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Telehealth-Based Support for Stroke in Australia: Exploring the Role of StrokeLine

by Muneeba T Chaudhry

Thesis submitted in fulfilment of the requirements for
the degree of

Master of Physiotherapy (Research)

under the supervision of Professor Arianne Verhagen,
A/Professor Caleb Ferguson, Dr Alana B McCambridge,
and Dr Peter Stubbs

University of Technology Sydney
Faculty of Health, Graduate School of Health

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Certificate of Original Authorship

CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Muneeba Tariq Chaudhry, declare that this thesis, is submitted in fulfilment of the requirements for the award of Master of Physiotherapy (Research), in the Graduate School of 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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Articles and Conference Communications

First Author Articles

(compiled directly from the research in this thesis and included in the appendices)

Chaudhry MT, McCambridge AB, Russell S, Yong K, Inglis SC, Verhagen A and Ferguson C. (2023). User profile of people contacting a stroke helpline (StrokeLine) in Australia: a retrospective cohort study. *Contemporary Nurse*. https://doi.org/10.1080/10376178.2023.2262619.

Chaudhry MT, McCambridge AB, Rivera E, William S, Stubbs P, Verhagen A and Ferguson C. A Qualitative Exploration of Stroke Survivor's Experiences of Using a Stroke Helpline. *Health Expectations* [under review]

Conference Communications

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Statement of Contribution of Authors

The Master's candidate was mainly responsible for the work compiled in this thesis, including the design of studies conducted, obtaining ethical approval, recruiting participants, data collection, data analysis and the preparation of the final manuscript.

Assistance in the process was provided by Dr Alana McCambridge, Professor Arianne Verhagen, Associate Professor Caleb Ferguson and Dr Peter Stubbs. Of note, Dr Alana McCambridge and Associate Professor Caleb Fergusson guided the conceptualisation and design of the studies included in this thesis. Dr Alana McCambridge provided further critical assistance during the research design process, obtainment of ethical approval, data collection and data analysis. Professor Arianne Verhagen and Associate Professor Caleb Ferguson contributed substantially to the interpretation of the data analysis and appraisal of written work. Finally, Dr Peter Stubbs provided valuable assistance during the compilation and appraisal of the final manuscript.

Professor Sally Inglis assisted with the critical appraisal of findings and written work included in the first study presented in Chapter 3 of this research.

Ms Katherine Yong and Ms Simone Russell assisted with participant recruitment and data collection processes, along with reviewing findings presented in Chapter 3 of this thesis.

All the aforementioned contributors to the thesis have been acknowledged as authors. Other contributors to the work included in this thesis but not deemed at a level to allow for inclusion as an author have been mentioned in the acknowledgements section of this thesis.

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prior to publication.

Muneeba T Chaudhry

Production Note:
Signature removed
prior to publication.

Prof Arianne Verhagen

Production Note:
Signature removed
prior to publication.

A/Prof Caleb Ferguson

Production Note:
Signature removed
prior to publication.

Dr Alana B McCambridge

Production Note:
Signature removed
prior to publication.

Dr Peter Stubbs

Production Note:
Signature removed
prior to publication.

Prof Sally Inglis

Production Note:
Signature removed
prior to publication.

Katherine Yong

Production Note:
Signature removed
prior to publication.

Simone Russell

Preface

This thesis is structured as a Masters by compilation. Chapter 1 contains a research overview and provides a deeper context to the research topic, including a rationale of the thesis and general objectives. An explanation of the research design and justification of the studies included in the thesis are included in Chapter 2. Chapters 3 and 4 consist of the thesis results and are structured as research articles. Chapter 3 is a retrospective cohort study that presents a user profile of StrokeLine, including who was calling, why they were calling and what StrokeLine staff provided the caller. Chapter 4 is an exploratory descriptive qualitative study using semi-structured interviews of stroke survivors who used the StrokeLine service. Chapter 5 provides a summary of the research, a discussion of findings, limitations of the work and recommendations for future research.

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List of Abbreviations and Definitions of Key Terms

CALD	Culturally and linguistically diverse
CRM	Customer relationship management
Episode of service	A single occasion of StrokeLine service delivery
Episode of care	One or more episodes of service
Helpline	A telephone service providing information and advice
HREC	Human Research Ethics Committee
Stroke	A sudden disruption in blood supply to the brain caused by a blocked or burst blood vessel causing injury to parts of the brain due to cell death
StrokeConnect	A stroke support program managing multiple initiatives for stroke survivors, their families and carers
StrokeLine	An Australian helpline delivering support for stroke prevention, treatment and recovery
EnableMe	An Australian website including information, tools and community support on a single platform for stroke recovery
Telehealth	The provision of remote healthcare through use of telecommunication technology
UTS	University of Technology Sydney

Abstract

Background

In stroke, transitions of care through the healthcare system are disconnected, leaving stroke survivors and their families feeling abandoned. Telehealth-based services such as helplines specific to chronic health conditions have a valuable role in supporting people to self-manage their ongoing care. In Australia, StrokeLine is a helpline service that allows people affected by stroke to seek support from qualified health professionals via telephone, email and social media. Helplines such as StrokeLine may help bridge the gap between transitions of care for those needing ongoing support to navigate the complexity of managing life after stroke.

Research Aims

The purpose of this research was to explore the role of StrokeLine in Australia. The first research aim was to understand how the service is used by describing the profile of people that called StrokeLine, reasons people called the service and the actions taken by StrokeLine in response to caller's needs. The second research aim was to explore factors prompting stroke survivors to call StrokeLine, their experiences during the call and the perceived impact of calling the service on their ongoing recovery.

Methods

The first study was a retrospective cohort study consisting of a descriptive analysis of call data obtained in two parts from the StrokeLine customer relationship management system. Categorically logged call data was analysed from the period between 1 November 2019 and 30 November 2020. In turn, free-text call data was obtained for analysis for two separate months: November 2019 and June 2020. The second study was an exploratory descriptive qualitative study involving semi-structured interviews with stroke survivors who had recently used the StrokeLine service. For the analysis we transcribed the interviews using qualitative thematic analysis.

Findings

In the first study, 34% of calls to StrokeLine were from stroke survivors and 38% of calls were from their carers and family members. They contacted StrokeLine for information and advice, practical solutions, emotional support, and referral advice to other services. The study highlighted limitations in StrokeLine data management processes, as there is significant missing data. In the second study, stroke survivors were prompted to use StrokeLine in response to the fragmented care provided after discharge from rehabilitation, requiring them to seek clarity and emotional support. Participants revealed individual agency in initiating contact with StrokeLine and appreciated the relevant expertise of StrokeLine staff during the call. Stroke survivors felt validated and empowered after the call, understanding the value of the service in enhancing their existing care. The study highlighted the importance of timely provision of information and advice in facilitating self-management of care in stroke.

Conclusions and Recommendations

StrokeLine is used by stroke survivors and their carers to seek person-centred information, advice and support when they most need it. For stroke survivors in particular, the service allows the self-management of their condition by facilitating reengagement with their ongoing care. There is a need to improve StrokeLine data management processes to ensure service provision remains relevant to the needs of those affected by stroke. It is also important to determine how StrokeLine can work with other services to better facilitate timely information provision and support during the transition to self-management of care in stroke across both culturally and geographically diverse settings in Australia. The impact of StrokeLine may help policy-makers make informed decisions about the sustainability of telehealth-based support services such as StrokeLine.

Chapter 1

Introduction

This chapter introduces the thesis and presents the foundation for the entire program of research. It begins by outlining the structure of the thesis. The chapter provides the background for the focus of this thesis. A definition of stroke and its prevalence is provided, before the consequences of stroke are outlined. A brief literature review expands on the research focus. Continuity of care in stroke is explained, with a particular emphasis on defining transitions of care and presenting the complexities associated with navigating the healthcare system post-stroke. The importance of self-management of care in stroke is outlined, with particular emphasis on the role of stroke support services in facilitating this. Limitations of existing services and meeting the needs of people affected by stroke are outlined. Telehealth models of care in stroke are explored and the implications for telehealth in facilitating self-management of care in stroke is expanded upon. From there, helpline-based care provision is introduced and the StrokeLine service is described. The chapter ends with providing a rationale for conducting the research presented in this thesis. Finally, the aims of the thesis are outlined, including key questions used to guide the entire program of inquiry.

1.1 Thesis Overview

This thesis is compiled in five chapters. This current chapter introduces the program of research. In recent years, an increasing number of people are living with the long-term effects of stroke (Guo et al., 2021). There remains a disconnect between transitions of care in stroke, especially between acute discharge, structured rehabilitation interventions and reintegration back into the community (Forster et al, 2012). Stroke survivors and their families report feeling abandoned and continue to need ongoing support to navigate through transitions of care through the healthcare system (Ghazzawi, Kuziemsky, & O'Sullivan, 2016; Wissel et al., 2013). Research into the services available to stroke survivors has identified a need for services that provide more personalised support (Forster et al, 2012). Recently, the success of telehealth in facilitating supported self-management across several chronic conditions has been well-documented (Arvidsson, Nylander, & Bergman, 2019; Boltong et al., 2017; Hanlon et al., 2017). These long-term conditions include rheumatic diseases, cancer, diabetes, heart failure, asthma and chronic obstructive pulmonary disease (Arvidsson, Nylander, & Bergman, 2019; Boltong et al., 2017; Hanlon et al., 2017). Research into the use of telehealth to support self-management of care for stroke survivors, however remains limited, especially in the Australian context. A brief review of literature is included in this chapter to aid in defining and contextualising key concepts, particularly around the management of stroke in Australia, models of care in stroke and the use of telehealth to provide care.

Chapter 2 describes the methodology used for the thesis. The thesis is guided by exploratory studies investigating the role of healthcare services for chronic conditions. The chapter includes justification of a multi-methods approach. The quantitative and qualitative components of the thesis are expanded upon in this chapter and described. This chapter clarifies how the research was conducted and provides context for the results chapters. To achieve the objectives outlined in at the end of this introductory chapter, two research studies were undertaken (Chapter 3 and Chapter 4). The first of the results chapters is presented in Chapter 3 as a retrospective cohort study. The chapter presents an overview of the use of StrokeLine. Descriptive analysis of data obtained from the StrokeLine CRM system over a 13-month period was performed to identify who was calling StrokeLine, why they were calling and what StrokeLine provided the caller. Qualitative content analysis of 'free-text' data, collected at two random months during the 13-month study period was also performed to further explore reasons for why StrokeLine was used and how enquiries were addressed. Chapter 4 explores the experiences of stroke survivors who have used StrokeLine through an exploratory descriptive qualitative study using semi-structured interviews. The chapter explores the factors prompting care, how care was provided by StrokeLine and what the caller perceived the impact of using StrokeLine was on their stroke journey. Thematic analysis was used to explore data from transcribed interviews. Finally, Chapter 5 discusses the thesis as a whole, bringing together the research and discussing the implications of findings. The chapter reflects upon the results and suggests strategies for StrokeLine service improvement. Recommendations for health systems, policy makers and future research are also highlighted. The chapter ends with outlining conclusions from the program of research.

1.2 Background

Stroke is an acute neurological event that occurs when the blood supply to the brain is disrupted, causing an injury to parts of the brain due to cell death (Hawkins et al., 2017). Globally, mortality rates associated with stroke have decreased over time due to advances in research and consequent improvement in treatment outcomes (Johnson et al., 2019). In Australia, the mortality rate of stroke declined by 70% between 1979 and 2010 but it remains a leading cause of long-term disability (Australian Institute of Health and Welfare, 2013). In 2020, approximately 445,087 Australians were living with the effects of stroke and the number of stroke survivors in the community is expected to increase by almost 40% by 2050 (Deloitte Access Economics, 2020). The majority of those affected by stroke are older than 65 years but the prevalence of stroke in young Australians is on the rise, with 24% of strokes in 2020 occurring in people younger than 54 years (Deloitte Access Economics, 2020). For Indigenous Australians, stroke is up to three times more likely to occur than the non-indigenous population and it is believed this figure may be underestimated (Australian Institute of Health and Welfare, 2021; Blacker & Armstrong, 2019).

The effects of stroke on an individual are sudden, diverse and can affect every aspect of a person's well-being (Olver et al., 2021). Depending on the specific areas in the brain affected, physical impairments associated with neuromuscular functioning can occur and may exist with cognitive, sensory, language and speech limitations (Olver et al., 2021). Consequently, the implications of stroke extend to psychosocial functioning and can impact an individual's ability to engage with activities of daily living and occupation activities (Walder & Molineux, 2017). These implications can persist long after the acute event and change (improve or worsen) over time, making stroke a lifelong disease process for most individuals and their carers (Olver et al., 2021). As such, the management of stroke has wider social consequences in Australia, adding a significant burden on the health care system and economy. In 2020 alone, stroke cost the health system approximately $1.3 billion across its associated trajectory of care (Deloitte Access Economics, 2020). Given the impact of stroke in society, it is vital to ensure the health services available to support stroke survivors and their carers across the trajectory of their care are evidence-based and meet the needs of consumers.

1.3 Literature Review

1.3.1 Management of Stroke in Australia

The management of stroke follows a trajectory of care with multiple transitions between care settings at each stage of recovery. Post-stroke recovery is often time-dependent and the time after a stroke has occurred is categorised in distinct phases that aid in establishing appropriate management processes (Grefkes & Fink, 2020). The hyperacute phase occurs in the first 24 hours after a stroke, followed by the acute phase in the first 7 days after the stroke. The early sub-acute phase occurs in the first 3 months after a stroke and the late sub-acute phase continues on from 4-6 months. Finally, the chronic phase of recovery begins 6 months after the stroke first occurred (Bernhardt et al., 2017).

Research into acute stroke services has seen rapid innovation, improvement and standardisation across settings of service delivery over the past few years in Australia (Australian

Institute of Health and Welfare, 2013). In Australia, stroke care begins with prehospital management coordinated through ambulance services equipped with the skills to asses emergent cases and diagnose potential stroke, ensuring relevant medical intervention is provided with minimal delay (Pulvers & Watson, 2017). Hyperacute and acute management is then initiated in the hospital, either within an acute stroke unit, intensive care unit or general ward (Australian Institute of Health and Welfare, 2013). This is then followed by discharge back into the community, transfer to a dedicated rehabilitation unit or program for further care or death (Australian Institute of Health and Welfare, 2013). The rehabilitation needs of stroke survivors are extensive and multiple models of care to address them exist at this stage, including inpatient delivery during the hospital stay, early supported discharge programs and structured community-based rehabilitation at home or in outpatient hospital settings (Australian Institute of Health and Welfare, 2013). Rehabilitation is these settings is delivered formally through structured programs immediately following a stroke and into the early sub-acute phase. Often formal rehabilitative care decreases in intensity after this point and stroke survivors are increasingly expected to self-manage their ongoing care (Warner et al., 2015). There remains, however, a disconnect within transitions of care in stroke between acute discharge, structured sub-acute rehabilitation programs and reintegration back into the community (O’Callaghan et al., 2022).

The true impact of post-stroke limitations may not be fully understood until stroke survivors begin to adjust back to daily life (Duxbury et al. 2012). Ongoing care decisions made during the discharge planning process may not account accurately for the evolving needs of a stroke survivor (Duxbury et al. 2012). As such, Stroke survivors and their families report feeling abandoned by the healthcare system, as they go through the transition to self-managing their care (Ghazzawi, Kuziemsky, & O’Sullivan, 2016; Wissel, Olver, & Sunnerhagen, 2013). Self-management in stroke relies on stroke survivors assuming responsibility and establishing power over their own care (Kidd et al., 2022). The move to such autonomy after a stroke, however, is a dynamic process that requires ongoing support to both establish and maintain (Fletcher, Kulnik, Demain, & Jones, 2019) .

1.3.2 Supporting Self-Management of Care in Stroke

Self-management support exists as a core component of multiple chronic disease management models, emphasising the role of the individual in managing their own health after an acute event and reducing the ongoing burden on healthcare systems (Grover & Joshi, 2014). As with most chronic conditions, self-management of care in stroke cannot occur in isolation and requires collaborating with healthcare professionals who can provide support during the ongoing process of managing long-term care needs (Lennon, McKenna, & Jones, 2013). Access to long-term services that can support stroke survivors to self-manage their condition are important, both for physical and non-physical needs. Psychological support, reassurance and being personally valued are non-physical needs that can often be neglected during transitions of care in stroke but are key to enabling empowerment (Peoples, Satink, & Steultjens, 2011). Stroke survivors often report that their diverse educational needs are not met during the transition from hospital to home and they lack confidence in taking charge of their own care (Lin et al., 2020). Self-management support initiatives take on a person-centred systematic approach to providing support that is not limited to the provision of patient education, where information is simply imparted as a means for transferring knowledge (Trappenburg et al., 2013). Self-management support relies significantly on increasing health literacy in conjunction with behaviour change, both of which aid in rebuilding a level of self-responsibility (Lennon et al., 2013; Lo, Chang, & Chau, 2018).

