomy and stoma care. This was his benchmark, point of comparison. He described that he was educated and coached in ‘what needed to be done, how to clean and manage my stoma in order for me to move on with my life. In order for me to live a more productive and comfortable life.’ ‘And they also send out mail, information, newsletters, that sort of thing in order just to keep me updated of news, updates about services and products that are coming out, seminars that are being conducted by specialists in the field.’
	Being self-aware	Maintaining focus on the mind and body, aiming for balance. Accepting imperfection and recognising that everything is in relationship to each other, and there are always consequences, both good and bad	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Keeping health manageable - Pro-actively avoiding risks	I can’t afford to get sick. I can’t afford to have little mishaps like this happen on a frequent basis. Get on track. Make sure my lifestyle’s going to be fit and healthy. Do my regular checks, ongoing treatment, diet. Keep at a managed level - eat right foods, exercise - it’s just basically ‘let’s manage that’. D - If I manage good lifestyle changes, I will minimise consultations or mishaps. D- don’t want to repeat - I have learnt a lot and do not want to make the same mistakes again.	Everything Darren has done and is doing now is linked to what he believes will contribute to and protect his future health. This helps me to understand his behaviours and how he prioritises actions across the past, present, future continuum. It also helps to explain his emotional response and disappointment when information is incorrect or the trust he felt in the information and the expert was found to be misplaced. Darren has researched how best to maintain continuity of his health information; he has been consistent in his trust of technology as both a source and a conduit of information. Darren has confidence in his ability to critique information sources for what he requires and recognises the benefits of having a trusted relationship with a ‘qualified health professional’. He used the word ‘balance’ and ‘symbiotic relationship’ – Darren explained that this required him to consider how everything was interrelated, for example his personal situation, family, and health. He
	Holistically caring for self	From a holistic perspective, I need to keep my health in check. Concentrate - go from the inner circle of making sure I’m all safe & well.	

		D- accept what I have, what has occurred - extremely important. D- take care of myself, so I can then take care of others e.g., father	expected shared responsibility – that he will do his part and the expert will do theirs. 'Play my role'. A type of social contract.
	Doing the best, I can – accepting	D- from previous illness experiences, I have a better understanding of what I need to do. I have had many years of enduring challenging and uncomfortable health experiences. D- work out how to life within the circumstances I am in, do the best I can. D- accept what I have, what has occurred - extremely important. D- life with what I've got	Darren used phrases such as 'we cannot be perfect', 'accept what I have', which suggested to me that he was reflective and was reminding himself to be accepting, in the context of his expectations of himself, others and his goal. I had the impression that Darren did not extend this acceptance of imperfection to his health professionals' knowledge or practice.
	Protecting access to information	Personally, managing my medical record – ready access to complete medical history I have rapport with all my healthcare providers. Ready access to expert health information	
	Personally, managing my medical history	D- I created a profile on MyGov website, where a summary of my medical records has been placed there. So, if I need to go to another Doctor, or somewhere else - I can just access MyGov and get a summary of my medical history. D - MyGov links all information easily and is immediately available - saves GP time. Benefit, I can personally manage my own medical records pretty much anywhere in Australia. Great system once utilised & set up. D- Gave GP permission 'go for your life' to put all info there. I would hate to have to carry file to another Doctor, have something go missing.	

Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Leveraging relationship	D – 'it's important to establish a relationship, rapport. Then you can see them when you need to. I know exactly who to call, ask'	Darren's predicted health needs are dependent on him having access to, and managing, information from qualified sources
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** I have access to what I need. Why? Ready access to information and supplies enables me to manage my healthcare efficiently and effectively	**Measure** Self-assessment Comparison to previous medical treatment and support services received. 'Did I have access to everything I need - information/ supplies/ support'. 'Are the instructions clear, is the provider qualified'. 'Can I access/ ask questions when I need to'.	Benchmarking against previous medical treatment and support services received for colostomy and stoma care
	I can personally manage my health. Why? In my health belief model, everything is connected. I need to proactively manage the risks to my health	Self- assessment – 'I understand what I need to do to be healed and on track forward'. 'I feel confident that information is correct, trusted and can be taught to me.' 'I can methodically work through what needs to be done. I can use this to learn and prevent or minimise future complications - down the track'. 'I am living a productive & comfortable life'. 'I am feeling self-motivated and that I am using my time well'	Referencing personal health belief model: I can be educated/ instructed / coached. I can add to / complement from other sources. I can access the medication/ supplies / support I need. I can make choices/ accept consequences - self-manage my time – I can access information/ expertise required to get results. I cannot afford to get sick or have mishaps. This is not good use of my time or resources. Technology can enable information transfer - reduce risk/ inefficiency - over / under/ wrong treatment
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Ensuring continuity and access to my medical history when GP retires D- 'my usual GP is close to retirement, have visited others at same clinic- feel quite comfortable with and plan to stay there - 'obviously, because they've got all my records' - the Encyclopaedia Britannica of files - my whole	2.There has been no correspondence between the Integrated care service & my local GP. D- 'I have had experiences in past, all very efficient & communicative between each other - so ethical about it – was just a delight'. D - my GP, he is the nucleus, all health-related info needs to come - so he has a full understanding, can inform decision making.	3.Improve safety and efficiency – improve access to wound care supplied and parking D- 'Having a 'Basic kit' (wound care) available – would be an efficient way of keeping the process & system moving forward - little bit more smoothly, little bit more efficiently'. D- 'Having safe areas for parking & accessing the integrated care service, for patients and visitors. Will help planning, give peace of mind, whilst also better use of time'.

	life. That's the reason I go back there, they've got all that info on me'	Information has got to come to a central node.	D- 'I would recommend they create a Health Zone, like a precinct. Including the roads around the hospital and the integrated care clinic. Limit speed to 40km/hr - similar to a school zone'.

Table L6: Pepe's Experience of Integrated Care

Attribute Coding: Pepe's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Pepe (P)	Date: Feb 2018 Location: Integrated care unit Arrived: drove own car Interview Length: 18 mins	45-50	Male	Own home, with family	Full-time Own Architect business	Researching exercise aids	GP referral a couple of years ago and been ongoing	initially weekly, then shared with community nurse	Wound Clinic	GPs Community Nurse Specialist (vascular surgeon)

Process, In Vivo and Values Coding: Pepe's Transcript

Sequence	Codes	Pepe's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Ongoing	'It started a couple of years ago actually, where I've had an ongoing issue of problems with my lower part of the legs in terms of circulation which they call venous insufficiency, which leads to ulcers. I was at the local medical centre, and they said, "Look, you need to have this looked at on a regular basis because they're pretty bad." And that's when they booked me into this place. And it's been ongoing since then.'	Pepe has had an extended experience of the integrated care and community services for the treatment of his ulcers. His descriptions suggest that he has, overtime and with intention, integrated the services provided by the integrated care unit into his everyday work and personal life and is open and willing to sharing the responsibility of caring for his wounds. What has arisen for me in listening to and reading Pepe's interview, is the personal 'work' or 'burden' experienced within self-managing the routine treatment
	Convenient Good use of time	'Initially, I used to come here [Integrated Care Clinic]. I think it was once every week from memory. But then they said, "Look, we	

		can do it from home, see the nurse from home.” Able to have treatment at home [weekly] & come to the clinic every 2-3 months. Suits me – it’s convenient’. ‘I don’t have to come in and sit around, I own my own business so even more important	of his wounds and the goal of improving his overall health. The ‘work’ is pervasive, meaning that it invades your whole life, every moment, it’s always there. It’s a big investment. Pepe’s need for reliability, in observing and assessing his wounds has highlighted a potential limitation of the group medical centre practice model in not having continuity in care provider and the importance of communication between providers. Which Pepe has experienced as happening within the integrated care and community services, but not with the medical centre general practitioners. Although it takes time and planning, Pepe mentions the convenience of the model of integrated care; I feel his assessment is biased by the overall inconvenience of his treatment and moderated by his personal motivation/ commitment to progress healing. There seems to be a big personal cost or investment by Pepe in self-managing and managing his time to access treatment. He has expressed an appreciation of the role he plays and what he needs and expects from his health care providers. Feeling like the provider knows him, that the provider shares his commitment to healing his wounds and will apply their knowledge and expertise to his needs comes through as important.
	Continuity	‘The services are the same. The nurse is just as good here [integrated care clinic] as I have when they come at home.’ ‘The nurse & clinic communicate; they report back and forth’.	
	Reliable	‘I rely on these people [integrated care clinic] to do the [wound] assessment’. ‘My GP? no I haven’t seen him since I was referred. Because the medical centre, they tend to change [GPs] there. It’s not a regular doctor like I used to have once upon a time.’	
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Observing and copying	‘Observing and copying … making sure that I follow what they’ve done’. ‘Because I observe and I just copy it, that’s all you need to do. You don’t have to reinvent the wheel, or whatever, you just do what they’re doing.’	
	Committing to the regime	‘Well, daily I need to change the bandages and I obviously keep it-- treat the legs in a clean fashion so that I don’t get any sort of cross infections, whatever. It’s just a day-to-day change. And also bandaging of compression stockings. So, keep the same sort of regime going that they do when they come over’.	
	Managing my time	‘Because it takes me, I’ve sort of timed it, it’s about 15 minutes out of my day to do the	

		proper job. Yeah, it’s not like a five-minute job or whatever’. ‘I allow for at least an hour travel time [to the integrated care clinic]. I’m not that far from here, about five minutes by cab. So, I lay out an hour. You’ve got to park down the parking station’. ‘It is timing, yeah’.	
	Planning my day	‘I organise my day - get up shower, then bandage- got to hit bandages first thing in the morning to stop that swelling of the leg’.	
Significance -What mattered most to you about your integrated care experiences?	Providers are knowledgeable and experience	I think it has to do with the [community] nurses or X [integrated care provider], knowing what they do and how to treat it because, I guess, people like me, I want to get to the end of that sort of road of looking after these ulcers. So, it comes down to their knowledge and that they’re pretty well experienced in how to handle ulcers	
	Willingness to be innovative & collaborative	I don’t want to prolong it on, and on, and on because it is a slow healing process. So, whatever we can explore to speed that up, all the better. I need some-one to value-add to what I’m doing	
	Personalised They’ve got an interested – invested	‘They’ve [integrated care clinic] got an interest in my health and welfare. They want to see that I do get better not just, “Aw, it’s just another name on a pad or a system.”’. ‘I know the medical centre doctor [GP] will just type in whatever. It’s not like he knows me, he doesn’t really know me’.	
Now – What’s happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Disciplined (what)	‘Make sure I follow what they’ve done - how to apply the bandages, the dressings; how to treat the wound’. ‘The same pattern’ ‘keep regime’.	Pepe appreciates that healing his ulcers is the ‘long game’ – he plans for slow and steady progress; he

		‘Don’t get any cross-infection’ ‘know the signs’	believes that consistently following a regime will result in progress. At home this regime gives him confidence and hope that there is a solution, he is progressing and that the investment of his time is validated. He is vigilant, in observing for warning signs, and likes a plan that he can measure against and take action if required
	Consistent (how)	‘The methodology; it is a certain way - just knowing that that gives you confidence, it is the same pattern that they do’.	
	Plan of action	‘Early intervention is best. I know the signs, I am assessing and monitoring all the time’. ‘If there is a situation just come in and see us [integrated care clinic]’	
What was useful when something unexpected happened or you were worried about your health? What happened	Confident that can take immediate action	‘Situation gone backwards - legs started getting worse’. ‘My criteria for something not right- leg hurts and red. This is a warning bell’. ‘I’ve had cellulitis. It’s my biggest fear, every time I land back in hospital’. ‘The minute I see somethings not quite right, I’d rather come in - So I came in and saw them’. ‘The option [to come in] is always there which is good’	I feel that Pepe’s example highlights that he has confidence in the integrated care clinic. He is self-aware, he knows his fears, he has had experiences which he has learnt from, and knows what he needs to avoid them. The integrated care clinic provided the option and permission he needed – to take immediate action
Actionable - What actions have you initiated at home that will promote your health?	Investing in improving	‘I currently use a boot, a hydraulic suit that fits around legs and pumps air in and out – massages’	Pepe is an Architect, has his own business. He works from home, long hours sitting behind keyboard & working large projects. He recognises the contributing factors to his ulcers and what he can do. Pepe has shared his willingness and motivation to contribute to his healing – that he is doing his bit – and is always looking out for other options to support progress in healing. Pepe is both realistic in his goals and open to alternative ways of achieving them. Again, he is self-aware re his habits and the changes he needs to make holistically – recognising the connection between diet, mobility and his ulcers healing
	Researching devices/ aids	‘Researched an elliptical trainer, it is highly recommended. You stand up and can fit beneath the computer table. Only in USA at the moment and not shipped to Australia.	
	Monitoring	‘I have been losing weight, I go down and then plateau. I haven’t gone back that’s the main thing’.	
	Changing habits	‘Improving my eating habits - trying. I’ve got a bad habit, I start my work without breakfast & keep going until late, then I am starving. I love bread, I love pasta - because being Italian. I’ve got to have more protein	

		and vegetables - I have started dinking chilled V8 juice.'	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Losing weight	'Most important thing is to lose weight'. 'Shed enough weight so that I can physically start doing other forms of exercise'	It is evident that Pepe's approach to his integrated care experience is related to what he predicts he needs now and is setting him up for the future.
	Increasing mobility	'Find ways to move my legs'. 'At the moment I am not fit enough, I have asthma'	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Progressing healing	'I saw the vascular surgeon who told me the problem but did not really gave me a solution'. 'The [integrated care] clinic here, gave me a solution'. '[integrated care] clinic is helping. I need the ulcers to heal, as the bandages make it hard to wear other devices'.	I imagine that Pepe's thinking processes are influenced by his architecture and design background – in being aware of the interdependency and benefits of planned structure
	Knowing signs	'Early intervention is best. I know the signs, I am assessing and monitoring all the time'	
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** My care is customised and promotes healing. Why? When treatment and progress is accurately assessed and adjusted to his personal circumstances – more efficient and reliable	**Measure** Self-assessment Customised – I am part of the process. Convenience – I have options, good use of time. Consistent – minimal #of care providers, good communication Observation – colour, pain Measuring – time, weight, mobility Progress – less bandages, then I can use other devices	Expectation that Integrated Care clinic is accurately assessing (looking) and adjusting/ customising treatment according to his personal circumstances. Being known as a person, his circumstances, is important to Pepe. When the wounds heal, he will not have to wear the dressing, and can then be better able to use other devices to improve mobilisation.
	I can attend to my care needs and initiate early intervention. Why? Pepe has consistently indicated his belief that - If I	Self-assessment – Able to follow regime - methodology. Have access to supplies – the same materials.	Pepe has consistently indicated his belief that - If I am disciplined, do the same thing (observe and copy) it will ensure results (progress healing).

	am disciplined, do the same thing (observe and copy), using the same supplies, it will ensure results (progress healing).	Able to contact for expert advice - immediacy - gives sense of permission – builds confidence / trust. Avoid cellulitis sequel / hospitalisation - reduces fear / anxiety.	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Improve reliability and efficiency in wound dressing method Visited by different community nurses who used different techniques. 'I have to brief them' 'I've got to explain'. Inconsistency in the person and the approach can delay healing – inefficient. Suggest a designated case manager, or organise the same nurse or same 2 nurses – who do the same regime	2.Improve access to wound dressing supplies 'This is important as I can't get the products from the chemist'. 'I understand budget cuts may see less access - I won't abuse, I am very careful how much I use. This would also benefit others'. Pepe feels this will impact on his healing, as cannot access exactly the same materials as are used in the integrated care clinic	

Table L7: Sally's Experience of Integrated Care

Attribute Coding: Sally's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Sally (S)	Date: Feb 2018 Location: Integrated care unit Arrived: drove own car Interview Length: 24 mins	50-55	Female	Own home, with husband	Full-time Own Retail business	Alternative health Spiritual healing	Self-initiated GP Referral (recommended by a friend)	3rd visit	Wound Clinic	Integrative GP Acupuncturist and Herbalist Oncologist

Process, In Vivo and Values Coding: Sally's Transcript

Sequence	Codes	Sally's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Getting professional advice	'I like to use essential oils as well as-- I do have like a proper cream that's from a doctor but mainly I'm based on natural treatments. But it's great to get their advice, they look at the wounds because they're pretty bad and they tell me that, "They're actually looking fine," or, "I think you need to do something," which I haven't had to do so far. But that's good to get that professional advice.' 'Because they're specialised in that field whereas my doctor, he doesn't. He doesn't know about that' "He doesn't know anything about the actual wound care."	In immersing myself in Sally's interview transcript I found myself to be surprised by the intensity, depth, and breadth, of what was conveyed over a relatively short period of time. I found it interesting that Sally had requested her General Practitioner (GP) to refer her to the integrated care unit based on the recommendation of a friend. Before this, she was not aware that the service existed. She was happy to keep an open mind and give it a try. I felt even though there was much that was unknown, Sally still felt she was in control. I did not get a sense of this being about naivety. She often referred to herself as being independent and liked to be the one making choices related to who and how she looked after herself. I believed her when she said she would give people a fair go and then decide whether she would continue or walk away. Sally described her experience of the integrated care clinic as being positive, she felt the advice provided was professional, and just as importantly respectful of
	Feeling respected	'[integrated care clinic] really respected that I like to use the essential oils for cleaning and for treating and hasn't sort of said, "Oh, no you shouldn't do that," or anything like that. very supportive of my opinion. They know how I want to do it - that's good'. '[integrated care clinic] very supportive too of my opinion. Knows that's how I want to do it and that's good.	

	Monitoring progress	'[integrated care clinic] Look to see how skin lesions are progressing. If there is an infection'	her preference for what she called her 'alternative' approaches and her views on the dangers of 'toxins' that could be found in some medicines. Sally later shared that overtime she had heavily invested her time and resources in seeking advice from different types of health professionals in relation to her skin lesions. I had the impression that the respect, professional support, and advice she received from the integrated care service was unusual. Sally gave the impression of being self-aware, she described her decision making as being 'intuitive'. Which was balanced with her need to plan and manage her time. Self-confessed as being stubborn natured, I got a sense it could all be a bit overwhelming at times. Once gauging the integrated care services acceptance of her and her alternative ways, Sally felt comfortable to test with them what she had heard or read related to her 'unusual' skin lesions and to clarify what words meant and the best products to use. This then abled Sally to plan, calculating her time and investment. This felt 'good' to Sally.
	Validating	'[integrated care clinic] actually said, "Well, they do look okay, so keep doing what you're doing," and that was good to hear.	
Meaning - What does 'being involved in your integrated care experience' mean to you	Making choices	'In being involved, well, I guess that I'm making the choices of how I look after myself and my skin and my body as a whole'	
	Planning	'Just planning, knowing what I need to have done and then allowing the time to actually get ready because it takes me so long to get ready with having all these legions on my skin. Yeah. Yeah. I guess it's just planning. Yeah. And then knowing what other plans I have to fit in as well. Yeah [laughter]'	
	Leaning in	'I guess I'm a bit stubborn... I'm scared to try other types of medicines because I hear about all the toxins and the bad results that people have. So, I've always been into alternative ways of looking after myself, my family, everyone. And now to be suddenly so sick. And so that's where I'm kind of leaning towards and I'm giving that my best go, you know?'	
Significance -What mattered most to you about your integrated care experiences?	Accessing qualified experience	'I really like that it is somebody who's experienced in that field, that can look at my skin and give me a proper opinion'. 'This (skin lesions) are a rare thing - nobody really knows what is going on'	
	Asking questions	I can check things I have researched or heard from others, 'I can just say, "Is this right?" Like, "Someone's told me this." And it's almost confirming whether it's right or wrong. Looking at my wounds, "Yes, they seem to be-- someone's told me that it's granulating I've never heard these words	

		before. And so, then I found out about it, and I ask him. Yeah. So that’s really good.’	
	Feeling known & respected (acceptance)	They really understand me. They know what I don’t like. I really like that they respect that about me - nobody else has.	
Now – What’s happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	New approaches	‘Probably, the introduction to different bandaging. Yeah, that was really good’	When self-managing at home, Sally had previously noted how long it took her to bandage her lesions each day and that this was a big investment of her time and resources. Knowing what to look for when investing her resources and what to do (technique) was most useful. Sally referred to the cost or expense of health-related services and products on several occasions. I imagined as a small business owner she was fiscally aware. I had the impression that Sally was happy to invest if she felt the return or impact was justified.
	Saving time and money	“I was told [by a friend] about being able to order online. And so, then I was ordering ones that had been recommended, but they were extremely expensive. And then coming here [integrated care clinic], they actually gave me some products. And then when they ran out, I knew what to look for and to order. And that’s been helpful. ‘I mean, it does cost a lot of money. The bandaging costs a lot of money.’	
What was useful when something unexpected happened or you were worried about your health? What happened	Nothing unexpected	If I needed to contact ‘I guess it would just be contacting the reception. Yeah. The number that I called originally [laughter]. I don’t know. That’s what I sort of would think of. Yeah.’	This was interesting, Sally stated that nothing unexpected happened, however also indicated that her unique circumstances meant that the unexpected is not unexpected
Actionable - What actions have you initiated at home that will promote your health?	Investing in different opinions	‘I keep trying all different things. Yeah. Sort of give things a few months. And then I just sort of go into the next stage of trying something different.’ ‘I have been going to Dr x, who’s an acupuncturist and herbalist who specialises in cancer, and I’ve been going to him for a few months, but I haven’t really had-- he has had really great results with a lot of people, but I think in this type of thing, I haven’t had really, really big changes. So, I don’t know	What stood out to me from the actions Sally had initiated to promote her health reflect her description of involvement in her integrated care, being making choices ‘Doing what I think is right in how I look after myself’. I also got a better sense of Sally’s holistic commitment to her health and well-being, in particular her use of non-traditional approaches to healing the mind, body and soul, acknowledging their connection. Sally also

		if it's time to kind of stop that. It's very expensive.' 'I'm just about to see another oncologist that my doctor has recommended, and he has a bit more of an alternative perspective as well. He can't do anything, but he can give an opinion, or he can just-- I'm not sure exactly. I know that everyone's ruled by the things that they have to say and do, but to get somebody else's opinion.'	recognised the benefits of social connections and feeding her inner happiness. Through this conversation Sally shared the 'full-time' effort or work of self-managing her health needs in the larger context of her life
	Dedicating time and attention	I've tried many different things. It feels like a full-time job. Yeah. And my other job is like, "Oh, do I have time to do the pays and the invoices?" 'It's all I think about, unfortunately'	
	Reconnecting with friends	'I've started to reconnect with some friends, and we have little get-togethers where we-- I don't know, you might think it's a bit weird, but alternative kind of things. And that's good because it just helps me to-- it's a part of my life that I kind of have let go of.' 'I suppose that's one thing that I'm doing for me. Dr X (Integrative GP) always says to me, "You have to find something that makes you happy."	
	Healing with the voice	'Healing with the voice, like we're doing little group where we just vocalise sounds and sort of singing. They say that's very healing and we're racing with emotions and stuff, so I'm doing that once a month.' 'It just makes you feel like-- well, makes me feel like I'm doing what I really love.'	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Healed skin	'Well, I'd like my skin to be healed [laughter], not have lesions. And yeah, I guess that's the main thing.'	The present and the future are directly linked for Sally, with healing her skin lesions being most important

Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Gives me confidence	‘I think just having X [integrated care nurses] opinion and looking at the wounds and things telling me that, “Yes, it looks okay.” or if something needs to be checked whether it’s infected or whatever then that makes me feel confident. Yeah. And they really understand me. They know that I don’t like any invasive things. So, I really like that they respect that about me. And yet they still have time to give me the advice and to have a look at the actual wounds whereas nobody else has.’	Sally’s experience of integrated care has played an important role in her future health and in her self-belief and confidence. My key message is that you cannot undervalue the importance of feeling respected. Sally has found a professional service that she feels she can trust and can access when she needs to and who will allow her to decide and lead the treatment plan.
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** Knowing that what I am doing is good, Its promoting healing Why? My skin lesions are all I think about, it drains my time, money, and spiritual energy	**Measure** Self-assessment – I have considered alternative options and the pros and cons of the proposed approach. My providers understand and respect me – appreciate my unique condition and alternative ways. I have access to professional advice. I can clarify and answer questions. I am investing my time and resources wisely.	Sally, although describing her approach as intuitive, she was always carefully comparing and weighing up the pros and cons
	I can live my life my way. Why? This my life philosophy, health belief model	Self-assessment – I feel independent. I am curious – I can test / experiment with different options. I can access professional advice. I am aware of what else I need to consider. I feel connected spiritually, to my energy source	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	‘Improvements, not really. Not that I’ve kind of come across. Yeah. I think because I do my own thing, it’s a little bit different.’		This response reflects Sally’s openness and curiosity, not wanting to label or predict something as an improvement until tested – and an appreciation that it may be good for her, but not for everyone

Table L8: Beth's Experience of Integrated Care

Attribute Coding: Beth's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Beth (B)	Date: Feb 2018 Location: Integrated care unit Arrived: drove own car Interview Length: 32 mins	80-85	Female	Own home, lives alone (Widow)	Retired (left well provided for)	Gardening Pilates Shopping Researching Volunteering 6 Children + grandchildren	Inpatient referral then self-referral as an outpatient –	been on & off over a couple of years	Wound Clinic	Same GP for more than 20 years Community Nurse Specialists (Lungs / Osteoporosis/ Colorectal)

Process, In Vivo and Values Coding: Beth's Transcript

Sequence	Codes	Beth's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Self-initiating	'People ask "How'd you get in?" Well, I just thought I was in - so I just ring up [integrated care clinic] and they give me an appointment'.	In describing her experiences of integrated care Beth comes through as being self-assured and self-aware. She is bold, she is going to seek forgiveness rather than asking for permission. I imagined her enjoying being a little mischievous, or playful, as she influences her experience so it's perfect for her. I appreciate that she recognises her want for control and that she can be stubborn, however she also seems to know her limits and when professional help is required. Beth met the integrated care nurse whilst she was an inpatient, she recognised that she needed him on her healthcare team, so she intentionally sought him out. Beth takes pride in her independence and the (moral) code that she lives her life by. I believe that she would not abuse any privilege, such as having mobile number.
	Feel trusted	'I have the mobile number - which I would never use'.	
	Interested in what's new. In good hands	'[integrated care clinic] so enthusiastic in what doing. You feel you're in very good hands because [integrated care clinic] always looking for something new'. enthusiasm in what doing, I find incredible'. 'Obviously into anything that's new, coming out'. 'Absolutely marvellous, the whole experience' 'They cured it (Ulcer). I went to so many Doctors. My experience here I found very, very good'.	

			However, having that number gives her the confidence to make choices and self-manage her health. Beth is at the centre of her health; she is integrally involved. She is resourceful and is happy to make changes to be able to achieve what she needs or to take on new information and see if it is effective. Beth is focused on maintaining her health and well-being, however, also thinks about what would be good for others. I was interested by her noting that the design of the health facilities was important for healing, I am unsure if this was taken from her 'research' or is her own insight or a generational factor. Some of Beth's assumptions that I noticed included: I can look after myself. I can tell if somethings not quite right. 'new' things are improvements on the existing. If people are aware they will use the service / take action I place faith in professional (specialist) opinion – it was what 'cured' her
	Professional	B - Very professional	
	Personal – perfect for me	'I think what is in place now, for me personally, is perfect'.	
Meaning - What does 'being involved in your integrated care experience' mean to you	Assessing	'I keep an eye on anything that looks as though it could be... ' 'I've picked things up by looking at it.' 'You can tell if somethings not quite right'.	
	Self-aware / monitoring	'I've just got to be careful not to go at things like a bull at a gate - If I feel it is beyond me, I will ring up and come in. I watch & if I feel I cannot do it. I will ring the I/C & get an appointment.'	
	Determining action	'It was pussy, it cleared in the time, I rang & cancelled, I felt I did not want to waste their time'.	
	Being flexible – fitting in	'I drive, with my life I can shift anything round anywhere. So, I fit in with what I can be given'.	
	Controlling	'I'm quite involved. I think you should be responsible. I suppose it's a bit of a control thing'.	
	Looking after self	'I think you should look after yourself as long as you can. I still live in my house. I've still got my garden. I am hoping to be carried out of their feet-first. So, I've got to keep myself healthy'. 'I like to look after myself. I don't like other people getting involved'. 'Activus transport - I've tried it. It meant the children didn't have to take time off'.	

	Taking the initiative	‘I’m stubborn, if someone says you can’t do that, I tend to work out a way that I can.’ ‘I love being told I can’t, then being able to.’ ‘If something crops up that I really could get my teeth into, I would do it’.	
	Researching	‘I find people not being enthusiastic about learning as they get older, it’s something that does not gel with me’. ‘I think people should be interested in their own health. Be interested in Life & things that are going on’. ‘I’m a great researcher, I research over the phone. Just looking up different things.’	
Significance -What mattered most to you about your integrated care experiences?	Accessing professional opinion	‘Professional opinion. Professional help very good.’	
	Trusted advice - trustworthy	‘I have complete faith in what they [integrated care clinic] tells me’.	
	Easy access and Appealing design	‘[integrated care clinic] presentation, it’s easy to get to; everything is nice & bright & appealing’. ‘Pleasant atmosphere - which I think can make people feel better anyway’.	
	Future option – reassuring	‘I know it’s there (for the future), Another one on my list that I can go to if I have problem’. ‘If I feel something is out of hand I can ring up. I find that very reassuring.’	
Now – What’s happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			

Relevance - What has been most useful at home from your experiences of integrated care?	Knowing backup is close by	‘The knowledge that I can if anything goes wrong. I’ve got someone quite close that will look after it (ulcer) and that in itself is reassuring’. ‘Very close back up, very close, it’s not far for me to come’.	What was most useful to Beth was knowing that she could keep managing her own health, with close by backup
	I’m in control	‘I make sure (ulcer) it’s covered’. ‘I take the covering off every so often to have a look at it. To see how it’s going. If it looks like its clearing, I’ll try to leave the cover off’.	
What was useful when something unexpected happened or you were worried about your health? What happened	Nothing unexpected/ worry		
Actionable - What actions have you initiated at home that will promote your health?	Watching diet	‘I eat very sensibly now. If I put any sort of weight on, I find it affects my breathing’.	I like how Beth has basically covered the determinants of health in her actions. Beth recognises the privilege of her circumstances in being well provided for, but recognises that health comes from the inside, no one can do it for you.
	Exercise routine	‘I go to Pilates twice a week’.	
	Keeping socially active	‘I go out every day’.	
	Keeping mind active	‘If feeling irritable, I jump in the care & go up to the shopping centre & walk up & down, up & down. I do all my Christmas shopping from January. You always see things, see bargains. I quite like pottering in shops. You see things’.	
	Serving others – volunteering	‘I volunteer, nothing to do with being good, I absolutely adore it’.	
	Supporting family	‘I provide family support, family with mental health needs. I am around all the time’	

Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Staying on top of health	‘Keeping my health in- line’. ‘I think you should look after yourself as long as you can’. ‘So, I’ve got to keep myself healthy’.	Beth’s integrated care experience, her involvement, her actions at home, are all linked to her achieving her healthy future goals
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	I know it’s there	‘The fact I know {integrated care clinic] is here, and if I feel something is getting out of hand, I can just ring up and get an appointment.’ ‘I have my list of people that I can go to if I have problems’. ‘I find that very reassuring’.	
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** I feel I’m in good hands. Why? I need their professional opinion so I can manage and lead my health.	**Measure** Self-Assessment I can see their enthusiasm. I can see they are researching, willing to try out new things and learn (just like me) I have things in place that are perfect for me. I can contact the Clinic if I need to They are close by; I have the number. I am cured – comparison to other health provider experiences.	Beth was constantly evaluating and was clear about what and why the integrated care service was good (for her)
	I’m keeping myself healthy. Why? It’s up to me. My goal is, when the time comes, to leave my home feet-first.	Self-Assessment I can maintain the level of independence / control of my life. I have a balanced lifestyle. I can look after myself. I can research and learn new information or ways. I can contact the Clinic if I need to	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Hospitals should make people aware of services available - you don’t know unless you research yourself		

	Beth could find because she is 'a great researcher' and likes 'looking up different things'. Concerned for others		

Table L9: Trent's Experience of Integrated Care

Attribute Coding: Trent's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Trent (T)	Date: July 2018 Location: Integrated care unit Arrived: got a lift Interview Length: 37 mins	40-45	Male	Lives with Mother in family home	Unemployed Tradesman	Walking group Social activities	Hospital referral as an out-patient attending hand clinic	approx. 18 months	Bulbuwil Health Lifestyle	GP Specialists Endocrine / Gastro / Neurosurgeon Pharmacy

Process, In Vivo and Values Coding: Trent's Transcript

Sequence	Codes	Trent's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Team of professionals	'I was introduced to the Aboriginal Health care team, the exercise physiologist, dietician, pain psychologist'.	For Trent his experiences of the integrated care program had been life changing I felt like he had had so many things happen in his life that had put him at a disadvantage, through inheritance, his own hand, or others. Trent had been adopted and separated from his aboriginal birth family. He had a history of Chron's Disease and steroid induced osteoarthritis. He had used illicit drugs, he had experienced loss of social status and he had eventually attempted to take his life. He felt judged by others, a burden to his mum and that he had nothing to live for. His experience of integrated care was in juxtaposition. His words and sentiment came across as genuine and sincere. Trent's description was grounded in his feelings of being welcomed, accepted, and cared for by the integrated care program /team.
	Feeling cared for	'Most caring place I've ever been.' 'People want to help.' 'They're interested - take an interest in you'. 'You're part of a group & it's like a family. It something really special' 'They're caring. It's the most important thing. They actually care'. 'You don't feel like you're a burden to anyone. They genuinely care, they're interested'.	
	Feeling welcomed	'X she organises stuff on the computer, she's at the door. Some people think she's just a doorman. No, she's straight out, walks down, gives you a hug 'How are you going' 'what are you doing' 'I'll get you a coffee''.	

		‘It’s not a patient thing, it’s like a family. Welcoming. Will do’ ‘I’ve never come to a place where you feel so welcomed, never, not even playing football, you know?’ ‘They will walk through fire for you, so welcoming’.	To him it felt like family. I am wondering if the process of having to identify his aboriginality to access the service was influential. That he felt he had found people who could see him as a person and who were interested in him and in each other, everyone was equal. There is a sense of cultural safety – however this is not mentioned. Trent commented about being watched, but in an unobtrusive way, watched out of interested and care, rather than from a surveillance or looking for what is wrong. Trent described what being involved meant for him, through how it made him feel. He felt motivated, he felt he could speak up and this contributed to him feeling like a person rather than an object. I imagine an object as having no say, things being done to or maybe ignored. In feeling like a person, he is then part of the experience, and hence he is involved. What Trent identified as significant about his integrated care experience was also framed around how he felt. That he felt motivated, he was doing it, no one was making him, he wanted to. In addition, he was safe, people were watching out for him, the doors were open, and he could choose to walk through. I understood from the way Trent described his experiences, that these feelings & experiences were different or unusual from Trent’s previous interactions with health services and providers. The impact has been phenomenal – in Trent’s words ‘life-changing’ – he had shifted from having nothing to live for, to feeling like he has a purpose, and he is taking control.
	Just turn up	‘You can access them any time’. ‘I’ve never been treated like this. You don’t even have to have an appointment. You can just turn up, grab a coffee, have a chat.’	
	Range of services	‘Services I use were the gym, walking group, stop smoking, anger control and art group’.	
	everybody is respected	‘There’s not one bad word said about anybody - nobody’s better than anyone else’. ‘I came here on NADOC day. Every person I know in this building came & gave me a kiss or a hug or shook my hand. Everybody. ‘Nobody is better than anyone else. We’re all equals’.	
	Safe – to be yourself	‘You can’t pull the wool over their eyes. They all know. No point telling a fib or trying to be better than what you are.’ ‘They take you as you are. They’re all taking to each other - that’s good - the left leg knows what the right leg is doing.	
	You want to keep going	‘Everybody knows my name. It makes you want to keep going’. (previous HC exp) I said, ‘good morning sir”, shook his hand. Told ‘I didn’t ask you to speak, sit down’. So, I walked out ‘Goodbye sir’.	

		‘Treated me like a piece of poo’, ‘didn’t even ask my name’.	
	Life changing	‘I can’t praise it enough. It’s changed my life’.	
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Personal	‘Being involved makes me feel like I’m somebody. You’re a person, not just an object’.	
	Using my voice	‘I’ve always got a say.’ ‘Have you got pain?’ Constantly surveying you, you don’t even know they’re watching’	
	Motivated	‘Watching the clock. I wanna come here’.	
	Planning – making adjustments	‘I can’t eat food in the morning. It’s easy to drive [till Monday when the rego’s due] or train’	
Significance -What mattered most to you about your integrated care experiences?	I am doing it myself	‘I keep coming here. They give me the tools. They don’t make me do it.’ ‘They put it in your head without realising mentally’	
	Belief	‘I gonna get stronger’	
	Feeling like I matter	‘The way they care, you can access them anytime, you’re not a hinderance.’ ‘You actually feel like a human’. ‘You’re a person not just an object’ is important’	
	Given me purpose	‘Life changing, it opened doors, I’ve got a purpose to live’	
Now – What’s happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Access to supplies	‘Access to patches, pretend cigarettes’. ‘They give you every piece of stuff you want’	What Trent found to be useful has been having supplies, techniques and the motivational attitude that will allow him to maintain the gains beyond the integrated care experience and integrate into his everyday life. Able to access back-up when you feel you need it was very important.
	Self-management techniques	‘Doing the breathing methods, I learnt’. ‘Stops me getting frustrated to the point of getting angry at my illness.’ ‘I can control my temper’.	

	Motivational goals	‘I’m actually doing stuff. Like I might mow the lawn’. ‘I walk to the shops some days’	
	Having back-up	‘If there is anything wrong, let us know, the door is open’	
What was useful when something unexpected happened or you were worried about your health? What happened	Safety Network Having a number to ring Reaching out Being honest Everyone is talking to each other	‘There was nothing wrong that day. I went to Spec Savers to get new glasses. Parked my car. They told me I gotta go to eye hospital with glaucoma. ‘Oh, another thing’. I walked straight to the pub, pulled dollars out of the bank & put through the pokies & drank myself stupid.’ ‘I could see myself doing it and I could not stop for love or money or anything. I got on the phone the next day [to the integrated care clinic] and said, ‘I need help’’. They [integrated care clinic] had told me ‘If you’re feeling really bad, ring this number”. ‘I told them honestly the things I’ve done, that’s not normally like me.’ ‘They contacted my doctor and told me ‘To go to the Doctor’. ‘Now I have a mental health care plan.’ ‘They are all talking to each other’	In sharing this unexpected/ unplanned situation Trent has shared his insights about himself - how he felt he was shifting from not taking responsibility or looking to blame something else – towards noticing, seeing his actions and being honest with himself. He was proud that he had initiated action, rather than being caught out or making up excuses. Being honest with himself was a different way of being for Trent, as was being honest with others – he seemed to appreciate that others could see through his stories. Trent said, ‘you can’t pull wool over their eyes, they all know, no point telling a fib, or trying to be better then what you are’. Knowing everyone was talking to each other was perceived by Trent to be positive, as he believed they all had his best interests in mind. This motivated him ‘to tell it how it is’
Actionable - What actions have you initiated at home that will promote your health?	Enjoying exercise	I enjoy the gym. I love my walks.	Trent’s actions are all doable by him, all within his locus of control. They are not dependent on external resources. The words he uses to describe are positive, fun, and the actions are self-regulated – ‘I am doing it’
	Being creative	I love doing art.	
	Being social	I am connected to family, cousins, community.	
	Having a go	I’ll do it, I tried it, they are not enforcing, policing. ‘I’m scared of food, they say ‘Don’t worry about it. Just get a piece of bread, put some vegemite on it, & every time you walk past	

		have a bite'. I've gone from nothing too much & now I'm sort of in the middle.'	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Avoiding health getting worse	'I don't wanna get worse - get healthy or stay healthy'. 'whatever's wrong with you, for it not to get worse - that's health to me'.	Trent had described how he had felt like he was stuck (negatively) in his head & habits. He was aware of the impact his health & life had had on his mum. Trent recognised that what was important was not going backwards (staying unstuck), that his physical and mental health were linked and that he could influence whether he took a negative or positive approach to his health.
	Thinking positively	'they've given me the tools to not think negative. I'll take it when it comes. If it happens, it happens. You follow that road'.	
	Keeping active	'Keep moving, do stuff, be happy'. 'Being healthy is being happy'	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Taking each day as it comes	Rather than sit there & just go 'Oooo I hate the world'. You look, you learn to look different. The road just doesn't stop here. Tomorrow is a different day	What I was curious about was that the changes in attitude and behaviours described by Trent were significant, and integral to his future health. I am wondering about why and how this transformation has happened – over what length of time and how often Trent accessed the service. He was very familiar with the staff and the environment, and his mother mentioned noticing changes over a six-month period. I am concerned that there appears to be an assumption that the service will always be there for Trent. I am unsure of strategies or doors that have been opened beyond the integrated care program that Trent could access if needed. His GP has been brought into the team, they are all talking to each other, which may be helpful.
	Setting up healthy habits	'Now I do it without even knowing. It has become automatic. I'm doing without realising. I'm sitting there doing stretches without even knowing I'm doing it. It's become automatic - rather than you having to think about it'. '[Integrated care] It's kept me alive; I don't even touch this stuff (pain medication) and I gave up smoking.'	
	Change over time / change takes time. Behaviours Influences others	'I'm not angry, I'm not frustrated. Mum said 'you've just been so different the last six months. We haven't even had an argument.'	
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care?	What Matters Feeling like I am somebody. Why?	Self-Assessment People know my name. I feel accepted – 'They're interested – take an interest in you'.	Trent was constantly self-assessing his progress towards his goals and was also taking on and seeking feedback from others

Measuring **-** What did you use to judge effectiveness	I know what it feels like to be seen and treated like I am not human, an object	I feel respected 'they take you as you are'. I feel welcomed. I feel cared for I feel heard, 'I've got a say'	
	What Matters Not being a burden to others Why? I want to be in control, take responsibility for my actions and the influence I have on others	Self-assessment Noticing that I am doing exercises without thinking about it. I can control my temper. I don't feel frustrated. I am seeking out help, being honest with what is happening. Feedback from mum (trusted person) 'I don't feel like I am a burden to anyone'. I am 'not a hinderance'	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	Advertise the place, hard to find out about it. Needs to be promoted. It's kept me alive - my mum says that too.		

Table L10: Carmen's Experience of Integrated Care

Attribute Coding: Carmen's Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Carmen (C)	Date: March 2019 Location: Integrated care unit Arrived: Drove own car Interview Length: 43 mins	60-65	Female	Own home, lives with husband	Retired Teacher	Social activities Swimming Children & grandchildren Exercising – walking Social media	GP referral (on request from Carmen)	around 18 months	Diabetic Clinic Bulbuwil Health Lifestyle program	Same GP for more than 34 years

Process, In Vivo and Values Coding: Carmen's Transcript

Sequence	Codes	Carmen's voice supporting the code	Researchers' interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	Gaining access	'I identified as-- at the end, I burst into tears and said, "Yeah, but I'm Aboriginal," and then they just swung into the resources that were available to me as being Aboriginal.' 'I could access the diabetes service, dietician, counsellors, artwork, cooking, ophthalmologist, swimming & walking groups'. They said 'here's a phone number where you can go for that sort of help. But we [Integrated Care] are here to help anytime... just come up'.	In sitting with Carmen's description of her experience and thinking about what was happening for her, I was taken aback by the complexity, of the many dynamics at play. When Carmen described how she came to be enrolled in the service I felt guilty and naïve, that I had not truly appreciated the layers of people's lives. Who they revealed what to, and under what circumstances. I felt privileged and a little overwhelmed that I would do justice to interpreting her transcript. Carmen, however, was relaxed and her words were free flowing throughout the interview. I had a sense she was telling the story that she was happy to tell. It was her voice. I was aware from my experiences that when feeling uncertain, vulnerable, or maybe drawing on previous
	Finding out	'I didn't know of any resources or anything here.' 'Seems like a lot of medical issues with Aboriginal people'.	