A range of interventions exist in supporting self-management in stroke and often involve shared decision-making, provision of relevant information and emotional support (Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019). In self-management support interventions, shared decision-making with healthcare professionals aims to empower individuals with the skills to identify and make the best decisions to manage their own health (Fletcher et al., 2019). Goal-setting is often involved and the individual is provided direction to increasingly take charge of maintaining, monitoring and managing their own care needs (Jaarsma et al., 2021). For stroke survivors, the potential benefits of self-management support include increased self-efficacy, confidence, knowledge of secondary consequences of stroke and enhanced quality of life (Fryer, Luker, McDonnell, & Hillier, 2016; Lennon et al., 2013; Lo et al., 2018). Most interventions take on a multi-disciplinary approach, often combining psychosocial education with physical interventions (Parke et al., 2015). Self-management support is provided across multiple structured sessions with qualified health professionals, combining both face-to-face and home-based interactions (Parke et al., 2015). The use of supplementary workbooks, videos and computer-based quizzes are further implemented in delivery models to aid with reinforcement of information provided (Lennon et al., 2013). In recent years, telehealth has been increasingly incorporated in the delivery of self-management interventions for stroke (Hwang, Park, & Chang, 2021). Telehealth models of care are known to be implemented across the early trajectory of stroke care to deliver cost-effective specialist intervention for acute management. (Nelson, Saltzman, Skalabrin, Demaerschalk & Majersik, 2011; Tan, Gao & Moodie, 2021; Kim et al., 2022). For the long-term management of stroke, telehealth models of care may be key to providing personalised support to stroke survivors when and how they need it (Hwang et al., 2021).

1.3.3 Telehealth Models of Care in Stroke

Telehealth involves remote access to health services through the use of telecommunications technology such as phone, internet and videoconferencing (Dorsey & Topol, 2016). In recent times and particularly in response to the COVID-19 pandemic, the utility of Telehealth has increased dramatically and health services are increasingly integrating its use in routine care (Smith et al., 2020). In stroke, telehealth models of care have existed for some time across the trajectory of care. In the prehospital and acute setting, telestroke or stroke telemedicine exists to remotely connect stroke specialists to hospitals with no specialists on site to provide immediate care to patients presenting with stroke and provide ongoing follow-up (Hess & Audebert, 2013). Pre-hospital treatment decisions related to the urgent administration of thrombolysis can be coordinated remotely between hospitals and ambulance services (Cooley et al., 2021). Remote doctors can access real-time brain imaging of the presenting stroke patient and can provide a timely diagnosis to initiate further appropriate management. In turn, telerehabilitation in stroke provides remote, cost-effective access to physical rehabilitation services for stroke survivors through telephone, internet or videoconferencing (Laver et al., 2020). The feasibility of telemonitoring in stroke through smart phone apps has also been recently investigated, particularly remote monitoring of blood pressure to prevent secondary stroke and the use of sensors to remotely monitor movement patterns during telerehabilitation programs (Eng & Pastva, 2022).

Research into the use of telehealth to support self-management of care for stroke survivors has also grown in recent years, particularly in response to the increasing number of interventions using telecommunications technology to supplement the care provided in other settings (Hwang et al., 2021). Telehealth-based components in self-management support interventions include using smart phone messaging applications, video-conferencing or email to provide stroke survivors with personalised reminders, encouragement, feedback and education (Hwang et al., 2021). The use of telephone-based communication is common and used as a way for qualified health professionals to contact stroke survivors during the course of a structured self-management program (Hwang et al., 2021). Telephone interactions can aid in providing more personalised support and information in response to particular concerns raised or questions asked by the stroke survivor (Crocker et al., 2021; Hwang et al., 2021).

Generally, self-management interventions for stroke remain significantly varied and may not always align with a stroke survivor's individual needs (Kidd et al., 2022). Little is known of the optimal timing of when self-management interventions may be most effective or the best method of delivery (Lennon et al., 2013). In turn, most interventions are often governed by set timeframes and pre-determined contact with health professionals (Kidd et al., 2022). A majority of telehealth-based self-management support interventions remain similarly structured in their approach, initiated by the healthcare professional and delivered over a set time-frame (Hwang et al., 2021). Such methods of delivery may fail to account for the long-term variability in post-stroke related impairments amongst individuals (Boehme, Toell, Lang, Knoflach, & Kiechl, 2021). As such, self-management interventions may not be flexible enough to address individual support needs of stroke survivors, particularly as they change over time. More flexible methods of providing support to stroke survivors need to be considered, as an alternative option to a one-size fits all approach (Kidd et al., 2022). Telehealth-based services such as health helplines exist for a range of chronic conditions and have been known to provide support to people who initiate contact with health professionals whenever they need it (Arvidsson, Nylander, & Bergman, 2019; Ekberg et al., 2014; Lopriore, Turnbull, & Martin, 2021). Research into the use of helplines in stroke, however, remains limited, especially in the Australian context.

1.3.4 Helpline-Based Care Provision

The provision of healthcare through telephone-based delivery models exist in different settings and can be a cost-effective method of delivering healthcare (Ekberg et al., 2014). Emergency services, health-related call centres, primary care consultations, and health helplines are among the most common models of telephone-based care, each differing in their management and practices. Contact with emergency services is often in response to the need for sudden acute support of a rapidly evolving health event (Sexton et al., 2022). Telenursing and telephone-based triage can often be established through call centres catering to the provision of general health advice, assessment and recommendations for seeking further care (Knight, Kenny, & Endacott, 2015; Ng et al., 2012). Primary care consultations are initiated with doctors in response to less urgent health concerns and involve an element of diagnosis. Health helplines exist in varying capacities to provide information and support for a range of pre-existing health conditions (Emmison & Firth, 2012; Harding, Parker, Hean, & Hemingway, 2018). The commonality between each of these services, however, relates to the inbound method of seeking care whereby an individual initiates contact with the service in response to a self-identified need.

Health helplines, in particular, remain unique in their ability to expertly cater to the support needs of a particular population (Emmison & Firth, 2012). In Australia, health helplines exist for a range of both mental and physical health conditions, such as depression and cancer (Clinton-McHarg, 2014; Pirkis et al., 2016). These helplines are operated either as government-funded national services (such as the Healthdirect Helpline) or by not-for-profit organisations that provide advocacy and support for those with a particular health condition (Healthdirect Australia, 2020).

Not-for-profit organisations such as Arthritis Australia and Kidney Health Australia provide helpline services for anyone with questions or concerns about arthritis of kidney disease in particular (Arthritis Australia, 2020; Kidney Health Australia, 2020). Services usually operate between routine business hours but in some cases can offer 24/7 support depending on the funding and staffing capacity of the service provider. Accessibility to health helplines can be facilitated in most settings by the integration of free language interpretation services or hard of hearing services, such as the National Relay Service in Australia (Department of Infrastructure, Transport, Regional Development, Communications and the Arts, 2023). Often telephone-based care provision is further integrated with web-based methods of contact using email, social media or website-based chat boxes.

Notably, the Healthdirect helpline in Australia operates as a government-owned generic health helpline. It provides 24/7 access to nursing professionals who can provide health advice and information over the phone (Healthdirect Australia, 2020). The helpline also provides multiple avenues of seeking care through a designated website containing condition-specific generic resources and other integrated health helplines, such as the Pregnancy, Birth and Baby service (Healthdirect Australia, n.d.). The strength of the Healthdirect helpline relies heavily on a steady stream of funding, appropriate staffing, telephonic integration with existing government services and sustainable service infrastructure. In January 2020, Healthdirect in Australia received an increase in federal funding to use existing infrastructure to launch the National Coronavirus Helpline. The helpline was launched in five days, operating between select business hours and expanded to 24/7 access a month later (Healthdirect Australia, 2020). The service received calls diverted from every state and national service provider with call diverting capability to ensure the provision of consistent advice and up-to-date clinical information. In March 2020, the service was estimated to receive 25,000 calls per day and within a week, staff numbers were increased from 35 to more than 800 to meet increased demand (Healthdirect Australia, 2020). Consequently, increased demand on data management processes facilitated a complete rebuild of the Healthdirect infrastructure to not only account for the increased demand but to also support service providers working from home across multiple locations (Healthdirect Australia, 2020). To facilitate consistency of information provided by all call takers, Healthdirect Australia also developed an online knowledge database for staff with regularly updated information. In turn, the COVID-19 Symptom Checker provided a consistent method for call takers to assess callers with COVID-19 symptoms (Healthdirect Australia, 2020). Little is known, however, of the use of Healthdirect for specific conditions and the service may be limited by its generic provision of healthcare information for a wide range of conditions. Where self-management support relies on ensuring care is person-centred, condition-specific helplines may be better able to contextualise the needs of those seeking support and better personalise service provision (Lawn & Schoo, 2010; Lopriore, LeCouteur, Ekberg, & Ekberg, 2017).

Globally, the literature on health helplines for a range of conditions reports most often on their overall use, the experiences of users and the way in which calls are handled in real-time (Bloch & Leydon, 2019; Harding et al., 2018). A retrospective analysis of call data collected from the Cancer Helpline in Australia noted most callers used the service to obtain information about cancer prevention and treatment (Jefford, Kirke, Grogan, Yeoman, & Boyes, 2005). Patterns of caller behaviour to a mental health helpline in Ireland were determined by analysis of call data across a four-year period and noted a marked frequency of repeat callers with ongoing mental health concerns (O'Neill et al., 2019). Callers to five major cancer helplines in the UK were interviewed and their experiences with seeking care highlighted the ability of helplines to address both the caller's information and emotional support needs (Ekberg et al., 2014). Boltong, Ledwick, Babb, Sutton, and Ugalde (2017) reported callers to cancer helplines across Australia, the UK and USA were better able to understand their condition and discuss it with other healthcare providers, their friends and their family. Arvidsson et al. (2019) explored how callers to a rheumatology helpline in Sweden perceived their encounter using semi-structured interviews. Callers reported being provided relevant information by the service which helped in managing their disease better and in the future would help facilitate contact with other health professionals (Arvidsson et al., 2019). Conversational analysis of helpline call recordings was often used across multiple studies to report on the real-time interaction between callers and call-takers (Bloch & Leydon, 2019; Emmison & Firth, 2012; Leydon, Ekberg, Kelly, & Drew, 2013; Lopriore et al., 2017). Analysis of calls to the Healthdirect helpline in Australia noted the complexity of delivering information and advice over the phone and provided recommendations to enhance service delivery (Lopriore et al., 2017).

Although limited in the Australian context, studies into the utility of helplines during the COVID-19 pandemic have provided further insight into healthcare seeking behaviours across the wider population in response to an unexpected change in context. Helpline calls increased in frequency and often related to mental health concerns or seeking information relevant to evolving health orders across the world (Brülhart, Klotzbücher, Lalive, & Reich, 2021; Hegde et al., 2021; Matthewson, Tiplady, Gerakios, Foley, & Murphy, 2020; Pavlova et al., 2022). As such research into the use of helplines and what they are able to offer callers adds to the relevance and applicability of helpline-based care provision, particularly within an evolving digital health landscape that has emerged as a result of the pandemic.

In stroke, helpline-based services exist globally in a limited capacity and research exploring their utility is scarce. Organisations that implement helplines routinely provide annual reports which can include a wealth of routine data on helpline usage, but are usually limited to the number of calls received during a given reporting period. *Table 1* provides an overview of stroke helplines around the world and the enquires received by each service in the most recent annual reporting period.

Table 1. Stroke helplines and number of enquiries received in most recent annual reporting period

Country	Helpline	Organisation	Enquiries Received*	Reporting Period
America	*Stroke Family Warmline*	American Stroke Association	Unreported	
Australia	*StrokeLine*	Stroke Foundation (Australia)	2,648	2020-2021
	1300 Telephone Counselling	Stroke Recovery Association of New South Wales (NSW)	Unreported	2020-2021
Canada	*Stroke Support Line*	After Stroke: March of Dimes Canada	Unreported	
Malaysia	National Stroke Association of Malaysia Helpline	National Stroke Association of Malaysia	Unreported	
Singapore	Stroke Support Station Hotline	Stroke Support Station	Unreported	
UK	*Stroke Helpline*	Stroke Association (UK)	18,771	2020 –2021
	Chest Heart & Stroke Advice Line	Chest, Heart & Stroke (Scotland)	2,953 calls	2020-2021
	Different Strokes Information Line	Different Strokes	382 calls	2020-2021

*Including phone calls, email and web-based contact (unless specified otherwise)

Collett (2006) explored why individuals contacted the Brain and Spine Helpline in the UK and their satisfaction with the service. Most often callers sought information and emotional support, aligning with research into helpline-based service for other conditions (Collett, 2006). The helpline, however, provides support for a range of neurological conditions and the number of callers particularly affected by stroke or calling with stroke-specific enquiries remained unknown. In contrast, Hanger and Mulley (1993) described the characteristics of callers to the Stroke Association Helpline in the UK and the questions they asked about stroke. Their work was expanded on 20 years later to describe whether questions asked by callers to the UK Stroke Association Helpline about stroke had changed over time (Dickerson & Forster, 2015). The study reported that there was little change in the type of questions asked over the years, even in response to improvements in stroke care in other settings (Dickerson & Forster, 2015). In Australia, no research currently exists reporting on helpline-based care provision in stroke.

1.4 StrokeLine in Australia

In Australia, StrokeLine is a national helpline that provides support to people affected by stroke (Stroke Foundation, 2022). Similar to other helplines, the service also provides information and advice to carers, health professionals and the general public on stroke-related inquiries. The service is operated during routine business hours by the Stroke Foundation in Australia and forms an integral part of the StrokeConnect Program - see *Figure 1* (Stroke Foundation, 2014). The service allows users contact a qualified health professional from an allied health background via phone, email or social media (Stroke Foundation, 2022). Call data are categorically logged by staff into a customer relationship management system after each episode of care and includes demographic information, reason for contact and actions taken (Stroke Foundation, 2014). StrokeLine staff provide information, support or referral to other services as appropriate (Stroke Foundation, 2014).

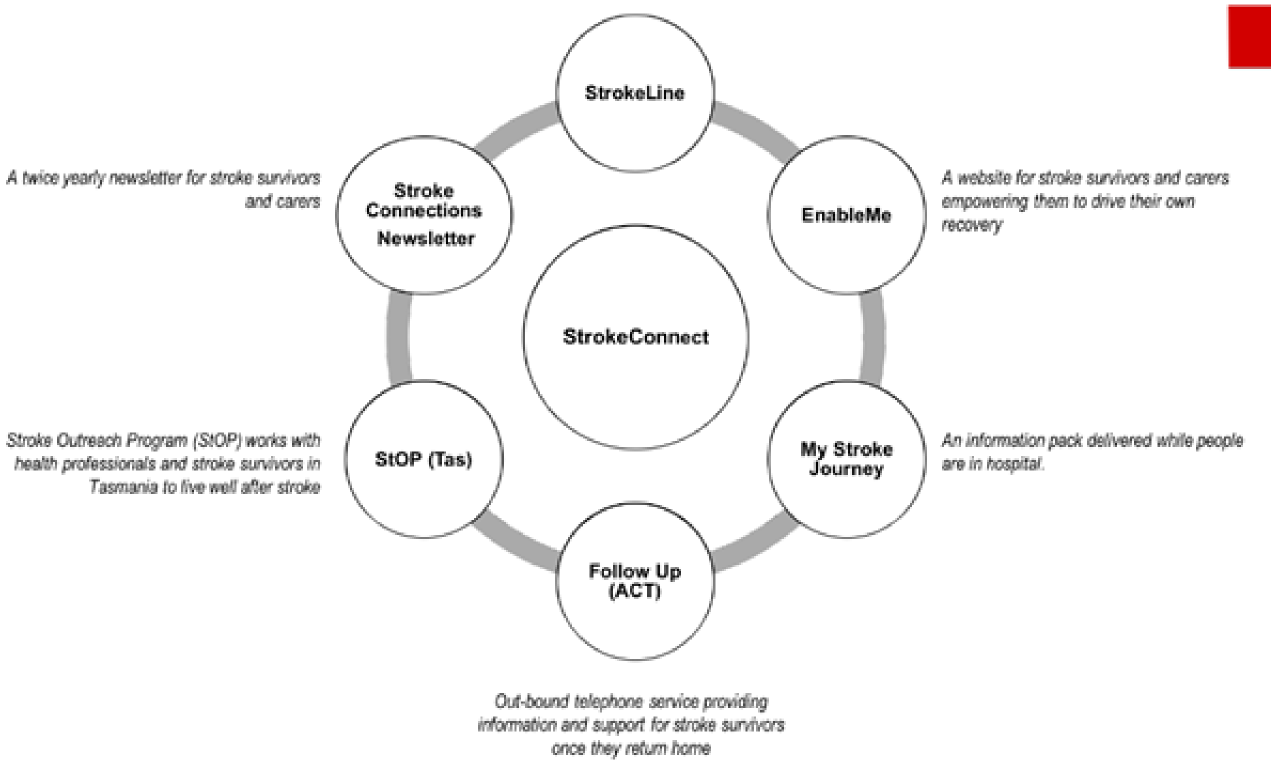

Figure 1. Stroke Foundation support initiatives as part of StrokeConnect (Stroke Foundation, 2014)

To ensure health services designed to support stroke survivors and their carers are meeting their needs, it is important to understand how services such as StrokeLine are being used.

1.5 Rationale for Thesis

To understand how StrokeLine is being used by stroke survivors, their carers, and health professionals, continual evaluation of user data is required to optimise service operation. In 2014, an internal evaluation report aimed to investigate the appropriateness, effectiveness, and efficiency of StrokeLine (National Stroke Foundation, 2014). The report provided a general overview of consumer satisfaction with StrokeLine and a basic evaluation of service provision. However, to ensure service delivery remains relevant to the real needs of stroke survivors and their carers using the service, continual evaluation using robust research methods is required.

Since 2014, there has been little investigation into how stroke survivors are using StrokeLine and the impact the experience has had on the stroke survivor's outcome. An in-depth analysis of StrokeLine user data will determine the most common issues and questions that stroke survivors are seeking to have addressed from this service. In particular, COVID-19 has significantly disrupted the lives of many people, adding extra life stressors, and potentially forcing more people to opt for online or telephone-based services such as StrokeLine. Understanding how stroke survivors seek and act on the information and advice provided to them by StrokeLine is an important factor for evaluating the impact telehealth services can have on the lives of stroke survivors and their carers. To date, however, no research exists exploring the use of StrokeLine in Australia and the individual's experience of using the service after having a stroke. Exploring the use of StrokeLine in this way can provide insight into the needs of stroke survivors and the potential gaps the service is able to fill.

1.6 Thesis Aims and Research Questions

This thesis explores the role of StrokeLine in Australia, particularly how the service is used by callers. The first aim of the thesis seeks to describe the people that call StrokeLine, to report reasons people engage with the service by calling and to describe the response provided by StrokeLine to the caller's needs. To achieve this first aim, the thesis will be guided by the following research questions:

i. Who is contacting the StrokeLine service by phone?
ii. Why are people contacting the StrokeLine service by phone?
iii. What is being provided by the StrokeLine service to people contacting them by phone?

The thesis also aims to explore the experiences of stroke survivors' who use StrokeLine, particularly by describing the factors that prompt them to call the service. As such, the second aim of this thesis seeks to describe both the experience of the stroke survivor during the StrokeLine call and the impact calling the service had on their stroke recovery. To achieve this second aim, the thesis will be guided by the following research questions:

i. What factors prompt stroke survivors to use the StrokeLine service?
ii. What do stroke survivors experience during their call to the StrokeLine service?
iii. What impact did calling the StrokeLine service have on the stroke survivor's recovery?

1.7 Chapter Summary

This chapter included an introduction to the thesis and begins with an overview of the thesis structure. The background to the research presented in this thesis is provided and a brief review of relevant literature outlining the focus of the work is presented. The rationale for undertaking this program of research is highlighted, along with outlining the aims of the thesis and key research questions. In chapter 2, the rationale for undertaking this research is expanded on and justification of the methods used are described.

Chapter 2

Methodological Considerations

This chapter outlines the methodological approaches used in the thesis and seeks to provide further context for the results presented in Chapters 3 and 4. The rationale for the design of each of the studies included in this thesis is provided. Further, an explanation of the data included for analysis and the methods used are further outlined. Aspects of research design and methodological rigour that must be considered when interpreting the qualitative results chapter of this thesis are also expanded upon, especially how the Master's candidate maintained trustworthiness during the research process.

2.1. Study 1 Rationale and Methodological Considerations

Organisations that manage the day to day running of condition-specific health helplines routinely collect data of service users within electronic customer relationship management (CRM) systems. Similar to electronic medical records, data collected in these systems can be used to better understand the ways in which a service is used and aid in improving service delivery and effectiveness. To date, few studies have explored the composition of calls to a stroke helpline and none have explored calls to an Australian service, such as StrokeLine (Dickerson & Forster, 2015; Hanger & Mulley, 1993). The first study presented in this thesis outlines findings of a retrospective cohort study using a multi-method analysis of a dataset of calls received by StrokeLine. Previous research reporting on the use of health helplines for a range of chronic conditions have similarly used both quantitative and qualitative analysis of retrospective datasets of user information, mainly due to the nature of the datasets (Jefford, Kirke, Grogan, Yeoman, & Boyes, 2005; Lopriore, LeCouteur, Ekberg, & Ekberg, 2017; Matthewson, Tiplady, Gerakios, Foley, & Murphy, 2020). In this way, using multi-methods in health services research is known to provide more comprehensive findings, as the research can be focussed on both processes and outcomes (O'Cathain, Murphy, & Nicholl, 2007).

2.1.1 Contextualising the StrokeLine Dataset

Data transformation or the redesign of data management processes and infrastructure in healthcare organisations is increasingly being undertaken to improve workflow, efficiency and care provided by services in response to changing digital landscapes (Sanmarchi, Toscano, Fattorini, Bucci, & Golinelli, 2021). The Stroke Foundation's processes for capturing StrokeLine data have evolved over the years. In March 2017, a cloud-based platform provided by Salesforce, Inc. was introduced to capture CRM data across all Stroke Foundation initiatives included under the StrokeConnect program under which StrokeLine also functions. At this time, the data infrastructure used to capture StrokeLine data was specifically set up for outbound follow-up calls for hospitals referring newly diagnosed stroke survivors under other StrokeConnect initiatives. As such, from 27 March 2017 – 30 October 2019, information from StrokeLine enquiries was captured using only free-text as most categories for data input were not applicable to StrokeLine enquiries. Consequently, in November 2019, existing Salesforce CRM infrastructure was expanded to include a dedicated StrokeLine customer relationship management system.

The Salesforce customer relationship management system now allows data for each StrokeLine contact to be entered manually by StrokeLine staff within relevant pre-defined categories using drop down menus and tick boxes. Further data can be input by staff in the form of free-text in designated boxes labelled to reflect the contents, offering a textual description of what was discussed during the call and what staff were able to provide. The data included in the free-text boxes is typed by StrokeLine staff after the call has ended. The conversational aspect of the StrokeLine interaction between the caller and call-taker is often reflected in the free-text data. Names of the callers and their family members may be captured and specific details about the callers' lives noted. Details of any email-follow up after the call are also attached to each contact entry. In turn, each enquiry received by StrokeLine is captured in the dataset as a separate episode of service, with the date and time an enquiry is both received (case opened) and resolved (case closed). An outline of categories defined in the StrokeLine customer relationship management system is included in *Appendix A* and further expanded on in Chapter 3 (see sub-section: 'Database') of this thesis.

At the time the StrokeLine dataset was extracted for analysis, the recent move to the new system led data capture processes to remain novel and inconsistent between staff members who were still working to standardise procedures. The COVID-19 pandemic is likely to have put a strain on staff working to establish consistency in data management processes and during the initial conceptualisation of this study, the COVID-19 pandemic had not yet commenced. Consequently, results presented in Chapter 3 of this thesis provide a retrospective descriptive analysis of StrokeLine data only from episodes of service received between 1 November 2019 to 30 November 2020. Data prior to 1 November 2019 could not be extracted with accurate labels due to the CRM system structure at the time. Thus, this data was unable to be categorised appropriately for analysis.

Further, due to the identifiable nature of user data captured with free-text, it was only feasible for a volunteer at the Stroke Foundation to manually de-identify two separate months of this data for analysis. As such, data was extracted only from November 2019 and June 2020. This free-text dataset analysed for the qualitative component of the study was extracted separately to the dataset containing information collected through drop down menus and tick boxes. The two months were chosen at random to coincide with the start and mid-point of the year the categorical dataset was extracted across.

By initiating contact with StrokeLine, people using the service are understood to be providing consent to the Stroke Foundation to use their call data for service improvement activities. A data-sharing agreement with the Stroke Foundation, however, needed to be established before the data was transferred for analysis – see *Appendix B*. Both datasets were separately extracted from the StrokeLine customer relationship management system by StrokeLine staff and transferred for analysis at different time points during this program of research. The complete dataset of categorically logged StrokeLine data was extracted as a Microsoft Excel file and transferred for analysis by StrokeLine staff in May 2021. In February 2021, the second StrokeLine dataset was extracted by StrokeLine staff for de-identification. De-identified data for both months was transferred for analysis as a Microsoft Excel file in May 2021.

It is also useful to note that the Stroke Foundation in Australia often increases visibility of its initiatives through advertising at distinct points throughout the year and in response to overlapping priorities. From April 2020 onwards in particular, the StrokeLine service has received increased online exposure in partnership with the newly launched 'Young Stroke Project' which targets working-age stroke survivors aged between 18-65. The choice of extracting free-text data from November 2019 and June 2020 was not informed by any marketing campaigns designed to increase visibility of Stroke Foundation initiatives.

2.1.2 Use of Quantitative Descriptive Analysis

The first dataset used for the analysis in chapter 3 of this thesis was data from the StrokeLine customer management system collected from 1 November 2019 to 30 November 2020. A quantitative descriptive analysis was undertaken on the dataset using Microsoft Excel to provide demographic details of callers to understand who was contacting StrokeLine, why people where contacting StrokeLine and what was provided to the caller by StrokeLine staff. Data was described numerically and by percentages.

Analysing the dataset quantitatively helped to objectively contextualise findings and provided a framework for discussion presented in Chapter 3 of this thesis around the use of

StrokeLine. Demographic details generated through quantitative analysis of data were also used to identify patterns and describe similarities and differences between key user characteristics. Further, due to the nature of the StrokeLine dataset, quantitative variables relating to why people contacted StrokeLine and what StrokeLine provided to the caller in response were further contextualised using the free-text data provided by StrokeLine. As such, qualitative methods of analysis were used in conjunction with the quantitative analysis (see 2.1.3).

2.1.3 Use of Qualitative Content Analysis

A multi-methods study design offers the opportunity for multiple methods of data analysis to provide a greater understanding into an area of research (Anguera, Blanco-Villaseñor, Losada, Sánchez-Algarra, & Onwuegbuzie, 2018). This differs from a mixed methods research design where findings from both quantitative and qualitative analysis are integrated together and findings from one study can inform the design of others (Johnson, Onwuegbuzie, & Turner, 2007). As such, findings from the qualitative analysis presented in Chapter 3 of this thesis exist concurrently with quantitative findings and are not completely integrated together.

Qualitative content analysis was used to analyse the second StrokeLine dataset consisting of data captured in free-text boxes for the months of November 2019 and June 2020. Content analysis is an approach to qualitative data analysis whereby themes and patterns are identified in the data. It can be used to analyse data both qualitatively and quantitatively, helping determine trends and relationships based on the frequency of coded data (Vaismoradi, Turunen, & Bondas, 2013). The NVivo12 software for Windows was used to analyse the free-text data.

StrokeLine data included in the free-text boxes provided a detailed summary of what was discussed during the call and what was provided as a result. Due to the concise style in which the data was captured, a summative approach to content analysis was deemed an appropriate method of analysis, as it focuses on quantifying content to explore usage rather than beginning by inferring meaning (Hsieh & Shannon, 2005). The analysis of free-text data reported in Chapter 3 follows the most common approach to the content analysis process outlined by Hsieh & Shannon (2005). Once codes are established, themes are generated by the frequency of their occurrence in the data, providing objective insight where the focus remains on the manifest or semantic meaning of findings rather than their underlying cause (Vaismoradi et al., 2013).

2.2 Study 2 Rationale and Methodological Considerations

For health services to remain relevant, it is important to understand the service they provide from the perspective of key users (McKevitt, Redfern, Mold, & Wolfe, 2004). The value of using qualitative research methods to understand health service provision in this way has long been noted (Weiner, Amick, Lund, Lee, & Hoff, 2011). Qualitative health research is able to focus not only on a person's experience with a health service but also provide insight into wider contextual factors affecting their overall subjective experience (Dew, 2007). Research into specialised helplines for chronic conditions often employs qualitative interviews with service users to understand how and why they used the service (Arvidsson, Nylander, & Bergman, 2019; Boltong, Ledwick, Babb, Sutton, & Ugalde, 2017; Ekberg et al., 2014). Currently no research has reported on the experiences of stroke survivors using a stroke helpline in Australia. As such, Chapter 4 of this thesis presents findings from a qualitative analysis of semi-structured interviews conducted with participants who used StrokeLine after having a stroke. Interviews were used to explore the experiences of stroke survivors who used StrokeLine to not only understand what they sought by calling the service, but to elicit their perspectives and beliefs about service provision in the wider context of stroke care. The methodology of Braun and Clarke (2006) was used to guide the qualitative thematic analysis of collected data.

In using qualitative research in this way, the second study presented in Chapter 4 of this thesis includes methodological considerations that need to be accounted for at each stage of the study design and are outlined in the following sections.

2.2.1 Participant Recruitment and Screening

The recruitment process in qualitative research is a dynamic process with recruitment plans evolving through the course of the research (Bonisteel et al., 2021). In this research, participants who self-reported as having had a stroke at any time, could communicate in English, were able to provide consent and had the capability for video-conferencing were considered for inclusion in the study. The participants needed to have also contacted the StrokeLine service in Australia within the last three months from the point they first expressed interest in participating.

Recruitment was influenced by stakeholder engagement, as the Stroke Foundation in Australia was involved at each stage. From November 2020 to June 2022, participants were indirectly sought through advertisements made available on multiple platforms including social media, specific Stroke Foundation newsletters and on stroke forums facilitated by the Stroke Foundation. All advertising materials were provided by the research team to ensure the credibility of information directed at potential participants.

Further targeted recruitment of participants was initiated by StrokeLine staff employed by the Stroke Foundation over two separate recruitment email cycles (see *Figure 1*). Staff extracted contact details from the StrokeLine customer relationship management system of callers to the service within the last three months. An email was then sent out to this group of callers outlining information about the study and how to get in contact with the research team. Additional approval for this was granted both by the UTS HREC (Ref: ETH20-5088) and the Stroke Foundation Research Advisory Committee.

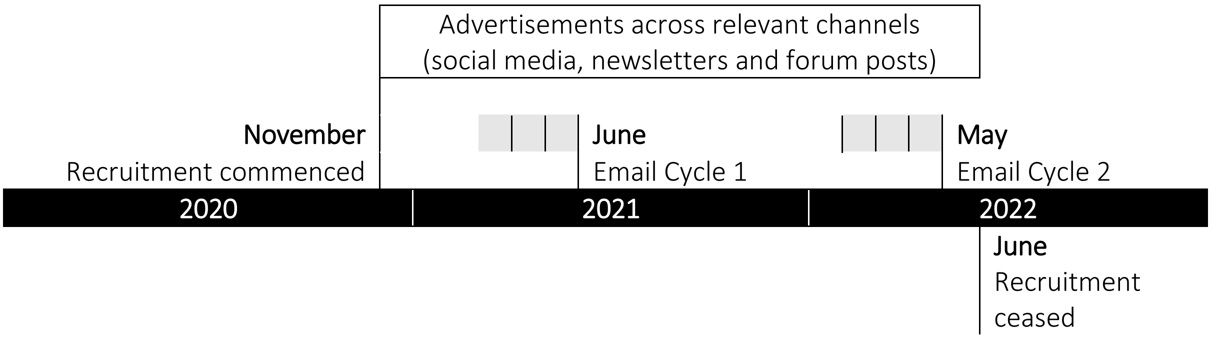

Figure 1. Timeline of participant recruitment

Participants who expressed an interest in participating in the study contacted the research team via phone or email. On the occasion an inquiry was received directly by StrokeLine staff, the participant was directed to get in touch with the research team for more information. A screening call was set up with potential participants to assess their suitability for inclusion in the study. A series of set questions were used to guide the initial conversation. Questions were asked to understand when the stroke first occurred, clarifying who contacted the StrokeLine service, when the service was contacted and how it was done. Details were also collected about the location of where the person first contacted StrokeLine from. The person’s ability to use the Zoom video-conferencing platform was also confirmed, along with who they lived with at home and how they found out about the study. Details of whether the person identified as being of Aboriginal or Torres Strait Islander descent were also collected. The participant was informed of their eligibility for participation at the conclusion of the call. If eligible, a time for the interview to take place was organised. After the call, a confirmation email was sent to the participant with a link provided to the online meeting.

The ability of the participant to provide informed consent was established by the potential participant themselves contacting the research team. Interest expressed in the study was confirmed during the initial call by clarifying the person understood what was required of being a participant. Cognitive ability of the participant was informally assessed on the basis of this initial conversation.

However, no formal cognitive assessment of participants was completed prior to their inclusion in the study.

Post-stroke deficits in speech and language were not considered as an explicit exclusion criteria for participation in the study. A Speech Pathologist with expertise in qualitative interviewing strategies for people with aphasia would be consulted if anyone with speech and language deficits expressed interest in the study. As such, suitability for inclusion would be assessed on a case-by-case basis as required. Aphasia-friendly participation information sheets, however, were not used during the recruitment process. It is likely this contributed to recruitment bias, where a majority of people expressing an interest in the study had no speech or language deficits.