	Tipping point	‘I’ve been diagnosed for 5 years, it was at the point I was put on medication, tablets, that I realised, ‘I’m in trouble here’ ... & that’s when I came here’. ‘I live in a very stressful family life & have for a long time, 40 years, I’m at the point that if something doesn’t drastically change, then I may have to leave just to survive... my Diabetes gets effected’.	experiences, people may choose to hold back from sharing personal or other information. That sharing information can at times be a disadvantage, an advantage or both. I was also aware of the possible adverse impact that this could have on a person’s health and well-being overtime. Carmen’s experiences prior to enrolling with the integrated care service seemed to have encapsulated this phenomenon. It felt like Carmen had been making, what I took to be difficult decisions as to what to share, for many years. I was interpreting from Carmen’s description of her previous life-experiences, that her norm or usual approach was to hold back and manage herself, until she felt she was ‘in trouble’, or her ‘survival was at risk’, then she would ‘attack’. I got a sense that Carmen had been self-managing an ‘internal fight’ for many years. She mentioned the need to attack her habits, that she had to be careful who she spoke to about what, and that she always started with doubting her own capabilities. Perhaps her ‘internal fight’ was linked to the stress she alluded to as experiencing for most of her life. Carmen also mentioned that she was a medically retired schoolteacher. I am not aware of the full circumstances; however, she did refer during the interview to her dislike of bureaucracy, of being held to rules and that she had lacked ways of managing her stress. I am interpreting that Carmen’s experiences as a teacher were not all positive. Carmen did show an appreciation of the approaches the integrated care staff took to engage people in learning
	Feeling appreciated	‘I feel a bit more appreciated. It’s not that my doctor doesn’t appreciate me, but he is there just to solve the problem’.	
	Feeling care for Holistically	‘I feel cared for. They’re interested in my whole body; it all seems integrated into my whole well-being”.	
	Feeling culturally and socially connected	‘It’s good to be able to talk - keep in touch with community’. ‘I’ve been isolated from the community in my growing up, my parents who would’ve been stolen generation. ‘I was invited to the [Integrated Care] Xmas party, it was like what my family was like when I was growing up. I got what they were joking about- their terminology - what was funny & laughing. I cried all the way home with joy. ‘I feel connected with the others, and with the staff’.	
	Safe place	‘I find here a safe place where I can come & don’t have to look after other people & not me’.	

		‘I like the idea that I could just come & whoever’s there is fine. You’ve got a safe place’.	new behaviours and skills. Carmen’s response that she was involved 24/7 in her health and the opportunities for improvement and measurement, suggested that she had embedded ways of thinking that were grounded in learning and critical thinking. What was important to her was being educated in skills and practices that would enable her to improve her health. I interpreted that education was empowering for Carmen. This lead me to be thinking about Brian Fays Critical Social Science Theory and its focus on social justice and empowerment, which had underpinned my previous work in Practice Development. Carmen mentioned being predominantly isolated from her aboriginal community and culture. I was surprised that Carmen was unaware of the disproportionate health related risks of aboriginal people. I interpreted this as an indication of her isolation. I was uncertain of the full circumstances of her isolation; however, she described the integrated care experience of being around her people, language, culture as ‘joy’. It brought back memories for her. Carmen also enjoyed expressing her emotions and culture through art. She mentioned that her family, including children and grandchildren, were encouraging of her artwork, and re-connecting with her culture. She described feeling pride. Carmen mentioned several times the sense of safety and empowerment that her integrated care experiences had given her. She noted the professionalism of the integrated care service and the ability to respectfully disagree, that people could justifiably hold different views and would take the time to explain why they held that view. This suggested to me that Carmen had previously either followed, or not followed, health advice. It was not usual for her to discuss the rationale
	Safe to talk	‘It’s a bit like a lifeline here, if I ever found myself in really dire straits, I could pop in - people would talk to me’. ‘You don’t have to tell everyone everything, and yet if you want to tell someone something, they just quietly go away and get it’.	
	Professional service	‘I love their [Integrated Care] professionalism’. ‘I like you can disagree on something with a staff member, but they will always explain why they disagree. ‘I have actually thought about moving down the coast - but it would be away from this service, not (worried about leaving) my GP, because my GP will move on’.	
	Encouraging Empowering	‘I feel I can ask any question without judgement’. ‘I feel more empowered as a person because of the way I am treated - we are empowered to do things, not do as your told - not a set of rules’. ‘Encourages us to manage our own situation. I guess that is where the empowering comes from.’ ‘Nothing this program says doesn’t give me hope. They always give me hope here. I think that’s the exciting thing, they’re empowering me to believe that I can be different in the future’.	

	Adult learning and positive reinforcement	‘[Integrated Care] they are more into not calorie counting, not weighing, but educating you on how to choose a good meal. How to research what a good meal’ ‘[Integrated Care] their philosophy is to get you to enjoy food & not make it a burden. It’s different to when you go to the Doctor. The Doctor says ‘don’t eat too many carbs ... don’t eat too ...’	behind the medical advice. Carmen mentioned several times that her doctor of 34 years was very busy, and his role was to (quickly) solve problems and get onto the next person. Carmen justified the GPs behaviour saying he was a ‘man with a lot of people to look after, while here there are a lot of people to share the load.’
	Preventing	“I think it prevents before it gets worse. It’s more of a preventative service to stop me ending up in a wheelchair.’ ‘They’re helping me to take responsibility for my own health’.	
	Contrasting Different rules	‘When you deal with that building [hospital] its bureaucracy. When you deal with Integrated Care its community & inclusiveness, they listen to the client’. ‘I come here [Integrated Care] and get it done (finger-prick). The hospital, I can’t get done anymore unless I’m on insulin. My doctor has also said no.	
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Continuously	‘I’m involved in my own health’. ‘So, my involvement is not just the hours I spend here, but 24hrs of every day, of every week, month, year’	Carmen is 18 months into her experience of integrated care, and she expresses her involvement as a full commitment, to her health, lifestyle and to others/ community. She has acknowledged what can get in the way of her commitment and has introduced strategies to ensure she meets her commitments.
	Personal commitment	‘It’s about attacking my lifestyle at my own pace & for my benefit & those around me.’	
	Commitment to others	‘My involvement is a commitment to the people who come, which might be different groups’. ‘I’m here for other people as well’.	

	Reciprocity Respect	‘They’re dedicated to giving. I feel they give me integrity, they care, but they give me respect & so ... I don’t find it hard to respect others & to be involved’. ‘Respecting one another. Having a point of view & allowing someone else to have a point of view’.	Carmen has personalised what matters for her. Her responses suggest that she has taken ownership, in that she ‘knows’ what she needs from the service and how to get it, and what she needs to do. She is invested in her health
	Expressing myself, my culture, my way - creative art	‘I express my emotions, feelings, thoughts through art (involved in Integrated Care art group)’ ‘Painting of the message sticks, we had to design what we wanted to go on it.’ ‘When artwork was at the hospital, I brought along my family. So, it’s a bit of a community. They’re absolutely over the top thrilled that I’ve got involved’.	
	Knowing my shortfalls	‘It’s not the sort of thing where if you miss one week, you’re in trouble. They will send me a SMS, and i get 2 - I’ve asked to give me two - they send one 4 days before & 1 on the day - that’s very helpful. Prods my mind to get ready for what we’re doing’. ‘I’m a real ‘doubting Thomas’. It’s my own doubt of my ability’.	
Significance -What mattered most to you about your integrated care experiences?	Being educated	I think it’s educated me on what Diabetes is & how to attack it	
	Planning for progress	I’ve lost weight. The more exercise I can do, the better off my Diabetes will be. If I can take stress out of my life, I think that will take a lot off too.	
	I have options	I know if I cannot speak to xx I can speak to xx	

	Genuinely interested	Knowing that there are people interested in my well-being. They're not just doing it for a job. They genuinely care.	
	Access to knowledge	'[Integrated Care] staff are Knowledgeable and available. They're informed & know where to go, who to put me in contact with. My GP does not have time to do that. He cares, but it's taken the pressure off him.'	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Practical exercises Doable options	'The fact that you don't have to run a marathon to get some exercise. I might do exercise in a chair, whenever I am watching TV. You don't have to have all the big machines - you can use a can of baked beans for weights'.	What Carmen has found useful at home is the practical application of the integrated care services advice. That she has adapted to her circumstances and been creative - I am assuming there is a link to her education / teaching background. Carmen responds well to data, this allows her to look beyond what she sees as her own faults, to look for an aide or strategy that will assist her efforts. She is problem solving herself, rather than outsourcing or avoiding the problem. Carmen can identify and draws on her own positive reinforcement for the new skills and behaviours she has adopted. Teaching others or sharing her knowledge and experience with others is an intrinsic motivator for Carmen
	Data informed. Diagnosis & treatment	"My CPAP machine makes a big difference at home. I did not realise how tired I was before because I wasn't sleeping. I was stopping breathing, it was a lot, I was really shocked, I didn't think I was'.	
	Practical skills	'I've never been able to cook and so now, I go & buy healthy ingredients & I go home, and I'll cook them for my husband and myself.'	
	Practical knowledge / guidelines	'I check every label for CHO per 100gm. It's a good guide for me when I go shopping. Check you CHO even more than your sugars, because the CHO include the sugars in some form.'	
	Confidence Teaching others	'If I'm not here [Integrated Care} to go swimming. I can do exercises in the pool. I	

		can do it because I have practiced over & over & over. I go visit a friend; we do it together in her pool.’	
	Following the rules	‘One of the things that really stuck in my head. I thought you could have 3 pieces of fruit a day & they’re now saying two.’ ‘You must have breakfast. I’m not good at that’.	
What was useful when something unexpected happened or you were worried about your health? What happened	Contact list	‘Yes, I’ve rung up and asked for someone to talk to.’ ‘it’s only at the weekend, and if I get severe depression or something’. ‘I’ve now got the phone numbers of people I can contact.’ ‘I’ve always been able to get onto someone’	Carmen has had positive experiences in being able to contact the service out of hours and feels confident that this will always be the case
Actionable - What actions have you initiated at home that will promote your health?	Committing to a routine	‘Little by little every day. Don’t give up. keep moving even if you don’t feel like it - walking 5 mins - walking around the clothesline.’ ‘You’ve got to keep moving - move it or lose it.’	
	Investing in aids	‘I bought a vibrator (exercise) machine’.	
	Socially connected	‘Keeping up social connections’. ‘Meeting with different people’. ‘I connect with people on Face Book’.	
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Self-belief / I have the ability - prepared (able to)	‘As I look into the future, I’m excited; about being able to say I can cook; about being able to say I did wake up in the morning & feel ok; about not just my weight, but my whole physical being, being healthier’.	Carmen’s sense of empowerment – her belief in her ability and knowledge, are central to her future health. Carmen is aware and recognises that she cannot be dependent on the integrated care service – it has served its purpose – but she needs to ‘learn to walk by herself’
	I make the choice	‘It’s my choice & it’s up to me. When you say the future, I guess it’s up to me. This [Integrated Care] is a wonderful crutch, but	

		they say you still got to pick-up the crutches and walk (that's not their description, that's mine)	
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	I believe in myself	'I'm a real doubting Thomas. Nothing this program [Integrated Care] says doesn't give me hope. They always give me hope here. It's my own doubt of my ability. I think that's the exciting thing, they're empowering me to believe that I can be different in the future.	The integrated care service has enabled Carmen to believe in herself – that she is able and can – instils and goes beyond hope. The integrated care service is a resource
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What matters** Self-belief – that I can Why – Because the future is up to me – it's my choice	**Measure** Self-assessment Comparison to other experiences (GP & Hospital) I feel empowered - it's the way I'm treated - I am listened to, I feel cared for, they are interested in my whole well-being. I can ask questions - they are open to explaining things to me, guiding me. I can have a different opinion – it's about taking responsibility rather than follow rules. I have hope – I can manage my own situation. I have pride and my family are proud. I am connected to my language and memories. I can creatively express my emotions.	
	I am being healthier. Why? I am informed, educated and confident in my ability to manage my health 24 hours a day.	Self-Assessment I am not waiting till things get unmanageable. I have a routine and I am taking preventative actions. I am regularly monitoring my blood sugar, exercise, diet, sleep and taking proportionate action.	

		I have reduced or avoided gaining weight, or the diabetes sequel. I have avoided going to hospital. I am connected – physically, emotionally, spiritually – to myself and my community. I am aware of medical issues aboriginal people are more susceptible to and actively protecting myself.	
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	1.Parking is the hugest problem, stress for me. Idea - they could set up a centre away from the hospital - like a centre in the community.	2.There's so much potential & yet to get here is stressful. The transport is a big issue because it's not near a railway station - you've got to drive; you've got to park. I always try and give a half hour extra. Idea - provide vouchers to use parking station.	3.We need to extend the service. Get people before they end up in hospital. The earlier we intervene with things like Diabetes & Mental Health - early intervention – for example my grandson has Down's Syndrome, and the focus is early intervention rather than waiting to treat. Idea - increase the number of rooms within the Integrated care unit, allowing more people and more preventative services
	4.I couldn't even guess how they would evaluate or whatever. When I fill in the survey, I'm always very positive, because it's wonderful. 'Why hasn't the government put money in'. They try to put band aids over stuff that is already broken. Why not soothing cream before it gets broken- these sorts of services do that.	5.I don't have much faith in government funding. But Integrated Care they're changing people's lives & you can't measure it (tick the boxes or manipulate the numbers) because its immeasurable. Ideas for measures: We're not going to end up on the suicide list because there's been a change. There's an intervention point. We're not going to end up without a leg because of Diabetes. We're more informed. I'd be interested to go back to my doctor (GP) & see whether I have visited him less than before. Been seeing my GP for 34 years.	6.Paperwork goes between Integrated Care & GP. I have to have a new case management plan every year. They must talk but I wouldn't know.

Table L11: Neil’s Experience of Integrated Care

Attribute Coding: Neil’s Interview and Basic Descriptive Information

Participant (Pseudonym)	Interview Logistics	Age Group (Years)	Gender	Living arrangements	Work status	Interests	Integrated Care referral	Integrated Care # Visits	Integrated Care Program	Other health services
Neil (N)	Date: March 2019 Location: Integrated care unit Arrived: walked. Interview Length: 24 mins	60-65	Male	Own home, lives alone	Retired Navy	Exercising Artist – painter & short film maker Son & Daughter up North	Hospital/ Emergency Department Referral – ‘they knocked on my door’	‘at least a year’	Bulbuwil Health Lifestyle program	Cardiologist

Process, In Vivo and Values Coding: Neil’s Transcript

Sequence	Codes	Neil’s voice supporting the code	Researchers’ interpretative musings
Past – What happened? Your Experience of Integrated Care			
The event/thing - Describe your experiences of integrated care – what was it like?	They came to me	‘Well, I remember [Integrated Care staff] came around to my apartment and knocked on the door and told me about it. I just can’t remember how they got my name down. I was probably in hospital here. Because my heart fibrillates every so often, they put me in. And they said, “Would you like to come along to the gym?” Cardiac rehabilitation. So that was it.’ ‘I’m not really sick. They told me I had a minor heart attack, but I didn’t even know’	What stood out to me when reflecting on Neil’s interview, was that there is a theme across the interviews that when a person is invited to talk about their health, being their involvement, daily activities, or goals, that their stories are simply how they live their everyday life. Health is embedded within their personal believes, values and activities. It’s what you do. What I was hearing from Neil, was him telling me a story about his life, the struggles within struggles, he was realistic yet optimistic, hopeful. Always thinking ahead, exploring ideas that would benefit him or any cause that he believed in. Neil does not associate his experience of the Integrated care cardiac rehabilitation or lifestyle program as a treatment for someone who is sick or needing medical advice. For example, in describing his annual visit to the cardiologist he says,’ he tries to kill me once a year
	Ongoing	‘Oh, gee. I don’t know. I don’t keep records or dates for these [visits to integrated care].’ ‘It’s got to be a year at least.’	
	Choices	‘Mainly the gym. Healthy Cooking once a month. Every now and then they have a community arts project which I get involved in. It’s just mainly the gym every week and cooking once a month.’	

			with a stress test’. Then when describing his integrated care experiences including cooking, diet, exercise, art and social activities, he talks about what he makes time to do every day, what he finds enjoyable, and will make him a little happier (‘he supposes’). I interpret that for Neil, medical (health) treatment is something that is done to you, you have little control, it is not meant to be enjoyable, and it is about a specific need or fault. There is a power difference, Neil does not hold the power. While health promotion to Neil is about living his life, he is in control and that he chooses to engage with the integrated care service, and he chooses to take on aboard any advice they may give. Neil holds the power to decide. I am assuming that because Neil is not sure how long he has been enrolled with the integrated care program, being at least a year, that it has become integrated as part of his health routine. Having reminder systems, flexibility in attending yet accountability to notify, and time/space for social interactions following health promotion sessions, appear to be contributing to the experience being enjoyable and a positive way of building healthy habits for Neil. Inviting Neil to share his creative and artistic talents, including purchasing and displaying Neil’s art, was an important acknowledgement of Neil, his expertise, and his commitment to the cause of ensuring that aboriginal art is authentic. Neil described that he had spent many years in the Navy. I imagine that he has lived and worked within an environment that is hierarchical and rule bound, yet also where you needed to work effectively as a team whilst also being accountable for your part. In describing what being involved meant to him, it was
	Personalised Promoting healthy habits	‘Well, the first time you turn up, they put you through your paces, see what you can or cannot do, and then design a series of exercises for you. And then, every week, you just do those exercises, try to improve every week.’	
	Not medical treatment	‘Well, it’s not for medical reasons. They can’t prescribe things or that sort of thing. As I said, they’re not doctors or anything.’	
	Enjoyable	‘Well, it’s they try to get us to eat healthy which we do when we’re here [laughter]. But it’s sort of a social thing as well. So yeah, it’s good. I think we’ve all enjoyed it.’	
	Socially casual	‘Well, it’s a social contact, of course, which is good.’ ‘We all sit around and talk. And it’s not a day, it’s a half day or so. Yeah, they’re good.’	
	Routine and reminders	‘Once a month, cooking. They always bring you up or give you a text, anyway, remind you.’	
	Investigating	‘And they did my density test a while back and everything. I got the bones of an 18-year-old. I said, “Really? Oh,” because I’ve never had a broken bone.’	
	Contributing Tapping into talent	‘Community arts project, we painted some posts which are going up to the hospital That wasn’t as popular as making your own painting’. ‘I actually ran one of them once [art class] When [Integrated Care staff] came around, I	

		had something [art] leaning up against the wall and they just had a look at them. Ended up buying one for here. So that’s how they knew that I did the art.’	about his thoughts and actions now and in the future. It felt like he was taking responsibility to find meaning and joy in his health, and for exploring strategies that would serve him well for the future. The purpose the Integrated Care program served was providing Neil with access to the gym and equipment, and motivation to keep active.
Meaning - What does ‘being involved in your integrated care experience’ mean to you	Doing something healthy	I do other things as well, but I just can’t sit in front of a TV and watch it or something. I just can’t. I’ve got to do something. Yeah. So, coming here is doing something, and it’s also gym. It’s healthy. So, it is the health aspect and also the social contact as well which is good. The arts part of it is good too. Everybody enjoys them.’	
	Keeping positive	‘Well, if you’re enjoying yourself rather than sitting at home grumbling, that’s got to be good for you.’	
	Looking into the future	‘I walk up here but there’s going to come a time when I won’t be able to walk up so I won’t be able to. I’ve always looked into the future. It’s something I’ve always been able to do for some reason. And I know in five years’ time, if I’m still alive, that I probably won’t be able to walk up here. I don’t have a car anymore. And then, so really, it’s just how you’re going to get around? That’s one thing I’m looking at now.’	
Significance -What mattered most to you about your integrated care experiences?	Accessing the gym	‘So, it’s just the gym, really, and that’s good. Come up here and yeah. So, I exercise at home, as well. But yeah, it’s probably just once a week at the gym. Well, I probably haven’t used it to the extent that I can because I’m still reasonably fit and healthy.’	
	Motivating - Keeping active	‘I’ve always exercised. Been fit. Most of it in the military, the Navy. They didn’t mind	

		if you drank like a fish which we did, but they also encouraged sports and activity. So, I've always been pretty active my whole life. So [Integrated Care] keeps you active and I am trying to use the machines up there.'	
Now – What's happening? From your experiences of integrated care, what do you believe has been of most benefit / use when self-managing your health at home?			
Relevance - What has been most useful at home from your experiences of integrated care?	Knowing what's available	'Probably information, knowing what's available. Yeah, it just hit me, I'm going to have to look into that. But yeah, like I said, I haven't really used the whole service, so I don't really know what it's about, actually. So, it's probably just going to the gym, really. Yeah. I'll have to see what else is available.'	What I noticed about what Neil had found to be useful at home, is that he sees the integrated care program as an extension of his own lifestyle. He was leading, or deciding, his experience. Being part of something, having a yarn and being social was important. Neil did not feel the need to learn new skills and referred to his moral code in that he held the individuals who were teaching staff, and their intentions, in high regard. He could see no harm in just going along with what was happening, rather than dampening someone's spirit who was trying. He shared the importance of being informed on what was available, whilst also confessing that he had not explored or fully made benefit of services beyond what was immediately introduced to him. He saw this as an opportunity rather than a deficit.
	Doing stretches	'There're a few exercises I do at home, mainly stretching. Yeah, I don't do weights or that sort of thing. It's mainly stretching. Do a hell of a lot of walking. I do, I take the different stretches home. Yeah.'	
	Learnt nothing really	'No because I've always been a good cook. So [laughter] I'll never starve, but. Some of the recipes are nice, but. But I've always eaten pretty healthy. I have a lot of vegetables and different sorts of meats and fish and whatever, so. I never tell X [Integrated Care Staff] this because she's terrific at cooking, but I haven't really learned anything [laughter].'	
	Having a yarn	'Oh, yeah. Yeah. Yeah, they [Integrated Care Staff] have to not actually kick us out, but we'll all sit around, have a bit of a yarn when it's over. Yeah.'	

What was useful when something unexpected happened or you were worried about your health? What happened		‘No, I’ve never contacted’. ‘I don’t even know their phone number.’ ‘Possibly. I got [Integrated Care] their business card. But yeah, no, I’ve never had to ring anybody up.’	Neil has not had anything unexpected and feels confident he would be able to make contact with the service if required
Actionable - What actions have you initiated at home that will promote your health?	Maintaining positive approach	Well, I’ve got a good diet, so that’s all right. Good diet and exercise, really. I’m certainly not going to sit down feeling sorry for myself.	Neil’s approach to his health was active, he maintained a positive frame, whilst also being conscious of the role his emotions and mental well-being played in his longer health. He is constantly scanning, internally and externally, for opportunities to improve or new ideas he could test. Neil recognised that family are part of his overall well-being, and I believed he would instigate significant changes in his life, for example move a long distance, if he decided it would be of benefit, bring happiness. Neil held strong beliefs or convictions, which he seemed to be aware of. He had courage, was not afraid to stand up for and fight for what he believed in or injustices in any form. I was curious if this was linked to his time in the Navy, the code of values and behaviours he served by. I was surprised just how helpful reviewing the Navy’s website was in providing a lens to help understand Neil’s actions and what was important to him. https://www.navy.gov.au/our-values-and-our-behaviours ‘The Navy’s Values guide our behaviour, they bind us together, are a source of strength, and a source of moral courage to take action. Our values are: *Service:* The selflessness of character to place the security and interests of our nation and its people ahead of my own. *Courage:* The strength of character to say and do the right thing, always, especially in the face of adversity.
	Moving closer to family	Thinking very seriously of moving to Northern New South Wales. I’ve got a son up there and I’ve got a daughter. I’ve got no one here, really. So, I’m thinking very, very seriously of going. So, it’ll be good to be near them. I’ll be a bit happier; I suppose.	
	Creative expression Meaningful cause - purpose	‘Well, I’d like a feature film.’ ‘I’m making another documentary now on all the fake Aboriginal art coming in from China & Indonesia, because 80% of all Aboriginal art sold in Australia is fake. 80%. Its terrible.	
	Fight for his justice, self-worth, pride	‘I refuse to give in. You can’t let them win. I’m trying to raise money. (In relation to my health) It makes me feel better if I can manage this. ‘To shove it right in their faces and say ‘you lot are wrong, I’m right’ (not shortlisted for finalist in an award for short films) ‘ I know I’m not part of the in-crowd and I’m not related to many of you (Aboriginal film making judges)’ ‘you got to be part of the in-crowd. So, I don’t like them & they don’t like me’	

			Respect: The humanity of character to value others and treat them with dignity. *Integrity:* The consistency of character to align my thoughts, words and actions to do what is right. *Excellence:* The willingness of character to strive each day to be the best I can be, both professionally and personally. To live Our Values, individuals will display Our Behaviours at all times to the best of their ability – It's up to all of us to hold each other to account on our behaviours. Our Values and Our Behaviours should be used to inform each and every decision we make - if it doesn't fit Our Behaviours - don't do it,or change course so that it does .
Future – What might happen? What do you foresee or hope for your future health?			
Predicting What is likely to be important for your health, at home, in the future?	Living my code	So, I got the good diet, the exercise. I keep my mind busy, as well. Yeah, I don't know. Probably being nearer to the family but I'm sort of looking at that now. I'm doing all right.	For Neil, it is about holding himself to account and making the decisions and taking action. Fully committed to living his values
Planning How might your integrated care experiences help you prepare your future health or avoid any threats?	Stimulating ideas & providing options	'Can give me ideas'. They really don't come and pick you up, do they? Well, from wherever I happen to be. Say I can't get to the gym, they wouldn't come and pick you up and--? Yeah. Probably not. Yeah.	For Neil, his integrated care experience has provided him with the resources, options and ideas he needed
Evaluation - How do you measure what matters to you and suggestions for improving			
What Matters to You - What stood out to you as important from your experiences of integrated care? *Measuring* **-** What did you use to judge effectiveness	**What Matters** Doing what's good for me. Why – I've got no one else, I know what I need, I need to work out how to do it, then I'll be ok.	**Measures** Self-assessment Feeling 'a bit happier' - 'if you're enjoying yourself rather than sitting at home grumbling, that's got to be good for you'. Feeling enjoyment – I am feeling in control / confident in myself, I am not fighting to be	Being physical, eating well, social contact and art - the things that Neil enjoys doing, finds rewarding, are in his control / feels confident about. Not about being sick, needing medical advice/assistance

		heard, I am making choices about being physical, eating well, social contact and art. Program is designed for me, for keeping me 'fit and healthy'. I can do it myself. It feels healthy, it's not about being treating illness, or needing medical advice/assistance	
	It's my idea. Why – Neil is creative, a thinker, a protector of what is authentic expression – he holds himself to account	Self-assessment I feel I can live by my values/ code. I am thinking of ideas and thinking my way around things – not being done to me. They get me - I feel respected – my art is on display. I am helping others (art class) I know that it is here - I could initiate if I chose - I have I/C business card with contact details.	His integrated care experience was an invitation, Neil made choices – followed his moral code - an equal - he owned the choice- not done to him
Continuously improving - What, if any, are the problems and/or improvement opportunities you have noticed	I think people with their-- if they're not sick, they don't really look into it. They don't. And I'm not really sick. They told me I've had a minor heart attack, but I didn't even know. And the heart fibrillates every now and then is bad enough to be put in the hospital. And even then, I didn't know about the Integrated Care programs. So perhaps there could be more information about what it's about. Yeah.		

Appendix M: Second Cycle Analysis and Synthesis Participants' Meaning and Purpose Master Themes

Second Cycle Analysis and Synthesis into Master Themes 'what did our integrated care experiences mean?			
Patterns of ideas source: Participant Interview transcripts & data corpus (including commonalities or differences)	An Explanation source: researchers' interpretations of what was going on (including any surprises)	Unifying Ideas Source: fusion of participant & researchers' ideas	Master Theme
Feels personal (P) – 'I am part of the process'. Compared to GP group practice who 'don't really know me'. We have a thing (G) – 'When making changes he'd say, 'how did that feel'. He'd ask, 'was that alright last time'. Asking questions (S) felt 'respected' and 'supported' by the integrated care clinic, in how they knew 'how I want to do it – that's good'. acceptance) (s)- prefers finding 'alternative ways' for herself and friends. 'They actually said, "Well, they do look okay, so keep doing what you're doing," and that was good to hear'. Empowered to do things (C) they are not giving me rules to follow. 'I was always told I couldn't cook', yet what her experiences of integrated care meant was that she felt 'encouraged and 'more empowered to do things'. [not] a good use of time (p)–noticed that he was being visited by different community nurses who he had to spend time 'briefing' and 'explaining' the wound dressing to. He raised concerns that inconsistency could prolong his healing, and suggested improvements to the process.	What stood out to me was that each person was involved in a way that felt right for them. There was consistency in expressing that it felt like they had a say; were playing their part, their way; Asking, listening, being heard. They were speaking up – sharing concerns re practices of limited value to their health, providing suggestions for improvement - taking accountability to problem solve. I imagined participants were experiencing; feeling influential/ having freedom / sense of agency/being part of a democratic system (in that they have the power to participate in decision-making) It's like there was a spirit of collaborative relationships; in this together; a desire to improve self & process	I have a sense of personal agency.	I am involved my way.
explaining why (h) 'I'm a bit of an analytical person, I ask questions' 'I want to know why, particularly if it's not working, I've got to do something you know'. Reassuring (l) – staff explained 'look we've really had a good look. There's nothing there'. They then invited, 'we	There was a consistent pattern in that it felt like the right approach for that individual; What they needed at that time. Provided them with the assurance and guidance they required – be it		

don’t expect to see you but you’re welcome’, this was important as ‘I don’t want to be seen as one of those worriers who turn up on the doorstep everyday… It comes from how you want to be seen’. Balancing support and services (d) – Darren referred to ‘information as key’ and being ‘methodical’. He felt anxious on his first visit, he had ‘a lot of thoughts going through his mind’. I did feel overwhelmed yet at the same time supported – the balance was good. feeling safe (c) sought out opportunities for getting a ‘finger-prick’ for testing her diabetes to see if she was keeping on track. The sense of feeling personally safe was multidimensional. Described her processes of continuously and critically processing her thoughts and feelings. Feeling cared for (T) ‘Your part of a group & it’s like a family. It something really special’ ‘You don’t feel like you’re a burden to anyone. They genuinely care, they’re interested’.	data, information, to feel invited or part of something, or a blend. I related this pattern to what I understood to be a person- centred approach. I formed the impression that each person’s needs, preferences, and health goals were influencing their involvement in, and expectations of, their integrated care experience.	My needs were being met [personalised]	
Abiding by the rules + Knowing my place (a) ‘It’s like the same as going to the Doctors’, ‘it’s a job for them’, a ‘free’ ‘friendly’ service. ‘I provide the wound’, ‘social conversation’ and be ‘available when they were available’. ‘I don’t complain, I don’t make suggestions or suggest changes’ (a) Explaining why (H) ‘The GP treatment is the same, it’s no different from what the (integrated care) clinic was doing’, however what was different was that ‘it (integrated care) feels very individual, not standard treatment’.	There was a pattern in that it was personal, although different for each person. They each drew on and made comparison to previous experiences to make sense of this experience. This was commonplace across participants. I used Anne and Helen to provide an example of how the construct of the integrated care service was understood to be familiar to their GP clinic. Interestingly, how they made sense of their experiences of the same wound clinic, were influenced by their personal objectives & goals. Anne sough expertise to progress her healing and would do whatever had to be done. Helen saw herself as the expert and was seeking to tap	I could achieve my goals, my way.	

	into different thinking & options specific to her personal needs. The structure and the responsiveness of the service meant both of their needs were met, just differently		
Knowing my place (A) ‘experience and professional knowledge’ We have a thing + I know what’s going on (G) ‘trusted’, ‘knowledgeable’, ‘professional’ ‘expert’. Being aware (D) – access to a professional; ‘Gives piece of mind’; ‘knowing that someone is there to help … and they know what they’re talking about’(D) Feels personal (P) - Access to ‘knowledgeable’ and ‘experienced’ providers. Access to a knowledgeable and professional service (c) - ‘knowledgeable and available. They’re informed & know where to go, who to put me in contact with’. Professional expertise (H) The GP is not good at diagnosing.... It’s just a fishing expedition, defensive medicine, whereas a good diagnosis and the right treatment is better.	There was a consistent desire to trust the professional, the expert. Belief that in accessing the knowledgeable professional, you were in good hands. People were discerning in who they allowed/ invited into their health care team. Health professionals are pre-recognised as trusted. They can also lose the person’s trust. Being the steward of your own health is a responsibility, that you cannot risk sharing with just anybody. Respect for ‘Certified authority’ was a shared mental model / heuristic by participants.	I had access to someone I knew I could trust to guide me [an experienced professional]	I have peace of mind.
Reassuring (L) – staff explained, ‘look we’ve really had a good look. There’s nothing there’, ‘you are probably safer’, I can ’relax & forget about it’. Getting professional advice (S) ‘I really like that it is somebody who’s experienced in that field, that can look at my skin and give me a proper opinion’. I’m in good hands (B) – ‘very professional’ have ‘complete faith’. being prepared (d) ‘highly qualified’ in that they were prepared and able ‘to answer all and any of the questions’. explaining why (H) ‘Anything I have asked has been answered’ ‘You know why’.	Trust in qualified, professional knowledge, meant that their explanations and treatment could also be trusted. Participants described a personal and interactive relationship – information was tailored for their personal needs, which helped then to make sense, which encouraged trust. The providers adopted the role of being trusted advisors. There was a broad belief / a shared mental model / heuristic by participants that experiences always lead to wisdom – which	I had access to explanations I knew I could trust [authoritative explanations]	

	was generational, linked to social & other health experiences.		
Caring team of health professionals (T)- ‘very professional outfit’ ‘they’re *all* taking to each other’ Access to a knowledgeable and professional service (C) – ‘I love their professionalism’ ‘I like you can disagree on something with a staff member, but they will *always* explain why they disagree’ ‘I like the idea that I could just come & whoever’s there is fine. You’ve got a safe place’. Good use of time (p) - ‘the nurse & clinic communicate; they report back and forth’.	This was more prevalent for those participants who had access to a range of integrated care services. Within the integrated care service staff, they experienced professional behaviours and communications between staff and with them. Professional ethics – privacy Feel safe – cared for	I could trust the staff. [a professional service]	
Not knowing (H) – ‘I didn’t have a number to ring’, ‘I got mixed up. Couldn’t remember’. Progress in treatment was, ‘because of my common sense of what I’ve chosen to do rather than what they (integrated care) said to do’. Being Disappointed (D)- ’the healthcare professionals need to give me the correct information, so that I can undertake the correct methods of treating and managing my wound, so that the best possible outcome is achieved. So, 50% is on the clinic. The rest of it’s on me’. Darren shared how what he had thought to be ‘a prescription for pain management’ was ‘written on a letterhead rather than on a prescription’ and that the pharmacist refused it. Then when he saw his family doctor’s associate, he ‘was not impressed at all’ to be asked to prescribe ‘a narcotic’, ‘a potentially highly addictive drug that can create all kinds of subsequent problems’. Darren was ‘quite disappointed to be honest’- found that his understandings were incorrect, he felt misinformed, the integrated care staff were unreliable. He initiated setting up a my Gov profile to manage his health records, so they could be ‘easily & immediately’ available.	When finding the expected trust in their health professionals had been misplaced, some people felt let down and exposed. This had the residual effect of amplifying their vigilance, the importance they placed on having a reliable source of information (Darren) and in maintaining overall responsibility for ensuring her safety (Helen). They both took action to protect what mattered to them. Stepping up and being a guardian for their health. It was also interesting that they both continued with the service and were positive about their overall experience. This pattern is related to other participants references to fears of ‘falls’, ‘infection’, ‘of toxins found in some medicines’, ‘being allergic’, ‘being alone’. Participants implicitly expressed their vulnerability and their motivations to prefer early intervention as a	I am prepared to step up and initiate action.	I am being vigilant.

	way of protecting their current and anticipated health needs		
Knowing my place (a) - ‘She (doctor) wrote a letter back to the referral doctor ‘next time you go just hand him this’. I know what’s going on (G) - ‘They (GP & Clinic) haven’t talked, but they know’. Not Knowing (H) - ’They had to phone up – the results had gone to the GP – I didn’t know. They don’t give you the thing anymore - the report in an envelope – which was useful because you knew you had them.’ Access to a knowledgeable and professional service (c) ‘When you deal with that building [hospital] its bureaucracy. When you deal with Integrated Care, its community & inclusiveness, they listen to the client’. Her GP of 34 years is a ‘very busy man with a lot of people to look after’ ‘I have to have a new case management plan every year. They must talk but I wouldn’t know’.	The sense of being part of their health experience did not extend to other health experiences beyond the integrated care service. Communication with other professionals and services, not part of the integrated care service, was consistently uncertain. Mostly participants were uncertain if or how the providers or services communicated with each other. Beyond the integrated care service, it was unlikely that the participant would be included or play any formal role in their care or communications, apart from a courier. This was acknowledged, however did not appear to be of great concern to most participants, it was expected.	I understand that beyond the integrated care service the roles I played would be different.	I analyse and adjust my involvement to fit the situation
pattern of ideas: Explaining why (H) – ‘went through everything’ ‘the fact that they thought of different options. What I couldn’t use and what I could… To know the rationale behind (not just treat surface symptoms)’ I’m in good hands (B) ‘in very good hands because [integrated care clinic] always looking for something new’. Reassuring (L) - ’the doctors, for whatever you’ve been there for, that they have done their job thoroughly’. Feels personal (P) – Integrated care service provided a ‘methodology’, was ‘someone to value add to what he’s doing’, providing a good return on his investment.	Some of the participants commented on the integrated care staff rigorous and methodical approach to assessment. Taking the time to meticulously assess and research a treatment that was best suited for that person, rather than a standardised approach. Participants whose preferences were to use a formula or framework to make sense of and process the meaning of their experiences, tended to consistently refer to the benefit of facts, data and rigour.	I benefitted from the health care professional’s logic and critical thinking skills. [aligned with thinking/ sensing processes]	I am benefitting
Feeling safe (C) ‘I feel cared for. They’re interested in my whole body; it all seems integrated into my whole well-being’. ‘genuinely’ and ‘holistically’ cared for ‘	Some participants commented on the integrated care staff engaging in positive human (personal) interactions.		

Keeping positive (N) – felt acknowledged. Feeling understood and respected (s) felt ‘respected’ and ‘supported’ by the integrated care clinic, in how they knew ‘how I want to do it – that’s good’. Feels personal (P) – ‘They’ve [integrated care clinic] got an interest in my health and welfare. They want to see that I do get better not just, “Aw, it’s just another name on a pad or a system”’. Feeling like I matter (T) felt ‘like a human’, ‘a person not just an object’, ‘interested in me’. Knowing them (g) ‘I know them (clinical staff) all’, ‘I don’t have a family that are going to help me’. Feeling cared for (T) ‘Your part of a group & it’s like a family. It something really special’ ‘You don’t feel like you’re a burden to anyone. They genuinely care, they’re interested’.	This generated a sense of being known; that the staff were noticing, interested in them as a person. Taking a holistic view – see the whole person. Felt like the staff understood them and their preferences for self-managing their health care. This raised for me the sense of empathy being experienced, that they were receiving compassionate care. Participants whose preferences were to describe how they felt or use intuition to process the meaning of their experiences tended to consistently refer to the benefits of a genuine caring human connection	I benefitted from establishing a genuine human connection with my health care professionals. [aligned with feeling/ intuitive processes]	
giving a go (H) – motivated, nothing is ruled out, ‘give that a go’ ‘I’ve been going to the GP all the time’ ‘the GP thinks all I’m doing is putting on the steroid lotion’. Motivating (T) ‘I wanna come here’ ‘everybody knows my name. It makes you want to keep going’ I’m doing it myself’ ‘life changing, it opened doors, I’ve got a purpose to live’. Keeping positive (N) – enjoyed being active and social interactions – actively avoiding ‘sitting down’ (N) was motivated by doing things that resulted in improvement. CONTINUOUSLY; PERSONAL COMMITMENT (C) ‘I’m involved in my own health’ ‘So my involvement is not just the hours I spend here, but 24hrs of every day, of every week, month, year’ ‘It’s about attacking my lifestyle at my own pace & for my benefit & those around me.’ Establishing habits (a) ‘health is everything’ I just do it by habit. It’s just part of the routine of the day’, ‘I do things.’	The participants consistently referred to their motivation as being intrinsically driven and that the rewards were personal, being linked to their everyday lives and goals. Health is something that is part of every day. It’s what they do and what they have to do. For example Helen was prepared to conceal, from everyone, that she was visiting different health services in order to optimise her recovery. There was a level of energy and excitement – willingness to be actively involved. This could also be in response to the conditions created by the integrated care service, yet the participants were consistent that their motivation was about how they felt related to progressing their health goals. Sensing they were setting themselves up for achieving their daily living goals.	I was motivated	I am choosing; to make changes that will benefit my health and life goals

Being prepared (D) ‘100% committed’ Feels personal (p) he was willing to work with the integrated care team to do ‘whatever we can explore to speed up’ the process. Feeling understood and respected (S) treating her skin lesions was a ‘full-time job’, that it was all she ‘thinks about’. In feeling ‘respected’ and ‘supported’ she responded by ‘leaning towards’ and giving it her ‘best go’.			
I know what’s going on (G) - ‘I manage to do things’- workarounds to achieve health goals. FEELING SAFE + empowered to do things (C) – ‘I was always told I could do; I am now encouraged / empowered to do things’. ‘I express my emotions, feelings, thoughts through art (involved in Integrated Care art group)’- this was new. Good use of time (P) – saw the efficiency of committing to a regime. ‘You just do what they’re doing’. Reassuring (L) ‘I watch people, try & take on board - I can do that’. Asking questions (s) - ‘I can check things I have researched or heard from others, ’I can just say, “Someone’s told me this, is this right?” Motivating (t) They had given, ‘me the tools’, felt he was building habits and doing it himself, ‘they don’t make me do it. They put it in your head without realising mentally’.	The participants were consistent in that their experiences of integrated care meant that they were tapping into their problem-solving skills, curiosity, and creativity. They were also learning new ways of working through challenges and were able to check-in if they were on track. They tended to methodically observe and then copy others as a way of building their capability, with the intent that they could then draw on in the future when independently self-managing their health needs. Growing & improving self & self-care processes	I was expanding my self-management capabilities	
pattern of ideas: I’m choosing to do something healthy (N)– ‘Well, it’s not for medical reasons. They can’t prescribe things or that sort of thing. As I said, they’re not doctors or anything.’ ’So, coming here is doing something, and it’s also gym. It’s healthy’, ‘it’s enjoyable’ social interactions	Neil was unique in his perspective that he did not initiate accessing the integrated care service for medical reasons. For Neil, he had been personally approached by the integrated care team (post discharge from hospital) and invited to join in the programs. To Neil, it was his choice to turn up, this meant he was choosing to be active and healthy.	I was choosing to be healthy	
Second Cycle Analysis and Synthesis into master themes ‘what purpose did our integrated care experiences serve?’			