Purposive Sampling

Purposive sampling is used to ensure characteristics of participants included in a study are relevant to the purpose of the research (Andrade, 2021). In the second study of this thesis, purposive sampling was used to ensure participants included were representative of diverse geographical settings in Australia and the trajectory of care in stroke. Geographic location was sampled across metro, regional or rural categorisation of participant's postcodes based on the Australian Statistical Geography Standard (ASGS) – Remoteness Area Framework (Australian Bureau of Statistics, 2023). Time since the stroke had occurred was captured for each participant and categorised as either acute, sub-acute or chronic according to the trajectory of stroke care standardised by Bernhardt et al. (2017).

2.2.2 Virtual Interview Process

Semi-structured interviews allow for an informal approach to interviewing, remaining focused on pre-determined topics yet guided freely by participant narratives (Liamputtong, 2009). In this study an interview-guide was used to prompt discourse around three key topics, with follow-up questions used to elicit deeper exploration where needed (see *Appendix C*)

Due to the social distancing restrictions resulting from the COVID-19 pandemic and the diverse geographical distribution of participants across the country, all interviews were conducted in a virtual format using the Zoom videoconferencing platform. Virtual interviews can increase accessibility for a range of participants and allow them to participate from the comfort of their homes (Varma et al., 2021). For stroke survivors, however, the potential of existing post-stroke symptoms related to communication, fatigue and cognition may in fact hinder participation. In turn, post-stroke deficits in speech are difficult to account for in online settings, especially in adapting the interview process to people with aphasia (Prior, Miller, Campbell, Linegar, & Peterson, 2020). As such, conducting qualitative interviews in an online format can have implications for the integrity of the data collected in this research (Varma et al., 2021).

Although this virtual interview process may affect the credibility of findings of this research in some way (as discussed in 2.2.4), every effort was taken to ensure participants in this study were screened appropriately and able to provide informed consent. Great care was taken to maintain rapport with participants throughout the interview process. Further, most interviews were scheduled in the morning to account for any post-stroke related fatigue which can often increase later in the day. This was often done at the request of the participant themselves or explored as a possibility by the researcher.

2.2.3 Use of Thematic Analysis

In this thesis, thematic analysis was used as the primary method to analyse data collected from semi-structured interviews. Although not without its critics, thematic analysis has grown over the years in academic acceptability. Main criticisms of this method of qualitative inquiry have stemmed from a poor understanding of its application but in recent years systematic approaches to its use have been established. Most notably, Braun and Clarke (2006) contributed considerably to the foundational application of thematic analysis in the field of psychosocial inquiry and the authors have continued to expand on their work over the years (Braun & Clarke, 2006, 2019, 2021; Byrne, 2022).

In this research, thematic analysis was used due to the flexibility and ease of use it affords in allowing detailed descriptions of data sets and contextualising findings in both social and psychological interpretation. In particular, the approach to thematic analysis outlined by Braun and Clarke (2006) was used to guide the analytical process, due to the rigorous and comprehensive instructions provided by the authors. This included first transcribing interviews for analysis and becoming familiar with the data by reading the transcripts multiple times. Initial codes were generated before themes were agreed on with a second coder from the research team. Finally these themes were reviewed and then defined (Braun & Clarke, 2006).

Inductive Thematic Analysis

In thematic analysis, the analysis process can be guided by different approaches which can either be inductive or deductive. A deductive approach is usually employed to test data against existing theories and as such provides depth to findings limited by a specific context (Vaismoradi et al., 2013). An inductive approach, however, is commonly used in instances where there is no pre-existing research and is able to provide deeper meaning to findings as categories are derived from the data itself (Vaismoradi et al., 2013). As the purpose of the second study was to explore the experiences of stroke survivors who had used the StrokeLine service and this has not been previously investigated, an inductive approach was used to ensure analysis remained ‘data-driven’. By not coding data to fit a pre-existing conceptual framework, analysing the data in this way ensured that the meaning communicated by participants was best represented in findings.

Latent Level of Data Interpretation

Themes derived from qualitative data can be intangible at times when using thematic analysis and it is important to report how they are interpreted (Braun & Clarke, 2006). The level of description required to interpret findings can depend on whether themes are derived from the manifest or latent nature of data. The manifest level of data interpretation provides only descriptive insight into the semantic content of the data (Vaismoradi et al., 2013). At the latent level, however, thematic analysis goes beyond the manifest nature of the data and provides an interpretation based on underlying ideas and assumptions (Byrne, 2022). In the second study, a latent level of data interpretation was mainly used to report findings, however, the manifest meaning of what was communicated by participants was not discounted. As the study aimed to explore the experience of participants, it was important to consider both what was directly communicated by participants and interpret the underlying meaning of data through the researchers’ understanding of the participant’s contexts.

2.2.4 Ensuring Methodological Rigour

In thematic analysis, the researcher takes an active role in the interpretation of findings and the consequent production of knowledge (Braun & Clarke, 2019). Themes are not simply found but are generated by the researcher during the analysis process (Braun & Clarke, 2019). For thematic analysis that takes an inductive approach, the interpretative nature of the process needs to be acknowledged in reference to the researcher’s subjective skills (Braun & Clarke, 2021). As such, to ensure the rigour and integrity of qualitative findings presented in this thesis for study 2, the criteria for trustworthiness first outlined by Guba and Lincoln (1989) is used to support findings (Nowell, Norris, White, & Moules, 2017). Consequently, a number of strategies to promote credibility, authenticity, transferability, dependability, confirmability and reflexivity in the research process were employed.

Credibility

Credibility determines the trustworthiness of findings by how accurately findings reflect the participants' views (Guba & Lincoln, 1989). Among other strategies, Guba and Lincoln (1989) emphasised the used of member checking to ensure credibility. In this thesis, all interviews were transcribed verbatim from audio-recordings and all transcripts were sent to participants for confirmation. Having participants confirm the contents of their transcribed interviews enhances the correctness of the collected data (Mero-Jaffe, 2011).

During the coding process, codes were discussed and refined until consensus was achieved between the two coders (MTC and ER). Initially data was condensed into suitable meaning units that were not too broad or narrow to capture the true meaning of what was stated by participants (Graneheim & Lundman, 2004). Categories and themes derived from these meaning units were then agreed upon between researchers and supported with quotations from interview transcripts (Graneheim & Lundman, 2004). Further, preliminary findings from each interview were checked against existing data from other interviews and discussed with members of the research team. Supervision by more experienced qualitative researchers in the research team (CF and AM) and sharing reflections during the ongoing analytical process, also helped to refocus preliminary findings established by the novice researchers by exposing potential biases and fostering alternate approaches to thinking.

Authenticity

Authenticity is an extension of credibility and allows for the research to be genuine and worthwhile in contributing to the wider field of work (Johnson & Rasulova, 2017). To increase the authenticity of the data collected, rapport with participants was established during the screening process prior to each interview, maintained during all follow-up communications and re-established during the interview itself. Ethics approval and gaining informed consent was further used to make certain participants feel safe and comfortable enough to share their experiences openly, allowing them to lead the interview process and ensure their most honest views were captured (for ethics approval documentation see *Appendix D*). The use of purposive sampling to obtain representation across geographic location and time since stroke ensured a wider representation of people relevant to the area being studied. Along with enhancing credibility of findings, sending interviews back to participants for review allowed them to remain engaged through the research process. This allowed for both an opportunity for any follow-up concerns to be addressed and any requested changes to be made to allow the participants to have an active 'say' in findings (Johnson & Rasulova, 2017).

Transferability

Transferability refers to establishing the potential generalisability of findings (Graneheim & Lundman, 2004). It requires enough description to be provided for future researchers to judge whether findings from the current research can be applied to their own work (Nowell et al., 2017). In this research, thick descriptive data was used to provide sufficient detail of each interviewed participant. In particular, this included reporting each participants' age, gender, geographic location, time since their stroke occurred and whether they lived alone. Reporting the distinct characteristics and context of the participant population in this way could enhance the transferability of findings to other contexts (Graneheim & Lundman, 2004). Further, clarity during the research process was also ensured by reporting the context through which participants were recruited and the way in which they were screened for inclusion. Information about the background of the researchers involved and how data was consequently analysed was also provided.

Dependability

Dependability of the research can be established if a logical process is followed to ensure data are a real reflection of findings (Nowell et al., 2017). During this research, clear field notes and reflections during and after each interview were maintained. Linkages between the data and findings were documented and discussed often with the second coder on the research team to ensure thought processes during analysis were recorded clearly. Although an audit trail to systemise the decision-making process during the research was maintained, the dependability of findings in this research may have benefitted from a formal audit performed by a neutral party. Such an audit by another researcher would have involved them being able to clearly follow the decision-making process and conclude similar findings from study 2 as presented in Chapter 4 of this thesis (Nowell et al., 2017).

Confirmability

Confirmability establishes that findings are clearly grounded in the data and can be ensured if credibility, transferability and dependability have all been firstly maintained (Nowell et al., 2017). Confirmability was enhanced in this research by the use of reflexive journaling, involving a second coder during the analysis process and including clear justification of choices made when linking data with findings. Further, including direct quotes from participant interviews to support the interpretation of findings ensured the research remained centred on the data collected.

Reflexivity

Reflexivity is the process through which researchers acknowledge how qualitative studies can be influenced by their own subjective views and context (Olmos-Vega, Stalmeijer, Varpio & Kahlke, 2023). Reflexivity allows for a multifactorial critique of personal, interpersonal, methodological and contextual factors that may affect the qualitative research process (Olmos-Vega et al., 2023).

Through the course of the research process for the study reported in Chapter 4, reflexive journaling was used extensively to record any personal assumptions and reactions to the participant data collected (Olmos-Vega et al., 2023). This included reflections during the conception of the study itself and throughout the interview and coding processes. When reporting and discussing the findings both in Chapter 4 and in the overall discussion of the entire program of research, reflexivity in this way was also continually ensured. A narrative autobiography was included in the initial reflexive journal entry to reflect on the researcher's personal context and experiences (Olmos-Vega et al., 2023). Further, field notes were maintained during and after each of the interviews conducted.

Collaborative reflexivity between researchers was also heavily employed during the qualitative research process. Collaborative reflexivity centres the research process on collaboration, acknowledging that personal blind spots cannot be fully identified in isolation (Olmos-Vega et al., 2023). As such, the research team met extensively during the study conception and data collection stages. Structured team-reflexive discussions were used regularly to understand each member's personal positions and the potential impact this may have on the research process. During the qualitative coding process, in particular, the coders in the research team (MTC and ER) met regularly to refine codes and reflect on any perceived differences of thought. Most members of the research team were also clinicians who had worked or were currently working extensively with stroke survivors during their rehabilitative process. As such, during team meetings, it was important to account for how extensive clinical knowledge of the researchers may influence the present experiences of the stroke survivors being interviewed.

Furthermore, each participant was contacted after their interview and provided a copy of their interview transcript. At this point, the participants were provided an opportunity to reflect further on what they had initially discussed with the researcher. This was done to ensure the data collected and the consequent findings from analysis remained centred in the participant's context (Olmos-Vega et al., 2023). In implementing this process, the power dynamic between the researcher and the interview participant was also acknowledged (Olmos-Vega et al., 2023).

2.3 Chapter Summary

This chapter provided an overview of methodological considerations for the research presented in this thesis. The use of both quantitative and qualitative methods of inquiry are justified and described. In particular the StrokeLine dataset analysed in the Chapter 3 is described. The recruitment strategy employed and sample used in the second study is also outlined. Finally, ways of ensuring the rigour of findings presented in Chapter 4 are highlighted. The next two chapters of this thesis (Chapters 3 and 4) outline results of the studies included in this thesis and are presented as research papers.

Chapter 3

User Profile of People Contacting a Stroke Helpline (StrokeLine) in Australia: A Retrospective Cohort Study

This chapter reports results of the first study included in this thesis and the research is presented as a retrospective cohort descriptive study. The chapter is structured as a research article and begins by introducing the background context and aims of the study. The methods undertaken in the study are then outlined. The design of the study, the nature of the StrokeLine datasets and the analysis completed is included. Descriptive analysis of data obtained from the StrokeLine CRM system over a 13-month period was performed to identify who was calling StrokeLine, why they were calling and what StrokeLine provided the caller. Qualitative content analysis of ‘free-text’ data, collected at two random months during the 13-month study period. was also performed to further explore reasons for why StrokeLine was used and how enquiries were addressed. The StrokeLine database explored in this chapter inadvertently highlights the complexity of the post-stroke experience for both individuals affected by stroke and health services providing them with care. Analysis of the StrokeLine database highlighted the need for healthcare infrastructure underpinned by robust data-driven processes to ensure service provision remains relevant to those who use the service.

This first study has been published online and the journal publication is provided as an appendix to this thesis – see *Appendix E*.

User profile of people contacting a stroke helpline (StrokeLine) in Australia: a retrospective cohort study

Muneeba T Chaudhry[1], Alana B McCambridge[1], Simone Russell[2], Katherine Yong[2], Sally C Inglis[1], Arianne Verhagen[1], Caleb Ferguson[3,4]

[1] Faculty of Health, University of Technology Sydney, Sydney, NSW, Australia
[2] Stroke Foundation, Melbourne, Victoria, Australia
[3] School of Nursing, University of Wollongong, NSW, Australia
[4] Western Sydney Local Health District, Blacktown Hospital, Sydney, NSW, Australia

Corresponding author:
Prof Caleb Ferguson
School of Nursing,
University of Wollongong,
NSW, 2522, Australia
calebf@uow.edu.au

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ABSTRACT

***Background**:* StrokeLine is a specialized telephone helpline led by health professionals to respond to stroke-related enquiries in Australia.

Aims: i) to describe the profile of people who called StrokeLine; ii) to report the reasons people called the service, and iii) to describe the actions taken by StrokeLine in response to the caller's needs.

***Methods**:* We obtained routine call data obtained from the StrokeLine customer relationship management system between November 2019 and November 2020. Demographic data, pre-existing risk factors, reasons for calling and actions taken by StrokeLine were extracted and descriptive analyses were performed. De-identified free-text data were obtained separately for November 2019 and June 2020 and analysed using qualitative content analysis.

***Results**:* Of the 1,429 calls most were from carers, family, and friends (38%) or the stroke survivor themselves (34%). Calls were also received by people affected by stroke who did not fit into other categories (6%) and donors to the Foundation (6%). Volunteers, advocates, general public and unspecified callers made up the remaining callers (16%). Most calls to StrokeLine were made by women (64%) and the average age of the stroke survivor was ≥65 years (33%) with the time since the stroke occurred <1 year ago. The main reason for calling was to manage stroke-related impairments (40%). Providing information, support and advice was the most common action provided by StrokeLine staff (25%). Content analysis of 225 calls revealed most stroke survivors called for emotional support, while carers sought more practical guidance. StrokeLine provided information for referral to relevant services and guidance on what to do next.

Conclusions: Most calls were received from family and carers, as well as stroke survivors. They contacted StrokeLine for information and advice, practical solutions, emotional support, and referral advice to other services.

INTRODUCTION

Stroke is a leading cause of long-term disability worldwide with more than 80 million stroke-survivors globally (Johnson et al., 2019) . In 2012, the Stroke Foundation (Australia) reported that by 2032, an estimated 700,000 Australians will be living with a stroke-related disability. The impact of stroke is significant and long-term management is often challenging (Boehme, Toell, Lang, Knoflach, & Kiechl, 2021). Stroke survivors experience a range of motor, cognitive and psychosocial impairments that persist into the chronic stages of recovery (Hawkins et al., 2017). Approximately two-thirds of stroke survivors will live with residual cognitive or functional impairment, including limitations to mobility, sensation, balance, and communication (Arienti, Lazzarini, Pollock, & Negrini, 2019; Broussy et al., 2019). Other residual effects such as depression, fatigue and pain further reduce quality of life (Broussy et al., 2019).

Care needs change and evolve, at each stage of recovery (Chen et al., 2019). As with most chronic conditions, sustainable recovery relies on engaging stroke survivors and their family caregivers to promote self-management of their condition (Taylor et al., 2014; Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). Stroke survivors report low satisfaction with post-discharge education and information provision, especially addressing long-term management of disability and accessing support services (Ferguson et al., 2016; O'Connell, Hawkins, Botti, Buchbinder, & Baker, 2009). Stroke survivors' express feelings of abandonment, when they navigate between complex transitions of care through the often-fragmented healthcare system (Ghazzawi, Kuziemsky, & O'Sullivan, 2016; Wissel, Olver, & Sunnerhagen, 2013). Improvements need to be made to the continuity of care provided to stroke survivors and their families after being discharged from hospital, focusing on patient-centred support, and interventions that support transition (Ferguson et al., 2016; Pearce et al., 2015).

Telehealth-based models of stroke care may be key to supporting stroke survivors in transitioning between care settings (Schwamm, 2019). Telehealth-based services delivered over the phone s are thought to play an integral role in the ongoing care of people living with chronic health conditions, especially in facilitating cost-effective support for self-management of care (Hanlon et al., 2017; Taylor et al., 2014). Specialised helplines allow healthcare professionals to provide timely and relevant information and advice to support a caller's immediate needs (Ekberg et al., 2014). It is therefore important to understand the role of such services in addressing the needs of the caller.