Patterns of ideas (consistent; Inconsistent) source: Examples extracted from data corpus	An Explanation source: researchers' interpretations of what was going on	Unifying Ideas Source: fusion of participant & researchers' ideas	Master Theme
Keeping informed (A) 'The wounds I've had were never painful. And they filled me in on the progress'. 'It's starting to granulate now, and that's good'. 'it's the same pair of eyes looking at your wound'. Monitor progress (g) 'tells me how it is going because I cannot see, got to be my eyes, to tell me how it is going' 'if it's improving'. Gives me confidence (s) 'I think just having X [integrated care nurse] opinion and looking at the wounds and things telling me that, "Yes, it looks okay." or if something needs to be checked whether it's infected or whatever then that makes me feel confident'. Plan of action (p) 'early intervention is best. I know the signs, I am assessing and monitoring all the time' 'the minute I see somethings not quite right, I'd rather come in - So I came in and saw them'. I CAN PERSONALLY MANAGE MY HEALTH (D) 'I understand what I need to do to be healed and on track forward' 'I can methodically work through what needs to be done. I can use this to learn and prevent or minimise future complications - down the track'.	Receiving and gathering new and personal information about their response to the treatment, served the purpose of being a point of reference. The person then had a sense of knowing where they were at and could then self-assess whether their actions were contributing to progress or if they needed to get help. Having consistency in the health care provider or having established trust with a team of providers, was useful in giving the person confidence in them and their assessment of progress. Avoiding infection, meaning preventing and protecting from, was important. There was an awareness and fear of the consequences of infection in delaying progress, potential hospitalisation and associated disruptions to daily living activities – work & social. In context of their experiences this pattern linked to the groups sense of benefit in finding peace of mind in being able to trust their integrated care providers judgement, that they themselves were maintaining vigilance and making choices	Providing me with the personal information I needed to assess my progress and the urgency of any actions.	Equipping me with the knowledge, skills and strategies to effectively and efficiently self- manage my current health care needs.
Having a diagnosis (H) feeling safe (h) Received a 'Good' diagnosis. 'The fact that they thought I might have poor blood flow… and that was thinking … that	The diagnosis, methodology, techniques, and treatment plans provided the person with a sense of certainty, which they could work with in their own way. They could use these to		

was good.' 'Having a treatment plan with instructions written on it'. Helping healing (P) 'I saw the vascular surgeon who told me the problem but did not really gave me a solution. The [integrated care] clinic here, gave me a solution'. This was useful as 'the methodology; it is a certain way - just knowing that that gives you confidence'. healing the ulcers was 'helping' ulcers to heal. New approaches (S) 'Probably, the introduction to different bandaging. Yeah, that was really good'. KNOWING I AM DOING THE CORRECT THING (D)- 'Doing the correct thing' 'trained in caring for the wound' 'having a guide - in the event I can look through & make sure I haven't skipped a step - my instruction manual - definitely useful - probably the most useful'.	anticipate, to follow, to monitor their progress. They could trust themselves and play their part with confidence. Made me think, that the more explicit the treatment and escalation plan is, the more confident a lay person is in putting the plan into action without supervision. In context of their experiences this pattern linked to the groups sense of being involved my way and having peace of mind in that they had clear explanations they trusted. They were benefiting from the evidence and judgement of their integrated care provider.	Guiding me step by step on what to do when self-managing my health care treatments and what to look for.	
Being prepared (d) '(the Clinic) provided me with some of the products that I needed in order to manage my condition…provided me with supplies and everything else that I needed, that was fantastic'. Feeling safe (H) provided her with samples of cream and she was 'able to test them to see if allergic'. Avoiding wasting money in purchasing, 'products that you may be sensitive to'. CHOOSING HOW TO INVEST TIME AND MONEY (S) preferred to base her treatment on natural products, which she called 'alternative' approaches. 'Coming here [integrated care clinic], they actually gave me some products. And then when they ran out, I knew what to look for and to order. And that's been really helpful. I mean, it does cost a lot of money. The bandaging costs a lot of money.'	The experience of receiving complementary samples of products that enabled the person to be able to test before purchasing was useful. There was recognition that self- managing health care can be costly and required considered personal investment. There was the impression that people had previously invested money on products that were not effective, right for them (allergic) or delayed their healing progress. They wanted to avoid this. This raises that when developing a treatment plan, it is important to consider the personal and ongoing resource implications of the approach	Supporting me to invest wisely in my health care treatments	
BEING PROACTIVE (L) now 'applies sunscreen' and was 'also wearing a marvellous little hat'.	The integrated care's practical lifestyle approaches to looking after your health-		

Keeping health manageable (D) ‘I can’t afford to get sick’ ‘If I manage good lifestyle changes, I will minimise consultations or mishaps’ ‘I have learnt a lot and do not want to make the same mistakes again’. Keeping myself healthy (B) ’I’ve got to keep myself healthy’ ‘you should look after yourself as long as you can’. All doable; CONFIDENCE TEACHING OTHERS (C) ‘The fact that you don’t have to run a marathon to get some exercise’. I am, ‘walking around the clothesline’. ‘If I’m not here [Integrated Care} to go swimming. I can do exercises in the pool. I can do it because I have practiced over & over & over. I go visit a friend; we do it together in her pool.’ Making it easier to adopt healthy habits (T) ‘I’m doing without realising. Learning self-management techniques like ‘breathing methods’ that I could use when feeling ‘frustrated’ or ‘angry’. CHANGING HABITS (P) ‘Most important thing is to lose weight’. ‘Shed enough weight so that I can physically start doing other forms of exercise’ ‘Improving my eating habits…I’ve got to have more protein and vegetables. I have started dinking chilled V8 juice.’ learning (A) ‘Being involved means ‘to do things to make your body better or whatever’s the problem’. ‘I do things.’ I have learnt about ‘making time to let heal’.	reinforced their existing beliefs & strategies and exposed them to new ways of thinking and doing. They felt confident they could ‘manage’ their health and to adapt the strategies to fit with their lifestyle. Each person’s future health goals had included keeping themselves healthy and well, so they could continue to live independently and enjoy life their way. They felt they were learning new and doable ways. In context of their experiences this pattern linked to the groups sense of choice in adopting behaviours & making changes that would benefit their life goals. It was both motivational and rewarding.	Teaching me practical skills and Do It Yourself (D.I.Y) strategies for now and the future.	Giving me hope practical and creative ways that I can adapt and enjoy when maintaining my health & well-being at home.
Expressing confidence (C) ‘Nothing this program says doesn’t give me hope. They always give me hope here. I think that’s the exciting thing, they’re empowering me to believe that I can be different in the future’. ‘As I look into the future, I’m excited; about being able to say I can cook; about being able to say I did	The way in which each person expressed the effect and impact of their integrated care experiences was personal to their health needs and what was important in their everyday living, now and in the future.		

wake up in the morning & feel ok; about not just my weight, but my whole physical being, being healthier'. Giving choices and permission to act (A) 'to stay in your own home as long as you can is very important' 'provided options that could be drawn on in the future' 'Informed of all the things that I'm eligible to have'. 'It's very important, I'm a carer for my husband. 'I'm his carer'. Asking questions and taking actions to prevent and improve (D) 'speaking to a healthcare professional, asking questions about what things do I need to do in order for me to improve my life so that this sort of thing doesn't happen again or minimise the effect of things returning.' They know who you are (L) 'My vision is not having to spend hours visiting Doctor surgeries' 'I want to do everything I can to avoid that - hoping it's not part of my future' 'I am hoping not to be using Health services at all'. Setting up healthy habits; taking each day as it comes (T) '[Integrated care] It's kept me alive; I don't even touch this stuff (pain medication) and I gave up smoking.' 'Rather than sit there & just go ' Oooo I hate the world'. You look, you learn to look different. The road just doesn't stop here. Tomorrow is a different day'. Keeping abreast of what's new & innovative (G) 'I'd like a wheel machine that I can stand up on, take me everywhere I want to go, so I don't have to walk at all. They haven't invented one that is safe enough. Doesn't take up much space. Would be good for me in the long term. Researching devices/ aids (p) 'Researched an elliptical trainer, it is highly recommended. You stand up and can fit beneath the computer table. Only in USA at the moment and not shipped to Australia.	The consistency was the sense of progress or movement and a self-belief or maybe determination that they had reached a milestone through the support of the integrated care service, and they were ready to keep living their life. The sense of feeling understood and respected, seemed to be contributing as positive motivation, served to enable them to look forward (into the future), excited, ready, and able to take one step at a time, appreciating that everything is connected. Gloria and Pepe expressed their hopefulness through researching innovations from around the world, looking positively to a future where they may be able to access and benefit from the devices.	Generating positivity and hope that I am progressing in achieving my future health and well-being goals	
Setting things up (G) 'if needed I would ring the Integrated Care clinic. I have their numbers.'	Knowing they had permission and were welcomed to access the expertise and knowledge of the integrated care service when		

Having a diagnosis; putting plans in place (H) ‘I know the clinic is here, I know I have bad circulation, they have provided suggestions.’ ‘Has made me think a bit. Think around what plans to put in place, making changes, what is safe’. ‘You can go back’ (L) ‘go back if needed’ “we don’t expect to see you but you’re welcome”. Anticipate that it could be something - go & do something about it. ‘I’ve actually learned that it’s OK’. Knowing backup is close by (B) ‘The fact I know he’s here, and if I feel something is getting out of hand, I can just ring up and get an appointment with him, I find that very reassuring’ ‘very close back up, very close, it’s not far for me to come’. Able to reach out when I needed (T) ‘if there is anything wrong, let us know, the door is open’. Early intervention plan – option to come in (P) ‘the option [to come in] is always there which is good’. Giving choices and permission to act (A) “I’ve got a phone number they gave me to ring if needed on anything’. Safe to talk (C) ‘It’s a bit like a lifeline here, if I ever found myself in really dire straits, I could pop in - people would talk to me’.	self-managing at home or beyond their immediate health care needs was highly valued (a benefit). Securing access to individuals or services that you know, and know you, that you trust will listen to you and advise you when you are unsure, or something unexpected happens, is reassuring and confidence boosting when self-managing your health at home.(gives peace of mind) This was a protective or future proofing strategy, that would avoid the worry of not knowing what to do next in the event something is not going as planned or as expected. Practical plan – strategic. In context of their integrated care experiences this pattern linked to the groups sense of benefitting and was a contributor to their peace of mind	Preparing a ‘just in case’ plan of action that I can self- initiate if necessary	Putting things in place actions to protect me now and my future health.
BEING KNOWN (A) ‘I know my Healthcare team and they know me. That the plans to stay home’ Gives me confidence. (S) ‘They really understand me’, ‘they respect me’, ’they still have time to give me the advice and to have a look at the actual wounds whereas nobody else has’. ‘My doctor (integrative medicine GP), he doesn’t. He doesn’t know about that’ “He doesn’t know anything about the actual wound care.’ Knowing them (G) ‘I don’t have a family that are going to help me’. ‘I know them (clinical staff) all’. ‘Gives you a leg in, I don’t hope to go there, but you have to be practical’.	Establishing relationships with the integrated care service was an investment for now and for the future. It meant letting your self be known, your vulnerabilities and your plans. This also meant getting to know and building trust with the integrated care team. I interpreted that establishing a network of health practitioners that you can trust and call on, was one form of security for those self-managing their health at home.	Making personal connections gives me a sense of being known and that I am welcomed to re-connect in the future (safety net)	

They know who you are. (L) It was important to have, ‘some sort of continuity with your history, so that they have some sort of background of who you are and why you are’. ‘you’ve got to click with someone’. PERSONALISED; THEY’VE GOT AN INTERESTED – INVESTED (P) ‘My GP? no I haven’t seen him since I was referred. Because the medical centre, they tend to change [GPs] there. It’s not a regular doctor like I used to have once upon a time.’ ‘I know the medical centre doctor [GP] will just type in whatever. It’s not like he knows me, he doesn’t really know me’. ‘They’ve [integrated care clinic] got an interest in my health and welfare’. LEVERAGING RELATIONSHIP (D) ‘it’s important to establish a relationship, rapport. Then you can see them when you need to. I know exactly who to call, ask’.	Intentional relationship building – knowing me: knowing you (I am involved my way) I had the impression it may also be in response to lack of relationship with other health providers such as GPs due to their retirement, managing a large practice or adopting group practice structure which meant the person does not have a regular GP or a relationship with their GP. I interpreted this as suggesting that contemporary models of General Practice and the retirement of General Practitioners (GPs) was changing the relationships people had with/ or were seeking from their GPs. In context of their integrated care experiences this pattern linked to the groups sense of being involved their way, making choices, being vigilant and analysing and adjusting in response to the situation they find themselves in.		
Yes but (a) ‘Oh, it was alright. Yeah. It was good. I mean, it’s a great service. It really is. And it’s free, which is a big thing. But I only had, and I never said anything to them, one little complaint.’ Giving them feedback (h) – ‘Senior’s week open day was advertised; I think they said free blood tests’. ‘I did get a follow-up call from seniors’ day, asking was it a useful referral. I said yes, I’ve gone to the clinic. I thought, I’ve already been twice already’. I said it was useful & all this kind of thing. I told them (about not getting the call back), they said ‘oh that’s useful feedback’.	The integrated care service had a survey and a follow-up phone call service in place. Anne and Helen had shared how they provided positive feedback, as the service was genuinely useful for them, and it was free. My surprise was that during the interview, Anne had shared that she had a complaint that she did not raise. Anne held strong views about what her role was in her health care, which was not to provide suggestions. Helen had also shared a complaint; I interpreted her amusement as being cynical about the feedback process. I was not convinced that she believed that the service was listening, organised or would act on her feedback. Rather	Playing my role in keeping the free service going for myself and others.	Inspired advocacy; stimulating me to think about ideas and test out improvements that will benefit me, others and

	than progressing her issue with the service she analysed her own thinking/actions as to what she could do differently next time. Informally, both Anne and Helen expanded on their experiences and concerns during the interview, providing insights and ideas for improvement that would have been of value to the service. Helen also said she had spoken to her integrated care provider		to protect and promote the service.
thoughts and ideas on improvement opportunities (c) ‘I couldn’t even guess how they would evaluate or whatever’. ‘When I fill in the survey, I’m always very positive, because it’s wonderful’. ‘I don’t have much faith in government funding. But Integrated Care they’re changing people’s lives & you can’t measure it (tick the boxes or manipulate the numbers) because its immeasurable’. improvements (t) ‘Advertise the place, hard to find out about it. Needs to be promoted. It’s kept me alive - my mum says that too’. improvements (n) ‘I think people with their-- if they’re not sick, they don’t really look into it. I didn’t know about the Integrated Care programs. So perhaps there could be more information about what it’s about. Yeah improvements (b) Hospitals should make people aware of services available - you don’t know unless you research yourself	The participants all shared that their experiences of the service were of use and value to them and that they wanted to provide positive feedback to support the service. Five of the eleven participants had self- referred themselves to the integrated care service, actively seeking out the service. For others it was the first time they had been aware of the service. There was consistency in that people felt that there needed to be more done to promote the service, rather than leaving it to chance, leaving it too late (as not relevant to them as they were not sick) or losing the service as it would not continue to be funded as the purpose of the service was not truly understood or able to be measured using the usual measures. In context of their integrated care experiences this pattern linked to the groups sense of benefitting and was a contributor to making choices	Raising my awareness of opportunities and threats for the continuation of the integrated care service	
IMPROVE ACCESS TO WOUND DRESSING SUPPLIES (P) ‘I organise my day. I make sure I follow what they’ve done. Keep the same sort of regime going that they do’. Pepe cannot access ‘exactly’ the same dressings as those used in the integrated care clinic.	Pepe (who runs his own business) had been experiencing the integrated care service for a couple of years, he reliably followed the same regime. This was an important part of his healing process. Pepe was also aware that he	Provoking me to think about ways that the	

‘This is important as I can’t get the products from the chemist’. ‘I understand budget cuts may see less access - I won’t abuse, I am very careful how much I use. This would also benefit others’. ‘I don’t want to prolong it on, and on, and on because it is a slow healing process’. IMPROVE SAFETY AND EFFICIENCY (D) ‘Having a ‘Basic kit’ (wound care) available – would be an efficient way of keeping the process & system moving forward – ‘little bit more smoothly, little bit more efficiently’.	could not access what he needed privately and that any budget cuts to the service may limit his and others access to the products. He shared how he could be relied on to not abuse the privilege; he could be trusted to be efficient. From another perspective, Darren’s previous and recent health experiences included free and easy access to supplies. He could see how making supplies available could make the service more efficient. Albeit through different frame of reference, both were positively motivated to think about how to improve the day-to-day operations of the service, whilst also advocating for others.	operations of the service could be improved for the benefit of all.	
Being Proactive - protecting skin (self) (L) ‘So, I need to be much more careful. ‘I’ve always been aware, but I’ve been lazy. So, it’s taken away that laziness feeling and that-- it’s not a kind of it won’t happen to me thing’. ‘that’s new’ advising others to take preventative action (L) living my code. (N) ‘So, I got the good diet, the exercise. I keep my mind busy, as well. Yeah, I don’t know. Probably being nearer to the family but I’m sort of looking at that now. I’m doing all right’. Preventing (C) “I think it prevents before it gets worse. It’s more of a preventative service to stop me ending up in a wheelchair.’ ‘They’re helping me to take responsibility for my own health’ ‘it’s my choice & it’s up to me. Giving choices and permission to act (A). ‘This won’t beat me’.	There was consistency in that the integrated care experiences had served to help everyone take stock, to identify what had and what had not been working for them in their daily lives. Each expressed an awareness and ownership of the changes they needed to make and the effort that was required. They had an appreciation of the work of maintaining and protecting their health, and the consequences of not taking personal responsibility or being diligent	Bringing to my consciousness what was working and what further work needed to be done to protect my health and how I can look out for others.	Recognising what was important everything is connected, holistic, how they think, behave, interact with others has consequences for their health and future
FEELING CULTURALLY AND SOCIALLY CONNECTED (C) ‘It’s good to be able to talk - keep in touch with community’. ‘I was invited to the [Integrated Care] Xmas party, it was like what my family was like when I was growing up. I got what they were joking about- their terminology - what was funny	The benefits of being socially connected were a consistent theme, whether directly related to their integrated care experiences or part of their overall health regime.		

& laughing. I cried all the way home with joy' 'I feel connected with the others, and with the staff'. DOING SOMETHING HEALTHY; SOCIALLY CASUAL (N) 'Well, it's a social contact, of course, which is good.' 'We all sit around and talk. And it's not a day, it's a half day or so. Yeah, they're good.' 'So, it is the health aspect and also the social contact as well which is good. The arts part of it is good too. Everybody enjoys them.' RECONNECTING WITH FRIENDS (S) 'I've started to reconnect with some friends, and we have little get-togethers where we-- I don't know, you might think it's a bit weird, but alternative kind of things. And that's good because it just helps me to-- it's a part of my life that I kind of have let go of.' SOCIAL CONNECTED; CONNECTED TO PURPOSE (L) 'Family & friends essential' 'Connections to other people' 'Social as well as physical - exercise then lunch with friends' 'community is important'.	Facilitating social connections was intentionally built into the Bulbuwil healthy lifestyle programs that Carmen, Trent and Neil attended. They all had significant personal reactions to strengthening their sense of connection to culture, family and others. They all identified a deep-rooted joy in feeling socially connected. Social connections were self -initiated & identified by others as part of their personal healthy living activities. Sally and Lucy both described that being socially connected provided a sense of personal reward and nourishment. It was interesting that Sally had described how self-absorbed she was in self-managing her health that she had let go of her social activities, which she was now reconnecting with. Being social was good for her spirit. Others mentioned the rewards of volunteering and being able to support their family, neighbours. A sense of community was seen as important	Introducing or reminding me of the benefits of being socially connected for my overall health and well-being	

Appendix N: Developments in the literature 2018-2023 –

N1: Papers directly relevant to this research

	GAP	METHOD	FINDINGS	FINDINGS	INSIGHTS
A qualitative study of patient experiences of care in integrated behavioral health and primary care settings: more similar than different. Translational Behavioral Medicine. 8(5):649-659, 2018 09 08.					
#24 Patients' experiences & perspectives on what aspects of integrated care delivery they identify as important. Qualitative – interview – Patient only (n=19) USA Advancing Care Together (ACT). ACT was a 4-year demonstration project (2010–2014) of primary care and community mental health centres (CMHCs) integrating care. We purposively selected five ACT practices (two CMHCs, three primary care practices) from which to draw the patient interview	health needs and/or the location of care Our team found no studies using qualitative methods to explore patients' experiences receiving care in these settings Quantitative studies demonstrate that patient satisfaction of care significantly increases following integration of care. However, quantitative instruments designed to assess patient perspectives on integrated care for research and quality improvement purposes have been developed using expert opinion rather than patient perspectives. Qualitative research engaging the end users of integrated care (i.e.,	provide a rich, yet straight forward description of the experiences of interest, suggest hypothesis, and inform theory formulation and concept development. We chose not to use existing theories or models to guide the process because we wanted to understand patients' experiences with integrated care in an unmotivated way. Our use of reflexivity, multiple reviewers, data saturation, and an audit trail are associated with trustworthiness and rigor in qualitative research methods. Analysis was in three steps. First, analyse individual patient interviews.	Findings: 19 patients described their experiences receiving integrated care; Regardless of the initial setting type (i.e., primary care, CMHC), patients described experiences with integrated care that were more similar than different. Three main findings **1.Patients feel cared for in the context of integration**: Patients felt cared for when integrated teams addressed the full spectrum of their presenting needs; they noticed when clinicians spent time with them to understand how life circumstances related to physical or behavioral health symptoms. **2.Patients reported benefits of integrated**	making health behavior changes (e.g., losing weight, stop smoking) and gaining insight into life events (e.g., job transitions, marital tensions). Interactions with integrated team members helped patients address their healthcare needs as well as to develop and/or improve coping skills Operationally, patients noted that integrated care facilitated communication and improved shared knowledge of care plans between clinical team members. Patients commented that the benefits of integrated care extended beyond themselves, as they encouraged other family members to seek care in these settings and shared	integrated care. Patients highlighted the importance of continuity and trust in practice team members Patients appreciated continuity in both clinical providers and practice staff. The study findings add to a growing body of research on patient-centered care and patient experience of team-based care and emphasize how patients appreciate being seen by medical professionals as people with complex lives, not just health conditions. Patients perceived benefits from integrated care related to personal and interpersonal growth and improved quality and access to care.

sample. These practices had hired staff, were tracking clinical indicators, and were actively delivering integrated care. Aim: to understand patients' perceptions of the care they received in ACT clinics (at the end of the 4-year program) and if these elements differ based on a patient's specific behavioral or physical	patients) may provide novel, critical insight into what aspects of integrated care delivery they identify as important. We analysed the in person, in-depth interviews using an inductive qualitative descriptive approach to	Second step explored how emerging findings manifest across patients paying attention to potential similarities and differences. Third, we reviewed each patient's rich personal story in light of the emergent themes looking for outliers or disconfirming cases.	**care**: Patients described personal, interpersonal, and organizational benefits of integration, regardless of the initial setting type. Patients shared stories of how medical clinicians, BHCs, and ancillary staff helped them work through challenging personal circumstances, including	lessons learned with others. **3.Factors facilitating patient access to and engagement with integrated care**: Service proximity (fostered by the physical closeness of services), relationship continuity, trust in practice members, and cost could facilitate or impede how patients experienced	Similar design/findings to my research - shows can be done through actively and empathically listening to their personal experience. Although different personal/ health/ life needs and wants – what looking for from health service is similar