In Australia, the Stroke Foundation is a not-for-profit organisation that provides information and advice services to people affected by stroke, as well as advocacy for prevention, management and support for people affected by stroke. Among these services, StrokeLine has existed since 2002, as a nationwide stroke-specific helpline that allows users to make inbound contact with a qualified registered health professional (such as nursing or allied health professional), via phone, email, or social media. The helpline supports stroke survivors, their families and friends and aims to educate the wider community on stroke detection and prevention.

Research into phone-based services aims to improve our understanding of how telehealth services are currently being used to obtain information and advice, and what role the service plays in attaining a successful outcome for the caller (Harding, Parker, Hean, & Hemingway, 2018). Analysis of phone-based support services could reveal common issues people living with stroke experience, and whether these issues can be resolved using phone-based intervention. Few studies have described how callers use stroke-specific phone services and no previous study has described an Australian service (Dickerson & Forster, 2015; Hanger & Mulley, 1993). Therefore, our aim is 1) to describe the people who called StrokeLine; 2) their reasons why they called the service; 3) and to describe the actions taken by StrokeLine in response to the callers' needs.

METHODS

Design

A retrospective cohort study using routine call data from the StrokeLine customer relationship management (CRM) system. Ethical approval was provided by the Human Research Ethics Committee at the University of Technology Sydney (Ref: ETH20-5088). Data transfer was approved by the Stroke Foundation (Australia) (19/02/2021)

Database

The CRM system collects data throughout a total episode of a caller's care. An episode of care was defined as one or more episodes of service provided by StrokeLine to address a caller's needs, with an episode of care ending only when no further service delivery is expected by the caller. An episode of service was any occasion of service delivery and can include other methods of delivery such as email follow-up. For each episode of care, demographic details about the caller and reasons for the call are recorded using pre-defined categorical variables by StrokeLine staff. StrokeLine staff use a codebook included in their designated training manual to ensure definitions of categories remain standardised. A combination of predefined responses and free-text boxes capture user information such as constituent type (i.e. a stroke survivor, carer, family etc), caller's age range, gender, when the stroke occurred, language spoken, where the caller is calling from and if the caller identifies as Aboriginal or Torres Strait Islander. Call information about reasons for calling was logged under predefined categories such as current symptoms, risk factors, prevention, health service treatment and care, community services treatment and care, managing stroke impairments, adjustment coping, practical issues, vulnerability, and risk. The pre-defined categorical variables related to why a person was seeking care included practical issues (e.g., accommodation, driving, finances), adjusting/coping issues (e.g., family relationships, occupation) and the type of health service treatment and care being sought (e.g., questions about tests and treatments, access to rehabilitation). StrokeLine staff also specifically logged if a person had multiple reasons for calling, spanning multiple domains or multiple stroke impairments. This information was input under pre-defined categorical variables using tick boxes to allow for multiple responses to be captured. A summary of the episode of care was entered by the staff member using free text outlining the issues discussed and actions taken. Evidence of any email follow-up provided to the caller is also attached to each call record. The total duration spent on each case was noted as the combined total of one or more episodes of service associated with the episode of care. The total time spent on other tasks (e.g. follow-up emails, calls to others) associated with each episode of care was recorded under 'call liaison'. We obtained categorically logged calls from the StrokeLine CRM system between 1 November 2019 and 30 November 2020. Free-text call data from the StrokeLine CRM system was supplied for two separate months: November 2019 and June 2020. All data were provided by StrokeLine as an Excel file and organised under variable labels and codes. We excluded cases from people living outside of Australia, public enquiries not related to the support of a stroke survivor and enquiries from health professionals. All identifying information was de-identified by a volunteer of the Stroke Foundation prior to data transfer to researchers.

Analysis

Microsoft Excel was used to analyse categorical variables and NVivo12 to analyse the free-text data. Data cleaning was undertaken to detect and remove duplicate data, along with incorrect or unexpected data that could not be verified. The percentage of missing data for each variable was calculated and reported. To understand 'who' was contacting StrokeLine, demographic data were presented as frequencies and proportion of total calls over months. To understand 'why' people were contacting StrokeLine, categorical data about the reason for the call was described and free-text data stored under 'Issue' in the CRM system was coded using content analysis (Graneheim & Lundman, 2004). To understand 'what' was provided by StrokeLine, the type of action provided was determined using content analysis of the free-text data stored under 'Description' and 'Actions/Plans' (Graneheim & Lundman, 2004). Finally, the 'Call Log History' outlining the summary of interaction between the caller and StrokeLine staff was analysed using content analysis to understand the number of interactions required to resolve the issue.

RESULTS

Dataset

The StrokeLine data set contained 1,429 individual cases and 159 variables. Unfortunately, many of the categories contained no data at all (missing data), some categories contained repeated data, and several categories had only a few cases (**Supplementary 1**). Notably, this included 38% (n=734) of cases where the reason for calling was uncaptured and 72% (n=1025) of cases where the type of intervention provided by StrokeLine was also missing.

The number of calls received varied between 80-140 calls per month (average of 109 per month). Most calls originated from Victoria, Queensland, and New South Wales (**Figure 1**). Call duration ranged from 15-30 minutes (n=352, 25%), less than 15 minutes (n=263, 18%), 30 minutes to an hour (n=218, 15%), an hour to two hours (n=23, 2%), and 1 call (0.07%) taking over 3 hours.

Population

Most calls received were from carers, family members or friends (n=545; 38%) or stroke survivors (n=482; 34%). Only 86 calls (6%) were received from a person not having a stroke, but indirectly affected by stroke and 6% (n=86) from donors to the foundation. Three percent of calls (n=43) were recorded as volunteers and advocates and were excluded from analyses. Callers were 31% (n=443) female and 11% (n=152) male, and 51% (n=734) of calls had no record of gender.

There were 778 calls (54%) where the age of a stroke survivor was recorded. Most of the callers were aged over 50 years (n=618; 79%) and only 3 calls concerned a person under 18 years. Time since the stroke had occurred was reported for 822 calls (58%), with most callers concerned about a stroke that occurred less than a year ago (n=566; 69%). There were also 67 calls (5%) where the caller was potentially experiencing stroke symptoms with further medical attention required. Only 88 calls (6%) indicated whether a caller identified themselves as Aboriginal or Torres Strait Islander. Of 425 calls (30%) the data provided information about languages spoken at home, including English (29%), Russian (0.14%), Greek (0.14%), Dutch (0.07%) and Korean (0.07%). There were 394 calls (28%) that provided information on pre-existing risk factors for stroke categorised under 19 variables, including high blood pressure (5%), high cholesterol (4%), cardiovascular disease (4%) and atrial fibrillation (1.5%). Vulnerability and risk for depression, drug and alcohol use, family violence and suicidal ideation were captured for only 67 calls (5%).

Reasons for calling

The reason for calling were captured under seven different categories (**Supplementary 2**). Most calls were categorised as “Managing stroke impairments” and “Community services treatment and care”.

Actions provided by StrokeLine

The type of actions provided were reported for 404 calls (28%). These included 362 calls where information, support, advice, or referral was provided, for 20 calls a ‘brief intervention’ (such as informal counselling for health promotion or disease prevention) was provided, and for 17 calls a letter or call to someone else was provided and for 4 calls (0.3%) provided with care coordination (**Supplementary 3**).

Free-Text Data

The free-text dataset included 103 calls from November 2019 and 122 calls from June 2020, with a similar number of calls received by stroke survivors and carers/family across the two months (**Supplementary 4 and 5**). Data were categorised into four themes:

<u>Issue.</u> Most calls from stroke survivors across both months included seeking emotional support, especially in seeking reassurance of post-stroke related impairments, including both ongoing physical and cognitive symptoms. Most calls from carers/family included seeking practical guidance on how best to support a stroke survivor, especially regarding managing a stroke survivor’s cognitive decline and transition from acute hospital care.

> “…has been unable to do her own housework, feels listless and can't understand why she feels this way.” (Case 122, June 2020, stroke survivor)

> *“Mum had stroke 3 weeks ago -back home -on Saturday mum was sleeping a lot, reported pain in her neck, left arm sore and left leg swollen - also slept most of Sunday -out of bed today - concerned about reported issues” (Case 54, November 2019, carer/family)*

> *"She is after information on health and support services after stroke…(Caller) aunt…was discharged 2 weeks ago with her niece looking after her. The situation has become untenable and she cannot be left alone. (Case 36, June 2020, carer/family)*

Description. Calls from both stroke survivors and carers were often prompted by a lack of information or when all other avenues of seeking guidance had been exhausted.

> "…had 2 x strokes and received no medical intervention. Wanting advice and information or referral to who can help." (Case 46, November 2019, carer/family)

> "…No supports with physio. Has discussed situation with his GP however, hasn't been linked with anyone." (Case 35, June 2020, stroke survivor)

Action Plan. For both November 2019 and June 2020, most calls received by stroke survivors concerned providing information on how to best manage their stroke-related impairments, along with providing reassurance and validation of the individual's experience with managing these. For carers/family, StrokeLine staff most often provided guidance and advice on what to do next regarding stroke survivors' care.

> *"Felt reassured that dizziness can be ongoing effect of stroke." (Case 2, November 2019, stroke survivor)*

> *"Recommended having Speech Pathology review regarding swallowing urgently to prevent further issues." (Case 53, June 2020, carer/family)*

Emails and Comments. Calls answered on the first try included 90 calls (87%) in November 2019 and 15 calls (12%) in June 2020. In November 2019, a voicemail or message left with reception was the first point of contact for 13 calls (13%), with a call-back provided by StrokeLine to initiate further episodes of service to resolve the issue. This was similarly the case for 107 calls (88%) in June 2020. Email follow-up after the call was provided for 38 calls (37%) in November 2019 and 29 calls (24%) in June 2020. Most email follow-ups provided included links to resources discussed during the call (eg. information sheets, websites or video links about stroke-related impairments and community services).

DISCUSSION

Most calls received were from stroke survivors and carers, family members or friends. Most callers were female, 65 years-or-over, and related to a recent stroke. However, those that identify as Aboriginal or Torres Strait Islander descent may have been under-recorded in these data. The need for an interpreter was also the main method of identifying culturally diverse callers, which again are assumed to be underrepresented in these data. The main reasons to call StrokeLine were related to health or community services for treatment and care and how to manage stroke-related impairments. A lack of direction around '*what* to do' and '*where* to go' were common motivating factors prompting someone to call StrokeLine. In most instances, people contacted StrokeLine, when previous avenues for seeking information were exhausted, or they were dissatisfied with the quality of care provided in other settings. Most often, StrokeLine staff provided both stroke survivors and carers with actionable items to discuss with their GP or specialist and helped formulate a plan of how to do this. For stroke survivors, StrokeLine provided reassurance and validation of the individual's experience with managing stroke-related impairments.

The geographic location of the caller was limited to only the state/territory the call was received from, with most calls received from Victoria and New South Wales (NSW). The strength and relevance of telehealth services lie in their cost-effectiveness and ease of accessibility. As such, it is important to understand the specific remote, regional, or metro locations of callers to provide better insight into what concerns are prompting enquiries both in the absence or presence of other healthcare services in each area.

Interpretation

StrokeLine's ability to provide practical guidance and emotional support is well aligned with studies reporting on the importance of social support from friends, family or stroke support groups in helping to normalise experiences (Ekberg et al., 2014; Jones, Riazi, & Norris, 2013). Such informal methods of accessing support emphasise the importance of self-management as a collective experience rather than one undertaken in isolation. One study found that when services designed to aid in self-management of care in stroke fail to account for individual needs and circumstances, the relevance of the information provided is unconducive to real behaviour change and addresses only basic educational needs (Jones et al., 2013). The real underpinning of supporting self-management relies on organizational structures that facilitate a relationship between individuals and health care professionals, allowing for the time and flexibility to enable active problem solving and shared decision-making. In many ways, the StrokeLine database is reflective of the complexities of stroke and the multi-faceted ways it can affect an individual. This study has highlighted the complexities of balancing person-centred care provision in a telehealth setting with data-driven processes that are needed to best support this.

Limitations

A major limitation of our study was the percentage of missing data. Although all information under each category should be collected during an episode of care, in most instances it appeared a data summary for each call was recorded instead using free text and much of the categorical data was left blank. This resulted in a considerable amount of missing data under most categories, but some of this data was able to be retained through content analysis of the free-text summary. Secondly, it was only feasible for StrokeLine to provide us with two months of de-identified free-text data for analysis and this may have influenced our findings, due to seasonal variation for example. Thirdly, we also did not include enquiries received via email or social media in analyses. Despite these limitations, a major strength of this study is the ability to provide a unique user profile and evaluation of the StrokeLine service in Australia.

Implications

Clinical implications: Findings from this study can be used to improve service delivery of StrokeLine and other comparable health care services. Exploring retrospective data collected routinely as part of service provision allows for an insight into the way a helpline works and can benefit the callers as well as their carers/family.

For StrokeLine, the current study highlights the express need for better processes to capture data and data infrastructure capabilities to support these. In turn, the need for appropriate staffing and training remains paramount. As the StrokeLine CRM system continues to evolve and the data entry procedures become more streamlined, improvements in the quality of the service are likely to better inform strategic planning and increase outreach. An ongoing challenge will be ensuring that the StrokeLine data infrastructure remains well supported by appropriate staffing and data-management procedures. With the remarkable growth of telehealth-based innovation in recent years, translating this to existing services to better adapt their role within a changing digital landscape should not be neglected. Building on StrokeLine’s existing capabilities, further work may look at service redesign to better capture those not actively seeking support to self-manage their condition, especially in the earlier stages of transitioning between care settings. Incorporating a greater outreach component to the current inbound service model may enhance the role StrokeLine plays in providing continuity of care.

Research implications: Appropriate funding and support from policymakers are needed to improve the quality of the data collection and improve the validity and generalisability of the findings. Several changes in data collection procedures have been implemented by StrokeLine following this study. As such, routinely reviewing caller information is an important component of improving service delivery and ensuring the service remains relevant to those affected by stroke. Further research is needed to understand how people are using the information and advice provided by StrokeLine and whether there are measurable benefits of contacting the service.

CONCLUSION

This study describes the utilisation of a stroke-specific support helpline by people affected by stroke. Understanding the issues prompting callers to seek care and what can currently be offered by StrokeLine staff, provided insight into the needs of survivors and potential gaps within stroke care in Australia. Inbound helplines such as StrokeLine are well-placed in disseminating timely and person-centred information and advice across the trajectory of stroke care.

Data availability statement

Due to the sensitive nature of the data collected for this study, requests to access the dataset from qualified researchers trained in human subject confidentiality protocols may be sent to the corresponding author.

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Conflicts of Interest

CF is a member of the Stroke Foundation (Australia) Research Advisory Committee.

SR and KY are employed by the Stroke Foundation (Australia).

Guarantor: CF

Contributor Statement:

MTC, AM and CF contributed to the conceptualisation and design of the study.

MTC, AM, CF, SR, and KY contributed to the acquisition and collection of data.

MTC, AM, CF, SR, KY, SCI and AV contributed to the analyses of data and report writing.

All authors approved the final version of the manuscript.

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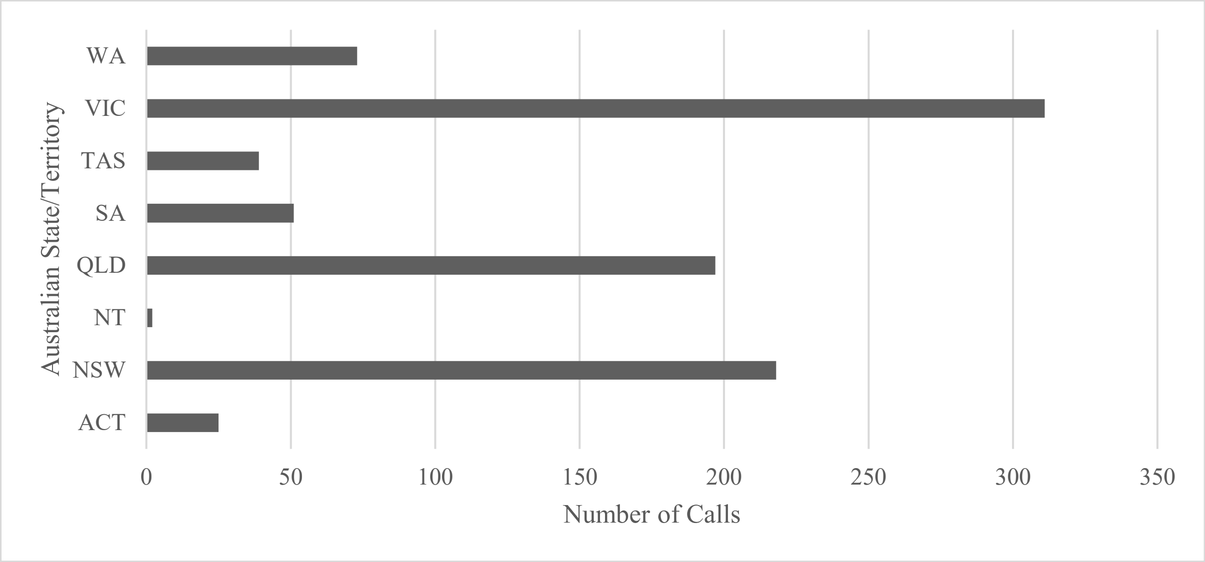

Figure 1. State-wise distribution of StrokeLine calls between 1 November 2019 and 30 November 2020.

Supplementary Appendices

Supplementary 1: Cases associated with missing data across the main categories in the StrokeLine database

Category	Number of Cases with Complete Data (%)	Number of Cases with Missing Data (%)
Constituent Type (Type of Caller)	1158 (81)	271 (19)
Gender	695 (49)	734 (51)
Age of Caller	645 (45)	784 (55)
Age of Stroke Survivor	778 (54)	651 (46)
Time Since Stroke	822 (58)	607 (42)
Aboriginal or Torres Strait Islander	456 (32)	973 (68)
Languages Spoken	423 (30)	1006 (70)
Interpreter Required	1429 (100)	0 (0)
Vulnerability and Risk	57 (4)	1372 (96)
Current Symptoms	1429 (100)	0 (0)
Risk Factors	174 (12)	1255 (88)
Reason for Calling	882 (62)	547 (38)
Type of Intervention Provided	404 (28)	1025 (72)
Mailing State/Province	916 (64)	513 (36)
Referred to StrokeLine By	426 (30)	1003 (70)
Call Duration	857 (60)	572 (40)
Call Liaison	542 (38)	887 (62)
Date/Time Case Opened	1429 (100)	0 (0)

Supplementary 2: Reason for Calling

Reason for calling	*Number of calls (%)*
Prevention	**0 (0)**
Health Services Treatment and Care	**331 (23)**
Questions/concerns about tests and treatment	210 (15)
Access to rehabilitation	151 (11)
Advocacy and Navigation	83 (6)
Discharge Planning	63 (4)
Community Services Treatment and Care	**489 (34)**
Questions About Services	222 (16)
Rehabilitation Services	191 (13)
Access Issues	101 (7)
Advocacy and Navigation	68 (5)
Aged Care	70 (5)
Concerns About Services	70 (5)
NDIS	52 (4)
Managing Stroke Impairments	**574 (40)**
Walking and Moving	227 (16)
Fatigue	180 (13)
Communicating	152 (11)
Emotions and Mood	156 (11)
Thinking/Memory/Judgement	139 (10)
Upper Limb	139 (10)
Vision and Senses	92 (6)
Adjustment/Coping	**200 (14)**
Personal Adjustment	150 (10)
Family Relationships	67 (5)
Roles and Occupation	40 (3)
Practical Issues	**186 (13)**
Driving	85 (6)
Accommodation	35 (2)
Work	54 (4)
Finances	39 (3)
Legal	12 (1)
Travel	9 (1)

Reason for calling	*Number of calls (%)*
Other	**94 (7)**
Current Symptom Concerns	17 (1)
Other Medical Conditions	15 (1)
Medication Support	14 (1)
Stroke Support Services and Resources	12 (1)

Supplementary 3: Type of Intervention Provided

Intervention Provided	*Number of calls (%)*
Brief Intervention	20 (1.4)
Care Coordination	4 (0.28)
Information, Support, Advice & Referral	362 (25)
Letter/ Call to Other	17 (1.2)
Total	404 (28)
Unknown	1025 (72)

Supplementary 4: StrokeLine calls by type of caller in November 2019 and June 2020

Type of Caller	**November 2019 (%)**	**June 2020 (%)**
Stroke Survivor	48 (47)	59 (48)
Carer/Family	55 (53)	63 (52)
Total	103 (100)	122 (100)

Supplementary 5: StrokeLine calls by type of caller in November 2019, June 2020 and Categorical Dataset

Type of Caller	**November 2019 (%)**	**June 2020 (%)**	**Total**
Stroke Survivor	48 (47)	59 (48)	482 (34)
Carer/Family	55 (53)	63 (52)	545 (38)
Total	103 (100)	122 (100)	1429 (100)

Chapter 4

Exploring the use of Telehealth-based Stroke Support in Australia: A Qualitative Study of Stroke Survivor’s Experiences

This chapter reports results of the second study included in this thesis and the research is presented as an exploratory descriptive qualitative study. The chapter is structured as a research article and begins by introducing the background context and aims of the study. The methods used in the study are then explained. The design of the study, how participants were recruited, the way in which interviews were completed along and analysis undertaken are all explained. Semi-structured interviews were completed with stroke survivors who had recently contacted StrokeLine. Interviews were transcribed before thematic analysis was used to explore the data. By exploring in particular the experiences of stroke survivors who used StrokeLine to seek support, this study is able to contextualise the role of StrokeLine in Australia within the perspectives of those most likely to use it. It also contributes to wider discussions on the support needs of stroke survivors in the community and why they are not potentially being met in other settings.

This second study is currently under review for publication and the submitted manuscript is provided as an appendix to this thesis – see *Appendix F*.

Exploring the use of Telehealth-based Stroke Support in Australia: A Qualitative Study of Stroke Survivor's Experiences

Muneeba T Chaudhry[1], Alana B McCambridge[1], Esminio II Rivera[1], Peter Stubbs[1], Arianne Verhagen[1], Caleb Ferguson[3]

[1] Discipline of Physiotherapy, Graduate School of Health, University of Technology Sydney, Sydney, NSW, Australia
[3] School of Nursing, University of Wollongong & Western Sydney Local Health District, Blacktown Hospital, Sydney, NSW, Australia

ABSTRACT

***Background**:* StrokeLine is a stroke-specific helpline used by stroke survivors and their families in Australia to access professional support. No study has examined stroke survivors' experiences of using the service and the perceived impact on their stroke recovery.

Aim: The aim of the study is to explore the factors prompting stroke survivors to call StrokeLine, describe the experience of the stroke survivor during the StrokeLine call and describe the perceived impact of calling StrokeLine on their recovery.

***Methods**:* An exploratory descriptive qualitative study was undertaken using thematic synthesis of data collected through semi-structured interviews of stroke survivors between December 2020 and June 2022. Participants were recruited using purposive sampling to obtain representation across geographic location and time since stroke. Interviews were conducted via video or teleconference, audio-recorded and transcribed verbatim for thematic analysis.

***Results**:* A total of eight callers (4 men and 4 women) participated, with the time since stroke ranging from between 3.5 months to 5 years. Four major themes were identified, including 17 sub-themes. Key themes included 1) factors prompting use of StrokeLine, 2) experience of using StrokeLine, 3) perceived impact of using StrokeLine and 4) conceptualising StrokeLine service provision.

***Conclusions**:* Participants perceived their experience of contacting StrokeLine as having a positive impact on their stroke recovery, leaving them empowered and motivated to take charge of their own care.

INTRODUCTION

In Australia alone, the number of people living with the long-term sequelae of stroke will increase to an estimated 700,000 people by 2032 (Deloitte Access Economics, 2020). The physical and psychosocial impacts of stroke are significant, with care needs evolving at every stage of recovery (Ghazzawi, Kuziemsky, & O'Sullivan, 2016; Wissel, Olver, & Sunnerhagen, 2013). As with most chronic conditions, facilitating self-management of care in stroke is essential to empower survivorship and reduce burden on health systems (Pearce et al., 2015; Taylor et al., 2014). Currently, there remains a low-level of satisfaction with information provided after discharge from formal care in acute settings, particularly around long-term management of disability and accessing follow-up services (Ferguson et al., 2016; O'Connell, Hawkins, Botti, Buchbinder, & Baker, 2009). Stroke survivors who require support to navigate between transitions of care through the healthcare system report a feeling of abandonment (Ghazzawi et al., 2016; Wissel et al., 2013). Telehealth-based care may be helpful in providing effective self-management support to stroke survivors across the continuum of stroke recovery.

Telephone-based services, such as helplines, are able to provide access to timely support (Lopriore, LeCouteur, Ekberg, & Ekberg, 2017). Specialised helplines exist globally for a number of chronic conditions such as cancer and rheumatic diseases (Taylor et al., 2014). These helplines are often serviced by qualified health professions who can help facilitate self-management of care (Taylor et al., 2014). An international study exploring the rationale, experience and impact of seeking care using telephone-based support for cancer found that callers were able to better understand their situation, facilitating further engagement with other cancer services (Boltong, Ledwick, Babb, Sutton, & Ugalde, 2017). In addition, a Swedish rheumatology helpline was effective at enabling constructive dialogue and providing motivational support for callers who had problems obtaining answers from other care settings (Arvidsson, Nylander, & Bergman, 2019). Ensuring telehealth-based care is relevant to the needs of the user is important to ensuring services remain sustainable in the future (Smith et al., 2020). To date, research into helplines for stroke survivors remains scarce.

In Australia, StrokeLine operates nationwide by the Stroke Foundation - a not-for-profit organisation and Australia's peak body and national voice of stroke. It is a free inbound stroke support service, providing resources for those affected by stroke. The service operates from a single site between routine business hours on weekdays. It is staffed by qualified health professionals from a nursing or allied health background who can be contacted via phone, email or social media. StrokeLine staff offer advice and support to stroke survivors and their families, health professionals and the general public. The role of telehealth-based support services for stroke survivors is not well understood and the impact of telephone-based stroke care in Australia needs further investigation. To date, research into stroke helplines is extremely limited, focusing only on user characteristics and a limited understanding of how they are used (Dickerson & Forster, 2015; Hanger & Mulley, 1993). There is no research that has explored caller experiences of contacting a stroke helpline in Australia and little is known about how stroke survivors perceive their encounter with such a service.

The aims of the present study were to first explore the factors that prompt stroke survivors to use the StrokeLine service. Secondly, to describe their experience during the call and thirdly, to describe the perceived impact of the StrokeLine call on their stroke recovery.

METHODS

Design

This study followed an exploratory descriptive qualitative study and was guided by the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007). Data were collected using semi-structured interviews with stroke survivors between December 2020 and June 2022 to explore their experiences of using StrokeLine, a telehealth-based support service. Informed consent from participants was obtained verbally using a scripted checklist at the beginning of each interview by the researcher. Ethical approval for this study was granted by the Human Research Ethics Committee at the University of Technology Sydney (no.: ETH20-5088).

Participants and Recruitment

To be included in the study, participants must self-report as having had a stroke at any time, be 18 years or older, had contact with StrokeLine in the past 3 months, be able to communicate in English, have access to and be able to use video-conference and be able to provide verbal consent. People who had contacted StrokeLine and were health professionals, members of the general public, and those not affected by stroke including carers and family members were excluded. Stroke survivors with aphasia were not explicitly excluded from this study, as suitability for inclusion would be determined on a case-by-case basis in conjunction with an expert Speech Pathologist familiar with qualitative interviewing strategies for people with aphasia.

The Stroke Foundation in Australia aided with recruiting participants for the study. Participants were recruited through study advertisements included in monthly Stroke Foundation newsletters, on Stroke Foundation and authors' social media channels (eg. Twitter and Facebook) and online forum posts associated with the Stroke Foundation's EnableMe (stroke survivor platform) service for stroke survivors and their carers (Stroke Foundation, n.d.). StrokeLine staff, in particular, sent pre-scripted emails directly to callers who were stroke survivors in two separate recruitment cycles, capturing only callers who had called StrokeLine in the last 3 months.

Potential participants contacted the researchers and an information sheet about the study was emailed to them prior to being screened over the phone for inclusion. Once a participant was deemed eligible, a time to be interviewed by the researcher was set up within a week.

Procedures

Prior to each interview, the participant informed the researchers of their age, location, time since stroke, if they lived alone and whether they identified as Aboriginal or Torres Strait Islander. Due the COVID-19 pandemic and recruitment of participants across Australia, all interviews with participants were conducted online using the video-conference platform. Interviews were conducted by a qualified member of the research team and lasted up to 30 minutes. The interviewer (MTC) was a female, Accredited Exercise Physiologist (AEP) experienced in working clinically with stroke survivors during their recovery. The interviewer was also supervised and trained in qualitative interviewing by a more experienced member of the research team (CF). An interview guide was followed to ensure key questions remained consistent across participants. Interviews were semi-structured and directed by participant narratives around their experiences of using StrokeLine. Narrative-inducing questions were used to primarily guide the interview with follow-up questions asked to obtain clarity where needed.

Table 1. Interview Guide - Summary of Key Topics and Main Narrative-Inducing Questions

Topic	**Narrative-Inducing Question**
Experience using StrokeLine	1. Can you please tell me about how you came to make the call to StrokeLine?
Impact of using StrokeLine	2. Can you please tell me about any changes in your life that have occurred as a result of contacting StrokeLine?
Evaluation of StrokeLine	3. Could you please tell me about your thoughts of the service you received by StrokeLine?

Purposive sampling was used to obtain representation across geographic location (metro, regional and rural) and time since stroke (acute, sub-acute and chronic) to ensure a diverse sample of participants was included. Participants were recruited until data saturation occurred, with the same comments made across multiple interviews, indicating no new themes were emerging.

Data Analysis

Each interview was audio-recorded and later transcribed verbatim for analysis. All identifying features of the data were removed before being shared amongst the research team. Written field notes were kept to aid with transparency of data collection and to add validity to interpretations made. Interview transcripts were also sent to participants for review to validate the data collected (Mero-Jaffe, 2011).

Data from transcribed interviews were analysed using a data-driven inductive latent approach to thematic analysis. Transcripts were read multiple times and coded into categories using Excel (Braun & Clarke, 2006). Transcribed interviews were read multiple times to aid familiarisation with the data. Next, data were broadly coded by two independent assessors from the research team and potential themes were agreed upon amongst the assessors, as patterns were identified. Themes were then reviewed, defined and named (Braun & Clarke, 2006). For each theme, sub themes were also named and identified. The two assessors from the research team ensured there was constant back and forth movement between all stages of the analytical process to ensure participant views were interpreted through multiple lenses at each step (Braun & Clarke, 2006).

RESULTS

Study Population

Eight callers (4 men (50%) and 4 women (50%)), ranging in ages from 28 to 82 years were included – see Table 2. The time since stroke ranged from between 3.5 months to 5 years, with callers either in the chronic (n=4 (50%)) or sub-acute stage of recovery (n=4 (50%)). The callers were from 4 different states in Australia with callers located in either a metro area (n=4 (50%)) or regional area (n=4 (50%)) at the time of the call. None of the callers identified themselves as being of Aboriginal or Torres Strait Islander descent (or both) (**Table 2**).

Table 2. Characteristics of Participants

Participant	Age at the Time of Interview	Gender	Time Since Stroke	Stroke Recovery Stage*	State	Geographical Classification±	Living Alone
1	62	Male	5 months	Sub-acute	QLD	Metro	Yes
2	82	Female	3 years	Chronic	SA	Regional	Yes
3	79	Female	8 months	Chronic	SA	Metro	No
4	54	Male	4 months	Sub-acute	NSW	Regional	Yes
5	57	Male	5 years	Chronic	VIC	Metro	Yes
6	44	Male	3.5 months	Sub-acute	SA	Regional	No
7	28	Female	6 months	Sub-acute	NSW	Metro	No
8	47	Female	4 years	Chronic	QLD	Regional	No

*As defined by Bernhardt et al. (2017) based on time since stroke

±Based on the Australian Statistical Geography Standard (ASGS) – Remoteness Area framework (Australian Bureau of Statistics, 2023)

Thematic Analysis

Data saturation was achieved by the fifth interview with no new themes emerging. Findings from a systematic review suggest that interview studies do not necessarily require large sample sizes to reach saturation (Hennink & Kaiser, 2022). Further, a homogenous study cohort may require lower sample sizes to reach saturation with participants ranging from 9 to 17 interviews. This is more likely to occur within an objectively defined scope of exploration (Hennink & Kaiser, 2022).

Four major themes were identified, including 17 sub-themes. Key themes included 1) factors prompting use of StrokeLine, 2) experience of using StrokeLine, 3) perceived impact of using StrokeLine and 4) conceptualising StrokeLine service provision (**Figure 1**).