N2: Papers indirectly relevant, yet of interest to this research

	Lens	Findings	Key contributors	insight	Musings
Experience of living with multimorbidity and health workers perspectives on the organization of health services for people living with multiple chronic conditions in Bahir Dar, northwest Ethiopia: a qualitative study BMC Health Services Research. 23(1):232, 2023 Mar 09.					
(#5) elicited personal meaning of experience of model of care. Qualitative interview – patient only (n=19) Ethiopia Not integrated care	Focus on the model of care. Person adapting/ alternate treatment to life circumstances / financial stress – is themed as poor adherence to treatment	Health system not appropriately prepared to provide integrated, person-centred, and coordinated care	Culture of limited communication – fragmented – conflict advice/treatment	People –describe current state – what feels like (not listened to) end up lying to Dr – too busy/ rushed. ideas for improvement	The safety risks are high. compliance focused – not listening. The person is invisible. Changing model of care – title or process – unlikely to make a difference
"I really had somebody in my corner." Patient experiences with a pharmacist-led opioid tapering program. Journal of the American Pharmacists Association: JAPhA. 63(1):241-251.e1, 2023 Jan-Feb.					
(#6) persons experience of / satisfaction with program. Qualitative interview – patient only (n=25) USA Not integrated care – promoting one model/ provider over another	Focus on model of care – compliance with program Comparison to CAU	Recommend Empathy for patient experience, prepared in advance for intervention, then personalised approach.	CAU does not have time to or capacity to support or address personal needs / keep accountable.	Conditions that promote agency present Convenience All had expectations & were personal – & not met. People feel improvements Not really a fair comparison – different service.	Are we listening? – are we just looking to increase compliance – are we unintentionally stepping on others to provide a 'better' service -? how is this integrated – what about others who are treated by their time poor colleagues
A Patient-Centred Medical Home Care Model for Community-Dwelling Older Adults in Singapore: A Mixed-Method Study on Patient's Care Experience. International Journal of Environmental Research & Public Health [Electronic Resource]. 19(8), 2022 04 14.					
(#7) patient experience of PCMH / Exploring the question - If our model is	PCMH has reported positive outcomes- while patient exp mixed – why?	Participants may not fully comprehend the concept of integrated care.	The perceived experiences in the qualitative part were observed to be a product	If previous care is comparator - assumes everyone had same exp. previously.	If the patients voice has historically been missing – it could be assumed that we have

working, why aren’t they all happy. Mixed method – survey (baseline 184; 6 months 166) / focus group (n=20) - patient & carer ‘proxies’ Singapore Internal integrated model (MDT) not integrated care system	Used PCMH domains to explore. Comparison to CAU	Patient experience is a multidimensional construct which includes any process apparent to patients. Patient experience is a complex, multidimensional concept influenced by patients’ characteristics that may not be easily measurable, such as prior expectations, preferences, attitudes, and available resources, which may have been already in place before a patient ever interacts with a provider	of interaction between their previous experience and understanding in usual care with the expectation and reception of the current service encounter. Studies reported challenges in the accurate measurement for patient experience due to various characterisation of the terms used. Patient experience is sometimes used interchangeably with patient satisfaction and as a derivative of patient perceptions.	People can tell difference ‘special model of care’ – each person understand model differently. Feels different. Convenience Expectations different (after hours) Assume everything connected – system	little understanding of how people have made sense of tradition models of care and how they get the most out of their interactions with HCP / services – what is a good outcome / what are their expectations / what do, we do with this perspective. Might be easier to describe or measure if they were involved in the design of the service in the first place
Aligning care with the personal values of patients with complex care needs. Health Services Research. 56 Suppl 1:1037-1044, 2021 10					
(#9) what could be (not happening now) working with the persons voice/ values to improve the ways that HCPs can offer value-aligned care – that reflects what is most important to patients. Qualitative -interview – person only n=24	Used six domains of health and well-being from previous research to elicit personal values most important for health and well-being – also captured emergent themes from interview. Adapted a Notecard mapping exercise –	Further work is needed to identify new approaches, new roles, and education for health care teams to routinely elicit and align complex care patients’ personal values with care. Values and needs were generally heterogeneous, values-aligned care can be	Health care designed to be efficient and to focus on single diseases. Clinic visits usually 20 min long. Clinical staff unlikely to ask about values. Patients are socialized to limit their discussions of their illness experiences to biological processes in visits with providers.	2-hour interview Help give voice through use of notecard mapping exercise – personal values and needs – select/ describe what was most important. Designing / planning care that identifies patients’ needs and aligns with their values – decreases the sense of burden – more likely to	Why not a patient designed model of care – people know who is good at what - they just want to feel known, listened to appreciate how health impacts on their whole life (not just the disease being treated) Wrap around.

USA, Washington Two-integrated care delivery systems Three groups of patients with complex health, behavioural, and social needs	personalise / choice/ invites conversation. Describe the role that personal values and needs play in the delivery of health care for complex care patients	accomplished through a combination of existing standard care approaches and tailored approaches to specific needs of each person - support a population-health approach that tailors care based on the characteristics of individuals	Likely that each patient will require individualized care based on their personal values and challenges (e.g., social isolation, limited financial resources). need to help patients voice how health care might be delivered to meet their personal values and needs.	be integrated in their lives then be work or frustrating/ tensions. Helpful in identifying what is a meaningful outcome for that person. Environment not ready for this – not set-up, not trained, role-conflict, will increase cost.	People see/ work the system every day. Does not align with current understanding of efficiency in service delivery.
Goal planning in person-centred care supports older adults receiving case management to attain their health-related goals. Disability & Rehabilitation. 43(12):1682-1691, 2021 06.					
#10 Testing whether older adults are able to use/ engage with a goal planning process. Person (n=233) Netherlands Community living adults accessing integrated care service	Goal planning procedure in the Embrace Intervention Group - Thought to enhance autonomy / self-efficacy and improve collaboration/ communication with care providers - improving impact. Use of visual analogue scaling scores - adapted from faces pain scale.	Older adults who formulated lifegoals mainly preferred maintenance of health, increased physical activity, and increased socialization. Health is thus an important goal, even when seen in a broader life-goal perspective. Heterogeneity of the goal plans.	The most important aspect we covered was the central role of the client in prioritizing, judging the relevance, and evaluating goals. Due to range of goals – required staff to have broad skills or be well connected. Mobility and pain goals not likely to be attained	All achieved one goal. median length of a goal time-frame was 283days (takes a while). Did better than they thought (higher score on completion than predicted)	So simple – engaging, rewarding. Adapt of visual scale builds confidence – helps realise/articulate what goals are / see that small steps are achievable –? might be good to reassess goals/ reframe after 12 months if not achieving
Patients' Attitudes and Perceptions Regarding Social Needs Screening and Navigation: Multi-site Survey in a Large Integrated Health System. Journal of General Internal Medicine. 35(5):1389-1395, 2020 05.					
(#11) – patients' perceptions of whether social needs	Looking to guide implementation of a social needs screening	79% return on survey	In assessing patient attitudes toward health system social needs	People lives are different and change – I like the comment 'social	Reinforces need for investing in shared understanding, the

affect health / attitudes towards introducing social screening. self-administered survey – patient (n=1470) USA Seven primary care clinics within an integrated health system	programs in a patient centred manner	69% identified one or more social needs have impact on health. Most think inability to afford healthy food & basic expenses affects health. 85% in favour of health asking about, 88% support helping address. 36%supported if included a fee/increased cost If have experienced a social need – have better understanding. No clear pattern in responses across age/ education and support for screening	programs and investment, our study captures the patients' perspective by design but does not capture patients' views, knowledge, or understanding of health system decisions regarding investment in social needs programs. Our study indicates there is a need to raise awareness of the linkage between health outcomes and social needs among patients generally.	risk or social need status is not a static metric'. Good engagement with the survey – conversation starter If people associate social needs with disadvantage – not unusual that would question, why they would pay more -? how could they	rationale as to why service/ model is important. - symptom of not being part of the decision in the first place To understand, need to be able have something to relate to/ compare with - Everybody & their circumstances are different. Health is wealth – health is bound to money – it costs money to be healthy
Are patients ready for integrated person-centered care? A qualitative study of people with epilepsy in Ireland. Epilepsy & Behavior. 102:106668, 2020 01					
(#12) readiness for participating and adopting integrated care. Qualitative – interview/ focus group Open, conversational style – emergent Patient only (n=27) Ireland	Shifting to integrated care model – assessing patients and HCP readiness Exploring the patients' expectations, perceptions, behaviours and values – as exists now	The findings (results) suggest that patient readiness to participate in and adopt a new integrated PCC paradigm cannot be assumed. Demonstrate that the challenge of translating reform policies into practice involves undoing and	Right now, people's thoughts/ actions / expectations are aligned with the traditional model of healthcare delivery – ingrained behaviours that influence their relationship/ interaction with HCP. 'unconscious cultural conditioning', driven by	Want consultant led care within hospital-based specialist setting – their belief is that primary care cannot cater for their needs. Desire (their version) of holistic care – not the aspirational integrated care models version	People do not know that the playing field, the players, the rules are changing – risk that will paralyse them (go back to being passive as don't understand – or angry and / resistant) Raises that person-centred care implies homogeneity – we are

Traditional healthcare model		resetting a range of entrenched formal and informal, conscious, and unconscious, witting and unwitting, everyday interactions that shape healthcare services and the experience of those who interact with it	the health system and HCPs to treat the diagnosed condition rather than the person. And the person may also be complicit in this, as their similarly culturally constituted lived experience has emphasized the primacy of the consultant epileptologist	Have learnt how to influence the current model – cannot spontaneously understand/ change. Findings imply a lack of healthcare system and patient readiness for integrated PCC rather than their disinterest in the concept. The importance of 'time' - linked to being listened to, involved, encouraged	more the same – but what people want/need is different. Again, expects the person to change to fit the system – give up / give in
What the elderly experience and expect from primary care services in KwaZulu-Natal, South Africa. African Journal of Primary Health Care & Family Medicine. 11(1): e1-e6, 2019 Oct 10.					
(#14) explore experiences & expectations to inform model of care. Qualitative – interview/focus group Patient only (n=28) South Africa Primary care (not integrated care model)	Interested in factors that might improve the quality of primary care services for geriatric patients (make primary care services more age-friendly)	Recommendations included: medical staff members need to be more empathetic; clinics should have an integrated service for all health concerns and there should be a priority queue for the elderly and very ill patients	Patient-centred and integrated care for older adults are well-documented principles considered essential for age-friendly services. The participants agreed with these principles.	Despite the economic and health benefits of organising integrated healthcare services for the elderly, there has been little success globally in achieving this objective	Know what needs to happen in principle – how to do it less confident. ? wondering if people really understand what 'an integrated care service' means

Patients' perspectives on integrated oral healthcare in a northern Quebec Indigenous primary health care organisation: a qualitative study. BMJ Open. 9(7):e030005, 2019 07 30.					
(#15) Patients perspectives of service Qualitative - multiple case study design & developmental evaluation Interview – patient only (n=14) Canada integrated oral healthcare Indigenous primary healthcare organisation.	evaluation of integrated healthcare services Used Picker Principles of PCC and Valentijn's Rainbow Model of Integrated Care as conceptual models as guide for interview/ analysis/findings	results demonstrate the value of clinical shared decision making and supportive environment as key features of PCC. Themes map to Picker PCC principles/ Rainbow. Suggests that the key features of PCC are the same in integrated healthcare irrespective of patients' profile, their type of health problems and the nature of the healthcare organisation.	patients valued the integration of oral healthcare in primary healthcare in regard to co-location, "free" oral healthcare services, coordination and continuity of care. Importance of cultural safety – use of language / recognising trauma/ mistrust Cultural respect / sensitive care – non-indigenous learning language participating in rituals	Patients could see / feel impact of staffing issues on waitlists - novel ideas for improvement & public health promotion shared - framed as barriers need to further strengthen the clinical and organisational integration identified - I got the sense this would be taken up by the organisation (alone)	Practice / program implications – if the person is at the centre, it will be inherently different yet same People / patients have novel ideas beyond their experience - interested in building the system – be part of broader improving
Experiences of patient-centred care in alcohol and other drug treatment settings: A qualitative study to inform design of a patient-reported experience measure. Drug & Alcohol Review. 38(6):664-673, 2019 09					
(#16) Patient experience of health care service delivery to inform initial stages of questionnaire development (PREM) Qualitative – focus group. Patient only (n=39) Australia	To improve health care service delivery and, benchmark / compare between & within services through developing a PREM to capture what people. identified as important aspects of patient-centred. care in AOD treatment.	Importance of timely access to integrated care delivered in a structured program by staff members who genuinely care. Positive experiences when services addressed the problems that maintain addiction, held them responsible for	The PREM for Addiction Treatment (PREMAT) is a 33-item measure (including 31 statements with Likert scale and two open-ended questions 'How could your experience at this service have been improved?' and 'What have been the best things about your	Focus group discussions brought out positive or negative experiences, but neutral experiences were overlooked. As a result, important experiences may not have been captured. The inclusion of open-ended items allow the opportunity to capture	People bring important insights – are capable of translating their experiences into an evaluation survey. Holding the space for conflict and disagreement is critical – my bias is that the inclusion of open-ended questions was

alcohol and other drug treatment settings	Used Picker Principles of PCC to guide	themselves and facilitated self-reflection. Stigma was an important negative experience of ADO treatment. Rigorous validation of the PREMAT is the next stage of the ongoing process of developing this measure.	experience here?') that captures what participants said regarding their experience of patient-centred care in AOD treatment. Although Pickers PCC domains appear to be a useful framework, some themes were not well captured by the Domains (e.g., importance of peers).	patient experiences that are not included in the PREMAT. statements. This resulted from the debate / significant discussion from consumers and HCP around items. Acknowledging inherently complex, multifaceted and emotionally charged issues. It was more appropriate to measure on a case-by-case basis when it is personally meaningful to the consumer, and the open-ended items provided this opportunity.	critical for continuous development – important that not set and forget – and that patients continue to be involved in the ongoing evolution of the tool. Existing tools can guide yet need to also be held lightly.
Patients' perspectives on care pathways and informed shared decision making in the transition between psychiatric hospitalization and the community. Journal of Evaluation in Clinical Practice. 25(6):1131-1141, 2019 Dec.					
(#17) Patient involvement and perspectives to evaluate and improve service/ design solution. Qualitative - focus groups – interview & open-ended Patients only (n=10) Norway	Explore patient involvement at the point of transfer of care from community to in-patient: A key transition point, Data themes were presented, and participants placed themselves somewhere along a continuum for individual themes or in	Despite the small sample size, we derived a rich and contextualized information from former patients about factors that were perceived as either facilitators or barriers in the care pathways for this transition. Move from an "evidence-based,	Four themes -each person placed themselves along a continuum & discussed. Patient participation/ activation/empowerment versus paternalism and institutionalization Patient-centred care versus care interpreted as humiliation. Interprofessional collaboration or	Example of solutions: Rather than notional or theoretical participation in their own care, they wanted this manifestly present in reality. Participating in the process of setting care goals together with staff advances patient autonomy and respect. the plan per se is not enough. It should be a	Innovative / effective approach to actively engage people – frame rationale for perspective and what improvement would require / look like

Not integrated care	a dynamic oscillation between them. This is according to an analysis model earlier reported by Hasson- Ohayon et al.	patient-focused" ideology to an "evidence informed, person-centred health and social care" in order to increase the person-centeredness of care provided.	teamwork versus unsafe patient pathways in mental health services Sustainable integrated care versus fragmented, noncollaborative care.	dialogical and ongoing communication relevant to the patient and informed by their perspectives, hopes, and preferences.	
A person-centered integrated care quality framework, based on a qualitative study of patients' evaluation of care in light of chronic care ideals. BMC Health Services Research. 18(1):479, 2018 06 20.					
(#23) Understand how people evaluate their care Qualitative evaluative study - record audit/ interview Patient only (n=19) Norway Not integrated care	Person-Centered and Integrated Care (PC-IC): A PC-IC process is believed to enhance both technical and patient-experienced quality of care. Unclear conceptualization of what PC-IC is, and absence of evaluation. tools that support improvement efforts.	An empathic and sensitive exploration of "What matters" is the basis for understanding what the "overarching goal" for the iPP is. From there flows a set of negotiated goals relevant for care, the care plan, care delivery, and care evaluation. We found that the informants assessed their care in terms of their long-term life goals, although some also focused on biomedical goals. Care planning was common for short-term single diseases, but not for long-term multimorbidity. Informants viewed the	The application of the PC-IC process framework to patient experiences showed that providers do not record nor share goals, care plans, monitoring of care delivery nor goal evaluation for persons with multimorbidity across the care system. We were able to demonstrate the fragmented and profession-centric nature of current care delivery. Our findings describe care systems as focused on professional and diagnostic centric goals. Health professionals focus on disease control, while patients link goals to meaning and well-	Measurement is one key to system change: It gives the basis for assessment of where we are at and can represent a guide to adjustment and improvement efforts. The process of capturing patient stories, as we did, is too cumbersome to be pragmatic in large-scale health service evaluations. However, the informants´ intuitive grasp of the framework is encouraging and attests to the feasibility of pursuing this line of inquiry. To be useful, the process needs to be simplified.	Person centred integrated care is remains an aspiration. Use of medical record audit alone would not give accurate record of events

		"care system", not the individual professional, as responsible for care delivery.	being (e.g., employment, family).		
Effects of a population-based, person-centred and integrated care service on health, well-being and self-management of community-living older adults: A randomised controlled trial on Embrace. PLoS ONE [Electronic Resource]. 13(1): e0190751, 2018					
(#25) Patient-reported outcomes RCT eight different questionnaires to assess patient-reported outcomes in three domains: 'Health,' 'Well-being' and 'Self-management,' as these outcomes are important to ageing in place and to participation in society. n=1456 eligible older adults participated (49%) Netherlands Community living integrated care	to evaluate the effects of the population-based, person-centred, and integrated care service Embrace on patient-reported outcomes at 12 months on three domains comprising health, well-being, and self-management among community-dwelling older people.	We found no clear clinically relevant changes after receiving twelve months of care and support by Embrace on health, well-being, and self-management in the total sample of community-living older adults and neither in the risk profiles. Embrace participants showed a greater but clinically irrelevant improvement in self-management knowledge and a greater but clinically irrelevant deterioration in ADL compared to CAU. This heterogeneous picture was also found in the risk profiles.	The care and support offered by Embrace had fewer beneficial effects and sometimes even unbeneficial effects on the domains of Health, Well-being and Self-management than we anticipated, which confirms the heterogeneous outcomes previously reported in RCTs on integrated care programs for community-living older adults. Based on these results, the implementation of integrated care services for older adults cannot be recommended.	A parallel study on Embrace (#10) showed that perceived quality of care improved. Moreover, in a qualitative study of Embrace, older adults indicated that they felt safe, secure, and more in control due to Embrace care and support. These results could contribute to decision-making and show the need for mixed method evaluations. Mixed method evaluation could also explain the absence of clear effects in the present study. Furthermore, future research should focus on the long-term effects of Embrace.	What works for who, when, why? ? maybe surveys (developed by expert opinion) not by the participants don't capture the nuances of 'transformational' models of care -

Healthcare and Research Priorities of Adolescents and Young Adults with Systemic Lupus Erythematosus: A Mixed-methods Study. Journal of Rheumatology. 44(4):444-451, 2017 04.					
(#26) patient preferences for research priorities Qualitative - interview/ focus group Patients 14 to 26 years only (n= 26) Australia Not directly related to integrated care	Healthcare and Research Priorities of Adolescents and Young Adults with Systemic Lupus Erythematosus The inclusion of patient preferences in research is advocated to make practice and policy more relevant to patient needs and thus reduce research waste – this is an example.	Adolescent and young adult patients with SLE emphasized the need for an integrated and multidisciplinary approach across medical and allied health specialties. They asserted healthcare and research should empower them to self-manage their disease, improve quality of life outcomes, and address the anxiety associated with the unpredictable nature of SLE either directly or indirectly.	The participants' prioritization was influenced by concerns for themselves as well as their family, other patients, and the wider population. Addressing deficiencies in care, focusing on improving quality of life and ensuring efficient use of available resources were believed to be important for minimizing the psychological, emotional, and financial stress on the community. They prioritized research focused on alleviating poor psychological outcomes.	Differences between age groups were apparent. Young adults – considered financial and personal cost of health services, career goals a driver, adolescents – peers important, minimise stigma & improve body image - priorities influenced by dependency on parents	Concern for others – wider community Resource wise Potential psychological impact far reaching. This is a nice place to start to build from – definitional clarity. Same, sam.e, different
An Exploratory Multi-Case Study of the Health and Well-being Needs, Relationships and Experiences of Health and Social Care Service Users and the People who Support them at Home. *International Journal of Integrated Care 2023; 23(1):11, 1–16.*					
(#31) explore experiences and needs of people who access and provide HSC at home. qualitative multi-case study - interviews	There is a plethora of literature containing evidence-based accounts of assessing need, planning, implementing, and evaluating IHSC models of care. Whilst	Findings: Interpersonal connections and supportive relationships were instrumental in helping all participant groups feel able to cope with their changing HSC	Promoting trust between people within HSC systems helped to strengthen their supportive relationships and communication, and collaboration was achieved when people	KEY LEARNING AND APPLICATION TO HSC PRACTICE In an online engagement event, members of the public, HSC service users, and informal carers, offered their	Conclusions: This study identifies indicators for improved HSC, advocating co-produced community-driven services to meet the self-defined needs

A Case = Patient + one or two people who supported them at home Service users [n = 6], Informal carers [n = 5] HSC staff members [n = 7] Scotland integrated Health and Social Care (HSC) model	these can guide HSC services and sectors in providing care, the experiences of service users can help to decipher health and well-being outcomes that are important to them. However, there appears to be a paucity of evidence on the experiences of those who access and provide such services. Interpretive Thematic Analysis facilitated the development of a framework for developing insights, concepts, and patterns of meaning across cases. Members of the public in a community network group were invited to explore preliminary thematic findings during analysis	needs and roles. They promoted reassurance, information sharing and reduced anxiety; when they were lacking, it negatively impacted upon experiences of HSC. They acknowledged the positive effect that integration could have on HSC services, with pooled information and resources to promote better outcomes for service users and informal carers. However, 'integration' appeared to be an abstract concept to many participants (across all groups). Services were reported as disjointed, adopting unsafe communication and information sharing practices when bureaucratic processes did not meet the needs of HSC staff, the services, or their HSC system.	were experienced, knowledgeable and flexible in their approach to working with others. When interpreting participants' experiences of fostering connections and relationships in a care provider receiver context, behaviours linked to applications of Bowlby's Attachment theory across the lifespan, were instrumental. To further acknowledge the influence of connection in an HSC environment, a 'blended' theoretical lens was adopted. Caring Theory, Person-centred, Relationship-Based Care theories and evidence informed propositions about experiences of people who access HSC were combined.	insights on how this study's findings might be applied to HSC practice in their local areas [n = 12] (July 2021). They were clear that they wanted their services to provide streamlined and holistic HSC, regardless of organisational or sectorial boundaries. The concepts of People-centred Relationship-based Care have been framed from the viewpoint of participants and entitled 'My People-centred Relationship-based Health and Social Care' (PRHSC) The active part that members of the public and key stakeholders played in developing ideas, study design and refining interpretations, is key to the credibility of these findings.	of those who access and provide care. This study provides a collective perspective – bring all voices together – I am cautious. However great opportunity to establish definitional clarity. Similar to others the aspiration does not reflect practice – 'an abstract concept' – I am wondering the risk of that

Games of uncertainty: the participation of older patients with multimorbidity in care planning meetings – a qualitative study. BMC Geriatrics (2021) 21:242					
(#33) Patient participation in care planning Qualitative study - observation & interview Patient only (n=10) Norway Norwegian municipal health services	Two research questions: What is the patients' role in care-planning meetings? How do patients experience participating in care planning meetings? Inclusion of theory: Game theory was deemed to be relevant because games can serve as a metaphor through which to understand patient participation. The more precise term for game theory is 'interactive decision theory' or 'theory of interdependent decision making'. According to this theory, the encounter between patients and health professionals can be understood as a two-way interaction in which the outcome is affected by the actions and choices of each participant, leading to different types of	In game theory, 'uncertainty' means that the outcomes of decision-making do not depend solely on the actions of the players but rather are subject to the invisible hand of chance. This element of randomness can be depicted as resulting from the moves of an imaginary player: Nature. We examined how the informant's assessed uncertainty in care planning by looking for statements reflecting beliefs about whether and how one could plan care and the likelihood that these plans would come to fruition. Finally, we examined levels of patient participation. At a low level, patients sought or received information without participating in	Finding - These interactions help us understand why some patients participate less in care planning than others. Conclusions: In care planning meetings, the level of patient participation may partly be associated with how the various actors appraise and respond to uncertainty. Dialogue on uncertainty in care-planning interventions could help to increase patient participation. Patients' individual beliefs and their perceptions of personal control influence. decision-making and self-management. There are several specific ways in which this issue could be addressed in the intervention. First, questions could be included about whether	This qualitative study is inspired by constructivism, which explores the realities people construct and the implications of those constructions for individuals' interactions with others. Keeping the game metaphor and the imaginary player Nature in mind may increase health professionals and patients' understanding of care-planning interactions. Because the influence of uncertainty does not apply to all patients equally, future research on the prevalence of this phenomenon is warranted. According to constructivist inquiries, concepts that are developed are open to continuous reconstruction because input from others leads to new or added meanings.	The care-planning interactions were influenced by uncertainty about the course of the disease and how to plan service delivery. Game theory Evening up the playing field Attending to peoples perceived uncertainty - Inviting people onto the field

	games. The roles of the players can be those of teammates, contenders, opponents, decisionmakers, or subordinates. The interaction patterns in our data correspond to three kinds of games found in theory.	decision-making. At a medium level, the collaboration involved dialogue, but health professionals made the final decisions. A high level of participation involved shared decision-making based on patients' preferences, medical evidence, and clinical judgment.	and how patients perceive uncertainty within their situation. We found that health professionals used most of the time in the meetings to collect and share medical information. Second, decision-making and goal setting should be adapted to the patients' temporal focus, that is, whether their focus is on the present or future.	We conclude that care-planning interventions for older patients with multimorbidity should mandate that health professionals elicit and discuss uncertainty to achieve goal-oriented care based on patients' preferences, values, and needs.	
How is the environment integrated into post-stroke rehabilitation? A qualitative study among community-dwelling persons with stroke who receive home rehabilitation in Sweden. Health Soc Care Community. 2022; 30:1933–1943.					
(#34) Patient perspective to inform service development. Qualitative – interview Semi-structured / open ended Patients only (n=17) Sweden Community-dwelling persons with stroke who receive home rehabilitation in Sweden	The aim of this study was to explore how the environment was integrated into rehabilitation at home from the perspective of patients after a stroke.	The main category that was constructed from the data was "Partial integration of person-environment dynamics in the rehabilitation", which was informed by three subcategories: (a) I recover in my home: Challenges and opportunities in the environment, (b) Following a generic approach to therapy: Limited integration of the environment, and	Our study showed that the environment was integrated in a limited manner. The participants were more informed about than involved in their planning of the rehabilitation. The results are important for informing the ongoing development of rehabilitation at home and person-centred care strategies.		Limited evidence of integration into home-environment

		(c) Informed more than involved.			
Consumer experiences of care coordination for people living with chronic conditions and other complex needs: An inclusive and co-produced research study. Australian health review: a publication of the Australian Hospital Association · November 2020					
(#37) consumer experience of care coordination program. Qualitative - interpretive phenomenology and Inclusive, co-production research methodology Interview Patient only (n=6) Australia Barwon Health's Hospital Admission Risk Program (HARP) located in Geelong, Victoria.	There is a paucity of research that has investigated care coordination programs and interventions from consumer perspectives. This inclusive, co-production approach was implemented through promotion of knowledge co-production, collaboration and by establishing a research team with a former HARP consumer, HARP clinicians, and researchers as co-researchers, to co-lead and co-produce the research.	Participants were asked about their lived experience related to accessing the service, communication, health, and supports before and after accessing the service. Results: Five themes were identified: (1) experiencing authentic, values-based care, (2) collaborative care and working together, (3) gaining independence, (4) improved health and quality of life, and (5) limited understanding of HARP at the start.	Overall, participants' experiences were positive, which related to improved health, quality of life, and sustainable supports. While gains were experienced, most of the participants identified that their knowledge of HARP was limited when services commenced, which is an area for service improvement. Implications for practitioners: The study informs practitioners of consumer lived experience of care coordination. Practitioners are recommended to apply the findings to practice by adopting an authentic, values-based and person-centred care approach.	described in the study findings. Service improvement initiatives are recommended to focus on increasing awareness of care coordination services through consumer participation and the meaningful inclusion of consumer voice, which could focus on education for referring health and social care professionals.	Fascinating – their subjective experiences are what they are – they don't really know what the model of care is – what is the intended outcome

Every day and unavoidable coproduction: exploring patient participation in the delivery of healthcare services. Sociology of Health & Illness Vol. 41 No. 1 2019					
(#39) Patient participation in the delivery of health services Qualitative 15-month ethnography of 45 patients in three HIV clinics in New York. Repeated (1–4) semi-structured in-depth, in-person interviews. USA The first interview focused on defining 'quality of care'; the second to quality and overall health; the third focused on the healthcare organisation and perceptions of how it worked; and the fourth interview followed up and clarified earlier issues. Also accompanied participants through	In the context of health care, coproduction describes the participation of service users (patients) in the healthcare system. Through coproduction, services have the potential to achieve greater efficiencies and an enhanced fit between patient needs and services delivered. Is the new framing obscuring coproduction's 'every day and unavoidable' character, that is already part of healthcare service delivery? While coproduction was not an initial concept driving the project, it emerged inductively as a central analytic when we found that patients in these long-term care settings talked about their ideal features of quality health care, and simultaneously	Taking up a 'health practices' approach, an analytic Simon Cohn (2014) has recently advanced as an alternative to a behavioural framing of health, its problems, and solutions. Health practices consider health as what and how people are 'actually doing' the 'social, affective, material, and inter-relational features of human activity', and how these features enable, limit and/ or reconstitute health activities and influence outcomes. Our analysis exploring the 'health practices' of coproduction asks: What do patients 'do' to coproduce – what activities do they perform? What effects do they have on services? And	By constructing a typology of activity types – Building, Accepting, and Objecting – and tracing patients' descriptions of activity performances, the paper shows how coproduction is forged by making and relying upon clinic-based relationships, and for patients also with a broader human community. 'Building' consists of patient activities to develop or improve upon the clinical delivery process. 'Accepting' activities arise from situations in which the service delivery process is not ideal, but patients respond in a manner of acceptance and even support rather than correction (as building)	Coproduction relied upon the blurring of bounded distinctions between people. For example, sharing in being human encouraged empathic actions with direct implications for activities in all categories. The most obvious contribution is to intentionally elevate and integrate co-delivery by bringing into design work and improvement planning an explicit acknowledgement of patients' pre-existing and ongoing actions and insights. Planning activities might include patients and providers jointly identifying the kinds of activities performed by everyone to coproduce services. By bringing in everyday coproduction, we may	Our findings indicate that patients should be recognised for their significant impact on service delivery systems Relationships, defined in several ways, are critical to patients' activities, both within and beyond the clinic. Going beyond means patients blur and collapse commonly health biomedical and operational distinctions and bring these conceptions into the clinic to shape it in profound ways. Doing so offers the opportunity to work with patients to jointly pursue efficiency and also larger goals for patients, which can animate healthcare practices in new and exciting ways. Novel approach

the public spaces of the clinic, recorded words and actions and general nonparticipant observations of public spaces of the clinic (120 days),	demonstrated their contributions to making and shaping its delivery.	critically, what are the social, material, interactional and relational features and factors surrounding these activities? A 'health practices' approach guided exploring patients' activities, their effects on clinical processes, and the conditions surrounding their performances.	or confrontation (as objecting). 'Objecting', defined by patients' explicit rejection of intentional or mistakenly delivered clinical processes. The first insight is that performing activities in the coproduction of services is indeed relational in several senses. At its most literal, coproduction occurs by acting in relation to other people.	move away from significant concerns about the authority providers hold over clinical operations, which is viewed as a barrier to achieve true coproduction. Our findings reroute these concerns away from the presumed challenges of power sharing to focus on what multifaceted, proactive patients are already doing.	Extending theory It's all about human relationships – and connecting with the boarder system of humans
Co-Creating Descriptors and a Definition for Person-Centred Coordinated Health Care: An Action Research Study. International Journal of Integrated Care, 2021; 21(1): 11, 1–13.					
(#40) Draw on the experiences and perspectives of participants to develop themes that translated to descriptors-that is, statements which described service user expectations of using the health service in Ireland. Participatory Action Research (PAR)	A study to elicit the essential elements of people's expectations of the health service. The aim of co-designing and co-creating a definition of person-centred coordinated care (PCCC) and developing a set of descriptors in the form thematic domains and constituent 'I' statements. The Patient Narrative Project's fundamental	In this study, it was the reflections of past experience of and future aspirations for care that the participants spoke of engaging with the health service. Themes represented a 'care without walls' approach where care is integrated, person-centred and collaboratively scaffolded around the	HEALTHCARE I AM CONFIDENT IN: The experiences of the participants pointed to the need to have healthcare that inspired their confidence. a). staff that are competent in delivering my care b) care that delivers me high quality and safe care c) care that is accountable	'Person-centred coordinated care provides me with access to and continuity in the services I need when and where I need them. It is underpinned by a complete assessment of my life and my world combined with the information and support I need. It respects my choices, building care around me and those involved in my care.'	Example of co-design Starting to get confused re all the different terms – appreciate emergence and local input – will be challenging to map across countries -? does that matter or is it about individual outcomes?

approach using mixed methods. 11 focus groups n=78 (service users, providers of care, patient reps) The study was conducted in partnership with caregivers and service user representatives. Ireland Irish Health Service Executive (HSE)	aim was to build trust and confidence in care by listening to service users' experiences. This study reports on phase one of the four stage project focusing on the development of a definition and description of person-centred co-ordinated care. While the term person centred care has been used interchangeably with patient centred care, Eklund et al., suggest person centred care's goal is to foster a meaningful life for the patient, while patient centred care is concerned with maximising functional capacity.	person and their life world. Three broad themes and sub-themes MY HEALTHCARE EXPERIENCES: This theme represented a major relational focus. a) communication that is understandable to me b) communication that provides me with the required information I need c) care that understands my life world including those who care for me d) care that demonstrates positive regard for me e) care that is based on authentic partnership and respects my choices	d) care where I experience continuity MY JOURNEY THROUGH HEALTHCARE: People rarely have a uni-disciplinary or single setting healthcare experience. a) care that has a holistic approach to my health and my world b) co-ordination of my care in health and areas outside health c) access to services when I need them Concurrently with the development of the 'I' statements, the following definition of PCCC was refined through critical reflection with the IPPOSI steering group which drew upon a synthesis of the 'I' statements	To achieve a health service that delivers what people want demands a reconfiguration of health services' delivery. While a similar process occurred in the UK [35] and the definition and descriptors have common foci with this Irish study, there are also divergences, representing the mapping of population and person-centred experiences, integrated at multiple levels	
	GAP	METHOD	FINDINGS	FINDINGS	INSIGHTS
"Caring About Me": a pilot framework to understand patient-centered care experience in integrated care – a qualitative study. BMJ Open 2020;10:e034970. doi:10.1136/					

#44 The aim of this study is to examine patients experiences in an integrated care (IC) settings in order to develop/ advance the model of patient centred care. Qualitative – semi-structured interview – Patient only (n=12) CANADA Two IC sites in Toronto, Canada: (1) a community-based primary healthcare centre, supporting patients with hepatitis C and comorbid mental health and substance use issues; and (2) an integrated bariatric. surgery programme, an academic tertiary care centre. This study sets out to examine patient-centred care experience from the perspective of patients with coexisting health	Notwithstanding the extensive research supporting the effectiveness of IC to improve population health outcomes, it remains unclear how IC promotes patient-centred care experience from the patient's perspective. While patient-centred care is a hallmark feature of high-quality care in IC, the construct is still in its infancy, with limited empirical and clinical evidence to indicate how this construct is conceptualised and operationalised in practice. The lack of consensus in defining related key concepts, such as 'patient-centred care', 'patient experience' and 'patient satisfaction', has affected how these concepts are operationalised and	Qualitative study using a constructivist grounded theory (GT) methodology. Constructivist GT is used to gain an in-depth understanding of phenomena while recognising how social contexts, interactions, sharing viewpoints and interpretative analysis of patient and the researcher influence understanding. Our purposeful sample included patients with coexisting mental and physical illnesses so as to gain an insight into the complexity of self-management of chronic health conditions and the value of physical and behavioural health integration from the patient's perspective. Eligible for participating if they had two or more physical and mental health comorbidities and have been	We used a constant comparative approach to simultaneously collect and analyse data. Analysis of interview transcripts was iterative and inductively driven, using line-by- Line coding, open coding, focused coding and axial coding, to abstract emerging concepts that informed framework construction. Analysis of patient interviews revealed that patient-centred care experience in IC settings is dynamic and evolving. Four interconnected themes explained this dynamic process from the patient's perspective. **Theme 1 'Caring About Me'** emerged as the overarching theme. Reflected their personal interactions; perceived care team to be genuinely caring despite variations in context, conditions, demographics; described similar exp. Of being at	wellness, felt confidence, empowered, accepted & respected, non-judgemental. Helped correct negative self-perceptions and increase trust in provider. **Theme 2 'Collaborating with Me' –** strong sense of alliance with the patient-care team. Fostered by access to timely care, advocating, connecting to resources, promoting engagement in a safe & open environment. South out team at times of setback. Learnt about support services. *While most patients aspired to gain autonomy for their care, some patients required an advocate to convey their care needs and to navigate the healthcare system to address their needs. IC was identified as a gateway for patients to find 'a voice' that they could trust to express their needs*	**Theme 3 'Sharing Knowledge and Developing a Monitoring Self'** Sharing knowledge & experience with others Finding commonalities in their experiences allowed them to question assumptions about their thinking, feelings and habits, to care for themselves. Develop coping skills and cultivate the capacity to self-manage their health and well-being. **and** **Theme 4 'Personalising Care to Address My Needs',** Patients identified their varied and individual care needs and highlighted how important it was to tailor treatments to address these unique care needs in order to improve their health outcomes. Recognising the patient's

conditions in IC settings. The aim is to elucidate essential care elements for a patient-centred care experience in IC to inform evaluation of patients' care experiences in IC.	assessed in practice.16–18 As a result, the absence of this empirical knowledge has limited our ability to reliably evaluate important care domains from the patient's perspective with respect to patient–clinician. communication and relationship construction.	receiving care at their respective IC setting for at least 3–6 months. Semi structured in depth interviews collected between 2017 and 2018. Interviews lasted approx. 90mins - resulting in 1080 min of recordings that were used for data analysis.	the centre of care; helped pats express their care needs, normalise failure & develop entrusted longitudinal relationships with care team. Helping pts recognise their needs & helping them address care preferences during illness and	*more confidently to the care team and to leverage system resources.* *A distinguishing feature of IC teams working with patients with complex comorbid illness was the ability to recognise patients' unexpressed needs and become an additional 'voice' advocating for patients and connecting them to necessary care services.*	whole situation. Helped in overcoming anxiety, stigma and difficulty trusting healthcare providers due to past relational trauma. Importantly, this study advances our understanding of the patient-centredness phenomenon by providing insights into how patients perceive patient-centred care in IC.

N3: Relevant literature reviews (of interest as consistent or extend my research)

Integrated health and social care in the community: A critical integrative review of the experiences and well-being needs of service users and their families. *Health Soc Care Community. 2021 Jul;29(4):1145-1168*					
(#29) This critical integrative review asked, 'what are the health and well-being needs and experiences of people who use IHSC?'. Key Terms Home; Health and well-being needs; Integrated health and social care (IHSC); Service user; Informal carer. The review synthesises empirical literature from six databases (CINAHL; MEDLINE; AMED; TRIP; Web of Science and Science Direct; 2007–2018).	Twenty full-text papers were included, from seven countries worldwide. Nine quantitative, seven qualitative and four mixed-method studies were included. Two papers in this review explore service user health and well-being needs as defined and perceived by the service user (Petch et al., 2013; Spiers et al., 2015). Further research that explores service user-derived health and well-being needs would add to the current body of evidence	CASP appraisal frameworks offered rigor to meaningful representation of the quality of each source. Quality appraisal of qualitative data revealed that a description of samples and justification for their selection was not always clear. Additionally, the researcher–participant relationship was not always considered. Consideration of bias was not always identified. Overall, the quality of papers varied but was generally observed to be low. However, low-quality papers do not necessarily indicate ineffectual evidence (Health Protection Scotland, 2017). Therefore, papers were	This literature illuminates how health and well-being is influenced through IHSC services, including a degree of understanding of some of the needs and experiences of people who use them. Three overarching themes were identified: 1) relationships as a cornerstone of well-being in IHSC, 2) maintaining and promoting well-being through IHSC and 3) delivering services to meet health and well-being needs. Sub themes Feeling able and learning to cope with changing HSC needs - Service users linked confidence to resilience. as time progressed, they felt more content and relaxed about their	Connecting with services and providers to achieve health and social well-being: Overall, models for delivering IHSC services were diverse. No consensus could be found regarding which of the many models for delivery of IHSC best met service users' needs. Early communication and accessing the right professional at the right time was important to service users who accessed IHSC. Professionals were expected to have a high standard of knowledge about the service user's condition and a lack of knowledge had a negative influence on the experiences of some service users.	More evidence is needed on the effectiveness of IHSC as an intervention that promotes health and well-being and its impact on the experiences of those who receive it. Further research that focuses upon the needs of people who use IHSC services, as defined by those people themselves is also warranted.

		not excluded on the grounds of low quality.	changing healthcare needs. Dignity, respect, autonomy, and control over their own services were identified as important to service users.	People who utilise IHSC at home expressed a need to have their voices heard and be involved in making decisions about their own care	
Impact of Integrated Care on Patient-Related Outcomes Among Older People – A Systematic Review. *International Journal of Integrated Care, 2019; 19(3): 6, 1–16*					
(#30) The aim of this systematic review is to investigate a range of patient-related outcomes to identify if any of them may be particularly important when assessing integrated care for older people with multi-morbidity. Patient-related outcomes explored in this review include patient satisfaction, hospital admission, length of hospital stay, hospital readmission* and mortality. Search of English language literature published between 1st January 1995 and 10th	*Hospital admission and length of stay* are outcomes of particular importance as they account for the majority of overall healthcare costs and constitute the starting point of further decline in health in older age. *Assessing patient-satisfaction* is important to understand the care consumers' satisfaction with the medical services provided and to identify the needs and expectations of the healthcare system. *Mortality* is of interest to assess as it is one of	We used the definition of integrated care by Kodner and Spreeuwenberg (2002). *"Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with*	14 articles underwent CASP quality assessment. Six of the studies were classified as having low risk of bias and five studies had a moderate risk of bias. Two studies were considered to have a high risk of bias and consequently excluded. Twelve studies were included (2 randomised controlled trials, 7 quasi-experimental design, 2 comparison studies, 1 survey evaluation). Five studies investigated patient satisfaction, 9 hospital admission, 7 length of stay, 3 readmission and 5 mortalities.	Five studies reported on patient satisfaction of which 2 reported a positive impact and the remaining 3 studies reported no impact. The inconsistency in the findings on patient satisfaction may be explained by a variety in the patients' expectations and the health status of the patients as perceived quality of integrated care has previously been shown to be most prominent in older people at the risk of frailty. Many older people regard deteriorating health as normal and may report being satisfied with the care provided because	Existing patient related outcome measures do not give much to work with. Understanding expectations – what is important to the person. I am wondering if they should all be called patient related outcomes – that should rename the more organisation facing measures to be about service quality measures