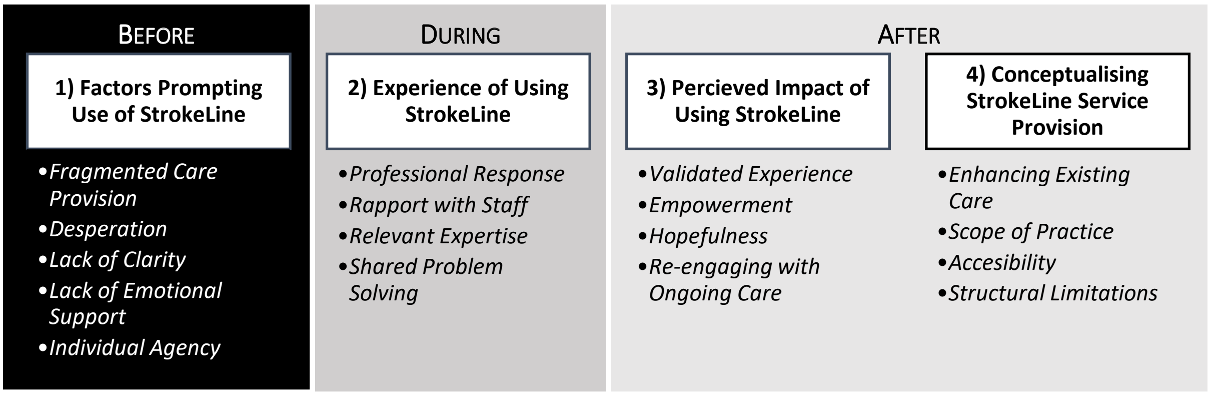

Figure 1. Themes and sub-themes across the call process

Theme 1: Factors Prompting Use of StrokeLine

[Sub-theme: Fragmented Care Provision] Participants noted a lack of follow-up once discharged from the hospital. Responses often noted very little direction given from healthcare professionals or other stroke services of what to do and where to go next. Participants further expressed feeling neglected by the healthcare system.

> *"…I spent about an hour and a half with the specialist and that's it. That was the end of my care in relation to my stroke. So there was no follow up. They gave me a mobile phone number to call the stroke clinic and made it very clear that if I ever had any questions, any concerns, I was to call that number, and if I didn't get through, I was to leave a message and they would get back to me. I must have rung that number 10, 15 times and never had a response. No one's ever picked it up, and no one has ever returned the phone call." (P6, male, sub-acute)*

Participants, however, noted receiving an information pack when discharged from the hospital. Most called StrokeLine only after finding the number for the service in the information pack, after some time had passed once they were home.

> *"The only information they gave me at the hospital when I left was a leaflet." (P6, male, sub-acute)*

[Sub-theme: Desperation] Participants often contacted StrokeLine as a 'last resort', only after exhausting all other known avenues of seeking solutions to their problems or after no longer knowing where to turn.

> *"…and it was a call of last resort because I still can't work out who I'm meant to talk to. I have no mechanism of getting in contact with anyone that can provide me with advice at all." (P6, male, sub-acute)*

> *"I think I rang on both occasions because I had exhausted my own mental and psychological resources - that's the point that I was at to make that phone call." (P5, male, chronic)*

[Sub-theme: Lack of Clarity] Participants contacted StrokeLine seeking clarity around their concerns. Concerns themselves were often complex, compounded by conflicting information, advice and support needs. As such, for participants in the study there was never a singular reason for contacting the service.

> "I *felt that I wasn't getting enough information from the medical profession that I felt made sense for me. And I'm one of these people, that I'm on a need to know basis. If I understand as best one can what's happening for you, then you can manage the situation. But if you don't know what's happening, you can't manage it because it's sort of a blind spot. And so to me it was logical because it was sort of to do with the stroke…that they were the logical people to perhaps give me some answers or at least point me in a direction that will be useful in terms of managing what was happening for me at the time." (P1, female, chronic)*

[Sub-theme: Seeking Emotional Support] Along with seeking clarity and practical guidance, StrokeLine calls where often also driven by participants' emotional states. Often calls were prompted with no real direction and very limited expectations, as participants sought out the service to make sense of their changed circumstances, under heightened emotional distress.

> *"I was quite keen to talk to someone who might have some level of understanding of what I've experienced and what is normal and what isn't normal." (P6, male, sub-acute)*

[Sub-theme: Individual Agency] Participants all revealed individual agency in their active involvement in seeking control of their current situation, prompting them to call StrokeLine and initiate continuity of their own care.

> *"It wasn't until it became quite evident that there was no support whatsoever in the process that I had experienced that I thought, well, I better be proactive here and I rang the StrokeLine." (P6, male, sub-acute)*

Theme 2: Experience of Using StrokeLine

[Sub-theme: Professional Response] Participants valued the way in which StrokeLine responded to their first contact. In particular, participants appreciated the timely and professional response of StrokeLine staff, even when their call was not answered on the first try.

> *"So I rang up and there was no one to answer my call and I left a message. And on both occasions the person got back really quickly. Like impressively quickly, as in when you leave a message you rarely get a call back in any... and on the first occasion - I got a call back from the lady, from one of them. And then another one of the ladies called back at the same time and I said, "Well, I think I'm already talking..." The response was impressive and the response was impressive like twice over." (P6, male, sub-acute)*

[Sub-theme: Rapport with Staff] Participants experienced good rapport with StrokeLine staff during their contact. They felt comfortable sharing sensitive information about their experiences and perceived a sense of familiarity when interacting with StrokeLine staff. Most participants emphasised how they did not feel patronised when sharing their concerns and instead felt listened to.

> *"I didn't feel like I was ringing up and there was a script that was being followed to provide me with guidance. I felt it was quite personal experience to what I experienced and it felt like... so the effectiveness of it, I think it was quite effective from that perspective." (P6, male, sub-acute)*

[Sub-theme: Relevant Expertise] Participants not only understood StrokeLine staff to be experienced enough to give advice based on their professional qualifications but also appreciated they had knowledge relevant to all aspects of their stroke care.

> *"I think the balance that you've got with the people that you have on the stroke hotline for me was ideal. It wasn't someone who had had a stroke, but I felt that they had - well, maybe they have, I have no idea, I couldn't tell - and they were able to provide me with caring advice." (P6, male, sub-acute)*

[Sub-theme: Shared Problem-Solving] Participants appreciated the way in which their concerns were addressed by StrokeLine staff, particularly in being included in the process and not simply being given the answers someone else thought they needed.

> *"…she gave me direction and a sense of purpose. I think which was...there was another person saying, "I now have heard what you're experiencing and I think that what you're experiencing warrants you should go and see your GP and you should go and take this course of action". And I think that was an important thing to gain from that conversation, which I haven't got anywhere else, not even from the GP when I talk to them." (P6, male, sub-acute)*

Theme 3: Perceived Impact of Using StrokeLine

[Sub-theme: Validation of Experience] Participants felt their experiences after having a stroke were validated and that there was value placed on the significance of their changed circumstances. In doing so, most participants felt they could allow themselves to better accept what had happened.

> *"She accepted what I said - she didn't sort of dismiss it as being trivial or not consequential. So for me, that was really good being confirmed in that way, that I had concerns that really needed to be looked at seriously, which was good." (P1, female, chronic)*

[Sub-theme: Empowerment] Participants felt empowered after contacting StrokeLine and felt better able to take charge of their care. They perceived their contact with StrokeLine equipped them with the skills they needed to be able to do things themselves.

> *"…and as a result… I listened to some podcasts, I downloaded books, and then I felt like I had more control about the experience that I was having." (P6, male, sub-acute)*

[Sub-theme: Hopefulness] Participants felt hopeful after their contact with StrokeLine, particularly in feeling like they could now get through the difficulties they experienced post-stroke.

> *"I'm trying to regain as much independence as I can, and people keep telling me how well I'm doing. And I think, you know, yes I have come a long way." (P1, female, chronic)*

> *"So there was that little glimmer of hope that things might go a different way and I might be able to go back to getting the therapy that I felt I felt justified in asking for." (P6, male, sub-acute)*

[Sub-theme: Re-engaging with Ongoing Care] Participants felt motivated to take appropriate action in response to their needs, noting their contact with StrokeLine prompted them to better engage with their post-stroke recovery.

> *“But they gave me the confidence to actually move on and say, okay, this needs other attention.” (P1, female, chronic)*

> *“I still felt overwhelmed about everything but I suppose there was that little bit of me that also was thinking that there is some light there and 'I' need to do something about it. So that was the thing. And I've learned that everybody has to fight for themselves. So nobody's going to knock on my door and say, " Hey, come and be part of the acquired brain injury unit." You've got to go out there and I suppose pipe yourself.” (P6, male, sub-acute)*

Theme 4: Conceptualising StrokeLine Service Provision

[Sub-theme: Enhancing Existing Care] Participants noted that they did not know what to expect when first calling StrokeLine. After the call, however, participants understood the service to be valuable in enhancing their existing care and they would use it again.

> *“As I said I've engaged with the process on two occasions and I guess they've sort of like been little stable points in quite a confusing, disjointed process where I guess I needed that contact at those times and have been aware since the first time that if I needed that I could reach out again and obviously get a great response. Not with an expectation that all of my answers would be there but there would be someone to listen to what I had experienced and give me some advice even if it's advice that I was aware of - just like having someone else tell you that this is something that you should do is quite powerful on occasions, you might know where the resources are, you might know what the prudent thing might be to do - like going visit your GP - but until someone articulates that and says it out loud, it's like maybe you don't get around to doing it.” (P6, male, sub-acute)*

> *“StrokeLine performed better than any other part of this system that I've stepped into.” (P6, male, sub-acute)*

[Sub-theme: Scope of Practice] Participants understood that StrokeLine staff were unable to provide them with aspects of care that were 1) professionally outside the scope of practice of StrokeLine staff and 2) outside the scope of telehealth-based service provision offered by StrokeLine.

> *"The lass* [female] *I spoke to was very good at listening and asking me questions that I felt were really relevant. And although I didn't expect a diagnosis - obviously they're not in that sort of category. She did point me into a direction, like she did say to me, you probably need to make an appointment with a neurologist." (P1, female, chronic)*

> *"I think I have a better appreciation of what can be offered having contacted them twice. I know even though I would love someone to be able to sort out the hassles I've got with the bureaucracy around the medical system, I know that they are not able to do that…" (P6, male, sub-acute)*

[Sub-theme: Accessibility] Participants appreciated the value of StrokeLine existing as a telehealth-based service, particularly in regards to the immediate availability of support from the service and the ability to improve access to care for people living in areas with limited post-stroke services.

> *"You can just call the number and they're there." (P8, female, sub-acute)*

> *"Well, I think accessibility and particularly, as I said previously, for regional people - and rural people would have the same issue. And I think it's a huge issue because I was talking to someone this morning and things are still [capital city]-centric. Nothing happens beyond our [capital city]. And so I think being aware that there are people out there in remoter areas that really would find a service like this useful." (P1, female, chronic)*

[Sub-theme: Resource Limitations] All callers understood there to be potential resource limitations with the StrokeLine service, particularly around staffing that led to delays in response time. Feedback around effectiveness of service provision consequently centred around the preference for calls to be answered on the first try, suggesting the need for improvement in this area.

> *"I felt frustrated that I had to leave a voicemail at first. I understand though, that's because they can't answer everyone's calls and there's a lot of people that call. But I think the actual service is very good and effective. Yeah. The one thing I found tricky was the leaving the*

> *voicemail and then also having to wait. You know, sometimes you might call because you're feeling something right in that moment, and you might want support right then. And then they call back when they're free an hour later or whenever it is, and you might not want to talk about it anymore, I guess, even though it's still...the emotions are still there, you might just not want to speak about it then." (P8, female, sub-acute)*

> *"They need to revamp their answering machine because it leaves you with the feeling there's no one there. It's the way it's expressed. It needs to say something like "all our professional workers are busy at the moment" rather than saying "there's no one here" or sort of thing and you're left with the feeling of should" I ring back or not?" (P1, female, chronic)*

DISCUSSION

Stroke survivors were prompted to use the StrokeLine service after experiencing fragmented care provision in their post-stroke recovery and feeling abandoned by the healthcare system. Contact with StrokeLine was often initiated out of desperation and perceived as a last resort when other avenues of seeking clarity and emotional support were exhausted. In contacting StrokeLine, all participants also revealed individual agency in their active involvement in seeking continuity of care. Participants had an overall positive experience while using StrokeLine and appreciated the professional response and relevant expertise of StrokeLine staff during the call. Stroke survivors felt comfortable sharing their concerns with staff and valued being involved in the process of helping them find solutions.

After using StrokeLine, participants perceived a positive impact on their stroke journey. They felt their experiences were validated, motivating and empowering them to take charge of their recovery. Participants felt a renewed sense of hopefulness and noted they would use StrokeLine again if needed, as they now knew what they could expect from the service. Stroke survivors were also able to better conceptualise StrokeLine service provision after the call. They understood the value of the service in enhancing existing care. They further understood the service was limited by both the scope of practice of StrokeLine staff and the telehealth-based model of care under which the service functions. Participants, however, also understood the potential strength of the service in providing timely access to support in geographical areas with limited post-stroke services. Finally, when suggesting recommendations for improving the StrokeLine service, all participants perceived there to be structural limitations around resource allocation and staffing. Consequently, most recommendations for improvement were believed unlikely to be actioned if these perceived limitations to resource allocation were not first resolved. Recommendations for improvement included increasing the likelihood of answering calls in the first instance and providing a more personable voicemail message if this could not be achieved.

Although participants noted receiving very limited care provision post hospital-discharge and even later in their stroke recovery, most participants in this study noted receiving an information pack when discharged from hospital in which they later found the StrokeLine number. A number of studies have highlighted the importance of providing information ‘just in time’ to facilitate the self-management of care in stroke (Eames, Hoffmann, Worrall, & Read, 2011; Pearce et al., 2015). If information is provided at a time when a person is not ready to take charge of their condition, most often people are left feeling overwhelmed and abandoned by their healthcare providers (Forster et al., 2021). As such, self-management of care is contingent on people revealing individual agency and seeking to take active control in the continuity of their care (Shim, 2022). Helpline interactions, therefore, are able to reinforce self-management by providing timely support, relevant information and empowering callers when the caller establishes a need for this (Moore, 2016).

In the current study, concerns discussed during the call were often multi-layered and there was never a singular reason for calling StrokeLine. Information, advice and support were often all sought during the same call and callers were unable to distinctly differentiate between what was offered to them. Interactions of a similar nature in helpline-based care provision are discussed extensively in the research. Arvidsson et al. (2019) noted that understanding the precise description of a caller’s problem when they called a rheumatology telephone helpline was difficult (Arvidsson et al., 2019). Initially characterising the caller’s experience by building a feeling of mutual trust and solidarity, however, later aided in clarifying the explicit reason for the call (Arvidsson et al., 2019). As such, the strength of telephone-based service provision lies in the call-takers ability to intertwine emotional support with practical information or advice (Ekberg et al., 2014). In Australia, approximately 20% of stroke survivors were known to have had another stroke after 5 years (Peng et al, 2022). Given this, it was interesting to note that participants did not appear concerned about preventing the recurrence of stroke and sought care only around their present challenges.

Strengths and Limitations

The strengths of this research extend to the depth and richness of the interview data. Interviews provided insight not only into the participant’s experience during and after the call but also before the call was placed. Understanding the wider context of factors prompting stroke survivors to call StrokeLine highlights the gaps in current provision of care in stroke. This study was also guided by industry engagement in close partnership with the Stroke Foundation in Australia, allowing findings from the study to support timely feedback for service improvement and relevant reporting to policy-makers.

The findings of this study, however, are limited by a number of factors that need to be considered. Firstly, close industry engagement during the research process may have influenced the extent of positive findings in this study. Callers who had a more favourable experience with the StrokeLine service may also have been more obliged to participate. The level of post-stroke impairment of each participant was also not explicitly captured during the interview process and the experiences and perceived impact of using StrokeLine in severe stroke versus mild stroke may differ. Although not an exclusion criteria, no stroke survivors with communication difficulties expressed an interest in participating in the study. Interview-based studies can be adapted for the inclusion of participants with communication difficulties, however, the online nature of the interview may have added another level of complexity and discouraged participation in this regard (Dalemans, Wade, Van Den Heuvel, & De Witte, 2009). In turn, there may have been recall bias around information resources given to stroke survivors on discharge that participants may have failed to account for.

All participants were also from a European background and findings may not be inclusive of the views of other cultural backgrounds. Although the small sample size of participants included in this study may be limiting in some ways, data saturation was achieved after the fifth interview with no new themes emerging. The use of purposive sampling to capture participant representation across geographic location and time since stroke, however, was unable to account for acute stroke and any rural distribution of participants, possibly limiting the generalisability of findings.

Recommendations

Future research should look to explore the type of information, support and advice in stroke care in Australia. This will aid in understanding how and when to best provide each across the continuum of stroke recovery and to better match the expectations of stroke survivors. Further research should also seek to understand how best to integrate services such as StrokeLine within existing health systems at an appropriate time within the trajectory of care in stroke. Better understanding factors prompting stroke survivors to reveal individual agency to take control of their care continuity may provide insight into when to best have services available to support their self-management. In turn, better understanding stroke survivor's knowledge and perceptions towards preventing the recurrence of stroke may be warranted. There is also a need to better understand why stroke survivors may not be using StrokeLine at all.

It is important to recognise how best to leverage person-centred care provision afforded by telehealth services such as StrokeLine that exist in organisational structures with competing priorities. In response to the COVID-19 pandemic, the relevance of telehealth-based care provision and a focus on value-centred healthcare redesign warrants an economic evaluation of StrokeLine service provision. As such, this study highlights implications for policy makers in supporting the future sustainability of services such as StrokeLine.