October 2018 in the following 5 electronic databases was undertaken: MEDLINE, EMBASE, Cochrane Library, Web of Science Core Collection and Ageline (EBSCO). (Only a small number of studies published before 1995)	the strongest indicators of treatment efficacy and considered the hardest outcome criterion conceivable. A challenge when studying integrated care is the lack of a universal definition of the concept and the many terms used in the literature.	*complex, long-term problems cutting across multiple services, providers and settings. The result of such multipronged efforts to promote integration for the benefit of these special patient groups is integrated care.”* This review focuses on patient-related outcomes and according to Donabedian’s Framework	Findings show that integrated care tends to have a positive impact on hospital admission rates, some positive impact on length of stay and possibly also on readmission and patient satisfaction but not on mortality. However due to lack of robust findings, the effectiveness of integrated care on patient-related outcomes in later life remain largely unknown. Further research is needed to establish the effect of integrated care on these patient-related outcomes	of lower expectations. On the other hand, older people who receive support from informal carers are often very satisfied with their help and may therefore not rank professional social care higher than informal care. Hence, inconsistency in the findings on patient satisfaction could also be due to other reasons including data being self-reported and assessed using various questions and scales.	
Consumers and health providers’ views and perceptions of partnering to improve health services design, delivery and evaluation: a coproduced qualitative evidence synthesis (Review) Cochrane Database of Systematic Reviews 2023, Issue 3. Art. No.: CD013274					
(#32) QES qualitative evidence synthesis objectives: 1. To synthesise the views and experiences of consumers and health providers of formal partnership approaches that aimed	For the purposes of this QES, the term ‘consumer’ refers to a person who is a patient, carer or community member who brings their perspective to health service partnerships. ‘Health provider’	This QES was co-produced with a Stakeholder Panel of consumers and health providers. The QES was undertaken concurrently with a Cochrane intervention review entitled Effects of consumers and	Method limits: There was poor reporting of researcher reflexivity in many of the included studies, which limited the transparency regarding the role of the researcher. Due to this lack of reporting, it is unclear whether the	We start each section of the findings with a link to the ‘CERQual summary ANALYSIS: identified 19 findings, which we grouped into the following five categories.	Example of co-producing literature review. Conclusion Successful formal group partnerships with consumers require health providers to continually reflect and

to improve planning, delivery, or evaluation of health services. 2.To identify best practice principles for formal partnership approaches in health services by understanding consumers' and health providers' views and experiences. Partnering with consumers in the planning, delivery and evaluation of health services is an essential component of person-centred care. There are many ways to partner with consumers to improve health services, including formal group partnerships (such as committees, boards or steering groups). However, consumers' and health providers' views and experiences of formal group partnerships remain unclear	refers to a person with a health policy, management, administrative or clinical role who participates in formal partnerships in an advisory or representative capacity. SEARCH: MEDLINE, Embase, PsycINFO and CINAHL published Jan 2000 and Oct 2018. Grey literature sources websites of relevant research and policy organisations involved in promoting person-centred care. We included qualitative studies that explored consumers' and health providers' perceptions and experiences of partnering in formal group formats to improve the planning, delivery or evaluation of health services. 33	health providers working in partnership on health services planning, delivery, and evaluation. evidence synthesis. We appraised the quality of each included study using the Critical Appraisal Skills Programme (CASP) tool. We did not exclude any studies on the basis of quality because this may have resulted in the loss of valuable insights. However, the appraisal formed part of the review authors' judgements when conducting the GRADE-CERQual assessment which assesses the extent to which the findings of the review are representative of the phenomenon being explored (Lewin 2018). We gave each finding an overall rating of confidence as high,	researcher/s may have influenced participants' responses or the analysis of these responses. All studies gave some description of the context, participants, sampling, data collection and analysis methods. A few studies did not have formal ethics approval, and this was noted during the CASP assessment. Based on our CERQual assessments, we had high confidence in 12 findings and moderate confidence in six findings, indicating they were good representations of the phenomenon of interest. We rated one finding as very low confidence indicating a weaker fit with the phenomenon of interest. Our main concerns with the very low confidence finding were data relevance, adequacy, and coherence.	1) Contextual factors influencing partnerships 2) Consumer recruitment 3) Partnership dynamics and processes 4)Perceived impacts on partnership participants 5) Perceived impacts on health service planning, delivery, and evaluation Best practice principles for partnering in formal group formats were developed from the findings. Principles included leadership and health service culture; diversity; equity; mutual respect; shared vision and regular communication; shared agendas and decision-making; influence and sustainability.	address power imbalances that may constrain consumers' participation. Such imbalances may be particularly acute in recruitment procedures, meeting structure and content and decision-making processes.

	studies included in qualitative.	moderate, low or very low.			

Patient perspectives on primary care for multimorbidity: An integrative review. Health Expectations. 2022;25:2614–2627.					
(#35) Our aim was to conduct a review that centred on the perspective of people with MM in multiple ways, including having patient partners co-lead the design, conduct and reporting of findings, and focusing on literature that reported the perspective of people with MM, irrespective of it being experimental or nonexperimental. In Feb 2020 we searched for published literature in CINAHL with Full Text (EBSCOhost) and MEDLINE All (Ovid). Only English resources conducted since 2005	The question guiding the review was: What do people with MM want their PC to look like? Twenty-eight sources were included in the review. Most of the included articles used qualitative methods including semi-structured interviews. we found five characteristics of PC that were particularly important to people with MM: (1) Care that is tailored to my unique situation; reflects the complexity of MM and how individual contexts impact how care should be designed, and how decisions should be made	(3) a healthcare team that is ready and able to address my complex needs; MM want to be active participants in their healthcare team, they depend on a high-functioning healthcare team that provides coordinated and expert care (4) supportive relationships; people with MM relied on mutually respectful relationships with healthcare providers to ensure treatments and recommendations fit their life, and that they could access information about the health system when and how they needed it and (5) access when and where I need it: means that timely access to	There are many intersections and connections that signify that the boundaries of each characteristic are somewhat artificial and that ultimately, they come together to describe what patients think it might be like to have PC that reflects their needs. Moreover, the results are intended to provide a different way of looking at PC that comes closer to how people with MM themselves see the role of PC in their lives, rather than providing a comprehensive description of ideal PC services. People living with MM highlight the importance of individualized	Due to the complex and often unique nature of their conditions, gaps in services can at worst be life-threatening and may contribute to poor quality of life. For our review, which focused on studies that described the perspectives of people with MM, it was particularly valuable to have patient partners with lived experience of MM to interpret the findings. This engagement was not superficial; it provided instrumental interpretations to see the body of literature and PC in a new way. While technology will likely play a significant role in the evolution of	How the person sees the service - not an ‘ideal’ or comprehensive version of the service Beneficial to partner with people living with MM to undertake the review. In discussing integrated care models, Hughes et al. (#36) suggest it might be important to evaluate models of care based on their meaning to patients, rather than their ability to predict population-level health outcomes. It is therefore important to find better ways to involve patients with MM in the design and

were included. Findings from experimental and nonexperimental studies were integrated into collaboration with patient partners. We conducted quality appraisal appropriate for each (e.g.CASP for qualitative). We included all studies that met the inclusion criteria regardless of methodological quality but used the quality appraisal to examine outlier cases in the findings.	reflecting collaboration between patients and providers. (2) meaningful inclusion in the team; means that they are listened to and appreciated for their expertise by all team members.	appointments for urgent health concerns, alternatives to in-person clinic appointments and timely access to other healthcare resources such as specialists are important to people with MM. This review demonstrates that one of the most significant challenges for people with MM is fragmented care.	approaches to care, including considering multiple conditions together, along with other social and emotional elements of each person's life, in the planning and delivery of their care. Ultimately, for people with MM, these characteristics of PC were more than a preference; they saw them as essential to quality care, and without them, they felt at risk of negative outcomes.	PC for people with MM, it is clear from this review that relationships continue to be a mainstay of PC. We found that the issues for people with MM were to have time with providers to adequately address their issues and that conversations were focused on the person's goals, preferences and specific context.	evaluation of new approaches to the care of patients with MM in PC.
Rethinking Integrated Care: A Systematic Hermeneutic Review of the Literature on Integrated Care Strategies and Concepts. The Milbank Quarterly, Vol. 98, No. 2, 2020 (pp. 446-492)					
(#36) There is currently a heterogeneous body of literature with the term integrated care used by different authors to mean different things. Most espouse "patient-centered" goals and	We therefore set out to make sense of the literature on integrated care by asking four questions: • How has integrated care been defined and understood by different scholars?	In sum, we have found this literature to consider patients' perspectives as formative (setting out that integrated care should be person-centered and coordinated),	This body of literature highlighted the recursive nature of structure and agency and the social practices involved in the organization of work as factors to consider in understanding how integrated care might be	Finally, even when integrated patient care is considered to be objectively achieved it might not be subjectively experienced as such by the patient if they are not, for example, provided with the space	Integrated care can more usefully be studied and understood as comprising an emergent set of practices intrinsically shaped by contextual factors than as an intervention that will

values. Few dispute the principle of integration. (Who would want care that is not integrated?) To date, consistent benefits from integrated care programs have proved elusive. This paper presents a systematic literature review aimed at deepening understanding of what integrated care is, how it is experienced, and how it is conceptualized. We employed a hermeneutic approach. An interpretive and iterative approach, our research questions developed over time as we critically engaged with the literature. A final data set of 71 papers: 31 primary	• What kinds of changes have been attempted to achieve integrated care? • What is known about patients' perspectives on integrated care? • What are the interpersonal, organizational, and economic features of integrated care? We agreed on two perspectives on ways of knowing integrated care (patient perspectives and conceptual models) and two perspectives on the story line of strategies (integrated care as an outcome of organizational strategies, or as the subject of critical and theoretical analysis).	interpretive (explicating meanings of person-centered care), subjective (what it is like to experience integrated care), and objective (measuring if integrated care is present). Findings about what patients value in relation to integrated care (eg, psychosocial, emotional and practical support) and how they understand the care that is provided to them indicates that patients do not necessarily know or value the same concepts of integrated care (eg, case management) as health care providers and policymakers. Patients, service providers, and policymakers had different ideas about, and different	achieved and how it might benefit patients. The authors theorized that patients' trajectories were unpredictable, yet not random. Patients' experiences as they accessed multiple health and care services could be understood as sequences of interactions with norms or rules that are generally followed (similar to the rules of a game). The choices patients made were shaped by the ways in which services were organized. Patients are not necessarily able to fully exercise control over their care or to self-manage. Their experiences are shaped not just by their own agency but also by the "rules of the game," that is, the norms and	or time to be seen as a whole person. Patients' subjective experiences are not determined by external factors such as services but produced by, among other factors, individual responses and choices. When patients do experience and value person-centered care, this is associated with relationship-based care— psychosocial support, feeling cared for, and involved. Recognizing rather than resolving these tensions would mean accepting that relationship-based care offering time and space for patients to be seen and heard is likely to be a necessary (if not sufficient) condition that can contribute to the achievement of integrated patient care. Moreover, provision of this care needs to be understood as not	achieve a predetermined set of outcomes. BAM !!! We conclude that embracing ideas of complexity can open up opportunities for understanding integrated care as multiple, dynamic, emergent, and inseparable from context. Those looking for universal answers to narrow questions about whether integrated care "works" are likely to remain disappointed. Models of integrated care need to be valued for their heuristic rather than predictive powers, and integration understood as emerging from particular as well as

research publications, 22 evidence reviews, 14 theoretical and conceptual reviews, and 4 policy documents.		experiences of, integrated care.	structures of health care services and wider contexts of experiences, such as aging.	necessarily aligning with organizational or system objectives of reduced cost.	common contexts.

N4: Relevant editorial & evaluation synthesis (of interest as consistent or extend my research)

Integrated Care in England – what can we Learn from a Decade of National Pilot Programmes? International Journal of Integrated Care, 2021; 21(4):5, 1–10.					
(#41) This paper represents a synthesis of empirical findings rather than a systematic review of the wider literature. Three major national pilot programmes for integrated care have been initiated within the NHS since 2008 (Integrated Care Pilots, Integrated Care and Support Pioneers and New Care Model 'Vanguards'). All three pilot programmes shared similar high-level aims, such as breaking down perceived barriers between service providers, improving the 'user-centredness' of care and providing more services in a community setting. However, there were differences between	In part, this heterogeneity was a deliberate policy choice, with a degree of 'bottom-up' design of precise objectives and delivery mechanisms being built into the programmes and an expectation that the rest of the country would learn from their experiences. **ICPS Programme** launched in 2008 following the NHS Next Stage Review. Sixteen pilots appointed in 2009 designed to support care integration. Focus shifted to aim of reduced cost. **Impact on patient experience:** Mixed response. No more likely to have discussions about how to deal with health problems, more likely	older people with multiple long-term conditions; high service users, those at risk of hospital admission **Impact on patient experience**: Data are being collected on MDT caseload patients' experiences of care received, and on the impact of being on an MDT caseload on health and quality of life. **Vanguards:** Launched in 2015 with the aim of using pilots to define new 'models' of care which could subsequently be spread more widely. Focus on horizontal and vertical integration between sectors. **Impact on patient experienc**e: No systematic study of patient experience across the programme.	The evaluators hypothesised that ICPs had the effect of 'professionalising' care rather than engaging with patients. No single programme has been able to distil key, generalisable 'lessons' that have then been applied subsequently. Indeed, successive programmes did little to build on one another in their conception nor to synthesise learning as they progressed. The root cause of this absence may lie in a lack of clarity and consensus regarding the precise definition of integrated care, and the objectives of policy makers and local health and care teams. Most programmes had an ambiguity at their heart	by focusing, not on what is done and within what organisational construct, but on what patients and carers consider to be needed and what will best support care workers of all sorts to work effectively together. In this conceptualisation, the precise 'recipe' for integrated care is likely to be highly context-specific and therefore generalisable lessons about 'what integrated care should look like' may arguably be unhelpful given that local experiences have been shaped by factors such as local leadership capacity, opportunities to make progress that are peculiar to local conditions and the shared history of stakeholders. More	Conceptualising integration as a form of work done by staff in collaborating may be a useful way of shifting focus from designing models to looking for simple fixes that make day-to-day work easier. It might also be argued that the design and implementation of at least some integrated care initiatives have tended to be dominated by professional views of effective care, not always focusing on engaging with patient/user-defined needs. Efforts were made to inculcate a user focus – for Pioneers through focusing on realising a set of user-focused statements created by national patient bodies and for Vanguards through public events.

the programmes and between the pilot sites within those programmes in the way that 'integrated care' was interpreted and how pilots were structured.	to have care plans. In case management sites: more clarity regarding discharge; less likely to have been given wrong medicine. But also less likely to be able to see clinician of choice and fewer felt opinions and preferences taken into account. **Pioneers:** Two waves of pilots launched since 2013 (14 pilots and 11 pilots respectively). Focus on three overlapping cohorts:	Individual Vanguards procured individual evaluations, but quality mixed. **WHAT DID THE PILOT PROGRAMMES ACHIEVE?** The integrated care programmes achieved only mixed results. The impact of ICPs on patient experience was more mixed.	as to whether integrated care primarily related to better inter-professional working, new types of health and care organisations, or the introduction of new types of clinical interventions– or all three. It is possible that this (ambiguous) conceptualisation is misplaced, and that integration is best supported	valuable might be the gathering of insights into the principles and processes that support staff to work together better. **Looking forward, future evaluation efforts**: could more usefully focus upon the extent to which any particular innovation helps or hinders cross-boundary working in the service of person-centred care.	However, engagement of citizens and patients receiving services in the design of the interventions was less evident. Given the importance of user engagement as a pre-requisite of effective management of people with long term diseases (a key cohort targeted by pilots) this would appear to be an important omission.

Research in Integrated Care: The Need for More Emergent, People-Centred Approaches. *International Journal of Integrated Care, 2020; 20(4): 5, 1–3.*					
(# 42) Editorial The International Foundation for Integrated Care (IFIC) recently celebrated its	needed to best inform policy and practice, particularly when addressing people-centredness. The workshop debated how research and	Based on subjectivism, aims to critique and transform practice. The **emergence paradigm**, the latest paradigm, a collective of stakeholders,	*Integrated care is the process of help, care and service, managed and coordinated by interconnected highly competent professionals, who by*	This might implicate that values like accountability and accuracy (empirical paradigm) and success and improvement (reference paradigm)	and engagement of patients, carers, families and wider community stakeholders. This is to the detriment of everyone and,

20th International Conference (ICIC20) through a virtual event that brought together patients and carers, academics, care professionals, NGOs, policy-makers and industry partners from across the global integrated care community. (IJIC) used this opportunity to host a workshop on published research in integrated care, specifically to reflect on the quality of existing scientific enquiry. It was concluded that there remained significant shortcomings to current methodologies – for example, in their ability to provide the depth of understanding required to support the knowledge	researchers must change their focus in order to better contribute to the tenet of people-centred integrated care. Reflection on the four quality paradigms for integrated care: The **empirical paradigm** the main objective is to measure reality and guide knowledge production to contribute to evidence-based medicine. Based on positivism and aims to explain, predict and control. The **reference paradigm** adds to the improvement of client care by using models, frameworks, protocols, or guidelines to develop and evaluate care. Research in this paradigm, often based on constructivism or	including patients and/or citizens, explore and co-create new solutions. Underpinned by the research philosophy of pragmatism or participatory research. Aims to inform our understanding of the dynamic interactions and lead to novel practice which respond to the real-world context of local levels. The **empirical** and **reference paradigms** fit best in circumstances that are certain or can be planned; the **reflective** and **emergence** paradigms fit best in circumstances which are uncertain and cannot be planned. Therefore, the science of integrated care would greatly benefit from ‘epistemic fluency’ (i.e., applying	*their synergy – together with the client and his family as partners – find solutions and create impact, continuously adapting to the context and circumstances.* By assessing all abstracts in IJIC published between January 2015 and December 2019 (n = 258) every article was placed in one of the four quality paradigms. The presence of each paradigm was studied in different contexts, looking at the countries of origin, the domain of impact in research, policy or practice and the role of the patient in the research. Summarising the results, the reference paradigm appeared to be most prevalent since 147 (57.6%) studies were placed in this paradigm. In addition, 55 (21.6%)	prevail over professionalism and wisdom (reflective paradigm) and flexibility and willingness to change (emergence paradigm). An active role of the patient, whether consultative or collaborative, was found in less than 20 percent of all the studies. **People-centred care needs people-centred research**: The other hot topic of the discussion was the importance of including people’s perspective in research, but the distinct lack thereof in actual research. Integrated care is by definition person-centred and integrated care strategies should be based on co-creation with patients or citizens in ways that involve,	especially in studies on integrated care, we seem to be missing the point of co-production and not practicing what we preach. Research needs to learn to redistribute power back towards people and gravitate away from a system in which professionals and researchers know best. **Recommendations for integrated care researchers**. A final reflection and challenge from the workshop was that articles published in IJIC should be much more clear on their perspective, about the aim of their research and about the context wherein the research was done and how this has influenced the methodology of the study. More attention

	interpretivism, aims to understand and reconstruct. The **reflective paradigm** the professional or group of professionals is the expert who reflects on the quality of care.	knowledge from all four paradigms). Van Kemenade & Van der Vlegel-Brouwer (2019) proposed a new overarching definition of integrated care, which acknowledges all four paradigms:	of the studies were placed in the empirical paradigm and 45 (17.6%) of the studies were placed in the reflective paradigm. Only 8 (3.1%) of the studies were placed in the emergence paradigm.	engage and empower them. Van Kemenade & Van der Vlegel-Brouwer's (2019) presentation clearly unveiled a consistent bias that exists in both research as well as in practice to the involvement.	should also be paid to co-creation with people in research itself
Always Look on the Bright Side – Lessons Learned from Another Decade of Integrating Care. *International Journal of Integrated Care, 2022; 22(4): 15, 1–3*					
(#43) Editorial 20th anniversary edition, which collates experiences from 21 countries through 13 policy and 1 research articles. Our editorial reflecting on IJIC's 10th anniversary argued that integrated	imperative to build relationships and collaborate across all levels of the system and the need for more robust research and evaluation. The editorial concluded that integrated care was a *'principle whose time had come'* with the hope that in ten	country is co-design with people and communities a key element in whatever direction. Similarly, the focus has continued to be on disease management and on solutions to address the unsustainable rise in	Discussing the key messages and reflections from the past decade with participants and authors during a World Café at ICIC22, the collective agreement was that regions still don't know "*how to integrate*", and thus struggle with implementation. This is	Outcomes-based commissioning and continuous evaluation are still largely an academic promise rather than a reality, as outdated monitoring and performance measurement systems continue to be the easier way out. Constructive	solutions tailored to their needs and to collaborate on an equal footing. Digital solutions must be implemented not as separate projects developed by specialists, but as an integral part of a wider implementation

care had begun to move from a *'backwater activity and into mainstream thinking'* and set out some likely emerging trends for the next decade including: the growth of e-health strategies; the move away from medicalised thinking towards embracing people as partners in care and promoting preventative activities; and system reforms in financing, governance and accountability that would lead to the growth in integrated care systems. But the authors also pointed to some prevailing shortcomings such as the	years' time integrated care would have become 'the norm rather than the exception in the way care is delivered in most countries'. Another ten years on and it would be fair to say these predictions are only partially true. Comparing the 21 countries, it is clear that integrated care as a public policy feature in most countries. In addition, international organisations including the European Union, the WHO and its regional offices have all produced frameworks and policies to strengthen integrated care, collaboration and people-centred services. In many countries top-down is still the prevailing way of implementation, with all its	demand for [acute] care rather than health promotion and prevention. While calls have become louder to move towards more proactive management of health and well-being within communities, most integrated care models still focus on single chronic diseases or a specific target population and rarely consider social determinants of health. The focus continues to be on integration on the organisational level, vertically between secondary and primary care, and horizontally between health and social care providers. There are few examples, which break through these rather traditional boundaries.	exacerbated by the vagueness of policies and a lack of measurable outcomes. How much structure do we need to work together? The consensus seems to be that first and foremost, we need to be more flexible as individuals, organisations and systems. Top-down and bottom-up approaches need to inform each other through continuous learning cycles where policy frameworks allow innovative bottom-up approaches to trial the implications in practice and trigger adequate policy responses in turn. This would enable a more dynamic and community-driven evolution of integrated care. Somewhat confusingly, pilot projects remain a popular approach	relationship building and interdisciplinary teamwork remain challenging as people often do not have the necessary time, energy or resources. The biggest challenge, however, remains the lack of person and community involvement, which sadly pervades all areas of integrated care. So how far have we actually come in these past 10 years? People and communities experiencing integrated care is still far from the norm, but the past decade has shown that with the increasing recognition of its importance and a wider understanding of the complexities, so the political interest and investment in integrated care solutions has multiplied. For the decade ahead	strategy. And another push needs to be made to include outcomes-based evaluation and monitoring as part of a wider data management strategy. We are on an exciting journey where integrated care is transitioning towards population-based solutions, and in the true tradition of emergent strategies, we cannot exactly say where it will lead us – but isn't that what research and life are all about?

	disadvantages and problems. And in no		despite the frustrating fact that everyone agrees that they rarely seem to lead anywhere!	the focus needs to shift to people and communities to give them permission, resources and the agency to come up with	

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