CONCLUSION

Stroke survivors used a stroke helpline in response to fragmented care provision in other settings and after using the service, most perceived a positive impact on their stroke recovery. In particular, participants felt empowered and motivated to take re-engage with their ongoing care. Stroke survivors also understood StrokeLine to be able to enhance their existing care. Structural limitations were perceived as the main driver for the delayed response time in answering calls in the first instance.

Data availability statement

Due to the sensitive nature of the data collected for this study, requests to access the dataset from qualified researchers trained in human subject confidentiality protocols may be sent to the corresponding author.

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Conflicts of Interest

CF is a member of the Stroke Foundation (Australia) Research Advisory Committee.

ORCID iD

Muneeba Chaudhry

Chapter 5

Discussion

This thesis aimed to explore the role of StrokeLine, a telehealth-based stroke support service in Australia by describing the use of the service. In particular, this thesis reports the characteristics of those calling the service, reasons why they called and what StrokeLine provided in response. Additionally, the thesis explored the experiences of stroke survivors who called StrokeLine, focusing in particular on the factors prompting them to call the service, their experience during the call and the perceived impact of calling StrokeLine on their stroke recovery. This chapter begins by presenting a summary of key findings from each of the studies included in this thesis. A general discussion will follow, contextualising the findings in the most recent evidence. Findings will be further synthesised and used to generalise the role of StrokeLine in Australia, integrating strengths of the service. Key issues highlighted in study findings will also be discussed. The implications of findings and recommendations for health services, policy and future research will follow. Finally, a discussion on the strengths and limitations of the entire program of research will be provided.

5.1 Summary of Key Findings

5.1.1 Study 1

The first study aimed to describe the utilisation by phone of StrokeLine, a stroke-support helpline in Australia. It particularly described caller demographics to understand who was calling. The study further explored reasons for why people contacted StrokeLine and what the service was able to provide in response to the caller's needs.

It was found that most calls received by the service were from stroke survivors and carers. Callers were predominately female and aged 65 years-or-over, with most calls related to a stroke having occurred less than a year ago. It remained largely unknown whether people identified as being of Aboriginal or Torres Strait Islander descent (or both). Similarly, the culturally and linguistically diverse nature of callers was unable to be determined for a majority of calls received. Identifying whether the caller needed an interpreter or if they spoke other languages besides English was the main method to ascertain this and in most instances was poorly reported. The main reason for calling StrokeLine related to enquiries around health or community services for treatment and care and how to manage stroke-related impairments. Further, StrokeLine calls were often prompted by a lack of direction around where to go and what to do. Callers were often dissatisfied with care in other settings and appeared to have exhausted other avenues of seeking information. In response to callers' needs, StrokeLine most often provided them with guidance on what to do next and information about other relevant services. Both stroke survivors and carers were commonly provided with actionable items to discuss with their General Practitioner or specialist and StrokeLine staff helped them formulate an action plan to do this. StrokeLine staff particularly provided stroke survivors with reassurance and validated their post-stroke experiences.

Data pertaining to where the caller was calling from was limited to their state/territory of residence, with most calls received from Victoria and New South Wales (NSW). As such, there was no way of understanding if the absence or presence of other healthcare services in either remote, regional or metro locations in Australia affected the nature of StrokeLine enquiries. Overall, there was also a significant percentage of missing data under most categories, as in most instances free-text within summary fields was often used to record call data instead.

5.1.2 Study 2

The second study aimed to explore the experiences of stroke survivors who had recently used the StrokeLine service. The factors prompting stroke survivors to call StrokeLine, their experience during the call and the perceived impact of calling the service on their stroke recovery were all explored.

Stroke survivors experienced fragmented provision of care after they had their stroke, motivating them to call StrokeLine after other avenues of seeking clarity and emotional support appeared to have been exhausted. The StrokeLine number was often found in resources given to them in the hospital but only used after some time had passed after they returned home. Stroke survivors revealed individual agency in initiating contact with StrokeLine to further their own care, even though calls to StrokeLine were often placed out of desperation and most considered it a last resort. During the call, participants appreciated the professional response of StrokeLine staff and the rapport they had with them. They perceived StrokeLine staff to have the relevant experiences to address their concerns and valued being involved in the problem-solving process.

After the StrokeLine call, stroke survivors felt empowered and motivated to further engage in their ongoing care. Having their experiences validated gave them a renewed sense of hope with their stroke recovery. Participants noted they would use the service again, as they better understood what StrokeLine was able to provide them. They understood StrokeLine could supplement their existing care as a telehealth-based service, especially when they most needed it themselves or for others with limited access to post-stroke services due to their location. Stroke survivors perceived the service was bound by the scope of practice of StrokeLine staff and what telehealth-based services can offer from a distance. Structural limitations of the StrokeLine service were also understood to exist around staffing and resource allocation, prompted by most calls not being answered on the first try. Stroke survivors accepted that their recommendations for calls to be answered on the first try may not be actioned until limitations to resource allocation were first resolved.

5.2 General Discussion

Findings presented in this thesis extend on the current understanding of self-management support in stroke. They suggest telehealth-based services such as StrokeLine in Australia are uniquely placed to provide ongoing support to those affected by stroke. This is consistent with the wider literature reporting on the utility of helplines in supporting self-management of long-term care in a range of chronic conditions by providing relevant and timely support when needed most (Arvidsson, Nylander, & Bergman, 2019; Ekberg et al., 2014; Emmison & Firth, 2012).

The StrokeLine database explored in Chapter 3 of this thesis inadvertently highlights the complexity of the post-stroke experience for both individuals affected by stroke and health services providing them with care. There were often multiple reasons for calling, ranging from topics around accessing existing services or managing physical impairments. These findings align with previous literature reporting on stroke survivors and their carers having insufficient knowledge and understanding of how to manage long-term recovery after a stroke, particularly in managing ongoing disability and access to support services (Burton et al., 2021; O'Connell, Hawkins, Botti, Buchbinder, & Baker, 2009). Stroke survivors and their carers often report dissatisfaction with post-discharge information provision, leaving them feeling abandoned by the healthcare system (Pindus et al., 2018). Self-management support interventions delivered soon after stroke may only address basic educational needs at the time and fail to account for the evolving nature of individual needs and circumstances in the long-term (Fletcher, Kulnik, Demain, & Jones, 2019)**.**

StrokeLine most often provided stroke survivors and their carers with information, support and advice but also practical guidance and reassurance. Social support has been known to help normalise experiences in stroke and StrokeLine’s ability to provide practical guidance to callers emphasises self-management of care as a collective experience (Jones, Riazi, & Norris, 2013). Providing adequate information in conjunction with support can allow stroke survivors and their carers to take a more active role in the management of their ongoing care (Forster et al., 2012). For stroke services designed to provide self-management support, fostering a flexible relationship between individuals seeking care and health care professionals is key to enabling active participation in the problem-solving process (Jones et al., 2013). Analysis of the StrokeLine database further highlighted the need for healthcare infrastructure underpinned by robust data-driven processes to ensure service provision remains relevant to those who use the service.

By exploring in particular the experiences of stroke survivors who used StrokeLine to seek support in study 2, this thesis is able to contextualise the role of StrokeLine in Australia within the perspectives of those most likely to use it. It also contributes to wider discussions on the support needs of stroke survivors in the community and why they are not potentially being met in other settings. The research emphasised that particular reasons for calling StrokeLine are multi-factorial and difficult to identify at first, as they are compounded by a range of contextual factors both emotional and personal in nature. This confusion is further marred by poor demarcation between what constitutes information, advice or support, as the practical and emotional needs of stroke survivors are often intertwined (Guo et al., 2021). In addressing both emotional and practical needs of stroke survivors calling the service, StrokeLine service provision aligns with wider research into helpline-based care provision. The timely nature of person-centred information, advice and support that can be offered by such inbound service provision may be key to increasing health literacy in stroke (Moore, 2016). Health literacy is key to being able to maintain long-term health through self-management, where information is translated to knowledge in partnership with health providers (Liu et al., 2020).

Stroke care pathways can often be highly structured and rigid in their approach to providing care, often limited by their focus on acute settings, the time-frame within which interventions exist and the lack of continuity into chronic care (Boehme, Toell, Lang, Knoflach, & Kiechl, 2021). Consequently in the long-term, self-management of care in stroke often becomes a replacement for health services whereby the primary power over care shifts exclusively to the stroke survivor (Fletcher et al., 2019). Self-management of care in stroke, however, cannot occur in isolation and needs to be approached collaboratively in a way where support remains available when needed, independent of the time since the stroke first occurred (Fletcher et al., 2019). Findings from study 2 revealed individual agency prompted stroke survivors to call StrokeLine, placing the service in a unique position where stroke survivors are able to take active control of their continuity of care and choose to remain under the direction of more knowledgeable health professionals when needed. As such, StrokeLine is able to support self-management in stroke by continually reinforcing individual agency.

Study 2 also highlighted that StrokeLine is able to facilitate stroke survivors re-engaging with their ongoing care, particularly with their existing care providers or by initiating care in other settings. Similarly, the concept of engagement in rehabilitation has been reported in the literature as being co-constructed between healthcare providers and the patient (F. A. S. Bright, Kayes, Worrall, &

McPherson, 2015). Kayes, Cummins, McPherson, Worrall, and Bright (2022) reported on the importance of developing connections to facilitate engagement in stroke rehabilitation, as engagement can decline in the long-term without appropriate input from both healthcare providers and stroke survivors. They further noted engagement is a participatory experience and if an individual is disengaged from their care it is never the fault of the individual alone (Kayes et al., 2022). The role of the healthcare provider and wider systems of care cannot ignore the role they play in the process of disengagement (F. A. Bright, Kayes, Cummins, Worrall, & McPherson, 2017). By supporting self-management of care, StrokeLine has the potential to help reinforce the individual agency of a stroke survivor. In this way, the service may be key in facilitating re-engagement with ongoing care and potentially could play a role in improving a stroke survivor's quality of life.

A representation of findings is presented in *Figure 1,* outlining the role of StrokeLine in Australia. The diagram proposes key outcomes of contacting the service and provides a foundation for understanding the wider impact of service provision. The representation of findings can be used by health services, policy-makers and researchers to guide future work related to StrokeLine service provision.

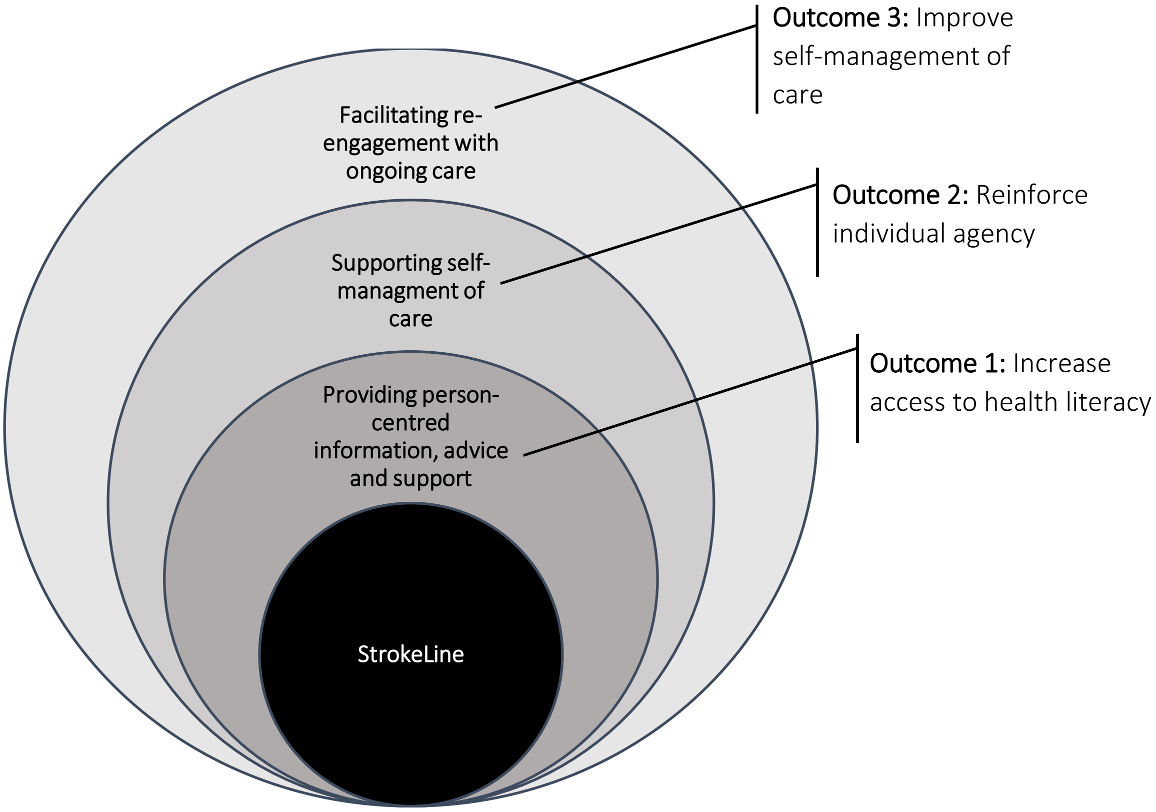

Figure 1. The Role of StrokeLine in Australia

5.2.1 Key Issues

Findings from this program of research highlighted key issues related to StrokeLine service provision and are discussed in the following sections. The issues highlighted have implications for health systems, policy-makers and researcher which are expanded on later in this chapter.

Data Management

Findings from study 1 highlighted limitations in StrokeLine data management processes and infrastructure. The way in which data is currently captured in the StrokeLine customer relationship management has implications for routine data extraction to aid ongoing service evaluation. The identifiable nature of free-text data, in particular, has ethical consequences for StrokeLine service providers and external auditors. In turn, research into helplines has often centred on repeat callers where the frequency of seeking care is often seen as a result of the complexity of the caller’s needs (Vivekananda, Cuppari, Jenkins, & Usatoff, 2021). For StrokeLine, however, there was no distinct method of capturing repeat callers as each episode of contact with the service was categorised under a different ID number. As such, there was no way of knowing if an episode of service was initiated by the same person. Further, repeat contact with the same individual across multiple interactions may in some instances be captured if the contact is a continuation of the same issue which first prompted contact. In these instances, a record of multiple contacts is outlined in the free-text summary fields and an aggregated total time of all interactions involved across the episode of care is captured under the call duration category. This has consequences for the accuracy of data capturing the duration of each StrokeLine contact, where longer call durations may in fact involve multiple contacts and there is no way of knowing what was discussed during each individual interaction.

Further, the significant volume of missing categorical data captured in the StrokeLine customer relationship management system is concerning and may in-part be reflective of the complexity of helpline-based care provision. Call-takers must balance the dual tasks of actively engaging with the caller to ensure they feel listened to and the administrative load of accurately documenting the interaction (Lopriore, LeCouteur, Ekberg, & Ekberg, 2017). In turn, a single contact with helplines such as StrokeLine may involve discussing multiple concerns and prove difficult to categorise what is discussed when documenting the call (Bloch & Leydon, 2019). Identifying flaws in the StrokeLine customer relationship management system can enable service providers to reflect on the relationship between how things are discussed during the call and the data infrastructure needed to best document each interaction. For StrokeLine, in particular, there is a need to also better understand how the interaction between the call-taker and the caller is being managed in real-time which may have further consequences for the redesign of current data infrastructure.

Diversity and Accessibility

Telehealth-based services are generally beneficial due to their availability and universal ease of access (Keenan, Tsourtos, & Tieman, 2022). From the data captured in the StrokeLine customer relationship management system, however, little is known of how the service is used by health disparity populations including racial, ethnic, sexual and gender minorities, along with geographically remote and rural populations in Australia.

At the time of the research reported in this thesis, the StrokeLine customer relationship management system only captured the state or territory a call was received from in 64% of the data analysed. It may be important to understand the specific remote, regional or metro locations of callers to contextualise use of the service in relation to the availability or lack of availability of other healthcare services in a given area. The geographical location of indigenous Australians, in particular, is known to impact post-stroke outcomes and life expectancy (Tiedeman, Suthers, Julien, Hackett, & Oakley, 2019). Apart from not capturing more specific geographical location of callers, in 68% of cases analysed in study 1, whether callers identified as being from either or both Aboriginal and Torres Strait Islander descent remained unknown. Tiedeman et al. (2019) reported that indigenous stroke survivors in Australia are provided with poorer post-discharge care than non-indigenous individuals and it is important to understand if this is reflected in the use of services such as StrokeLine.

It is also important for healthcare services to routinely collect and monitor information about the sociocultural background of their target population (Leydon, Ekberg, Kelly, & Drew, 2013). For helpline services such as StrokeLine where service provision is focused on meaningful interactions and providing person-centred outcomes, it is vital the cultural background of those contacting the service is given due consideration. Data about ethnicity can provide insight into health-related patterns and indicate commonalities between population groups, providing a basis to improve health inequalities (Leydon et al., 2013). Data from the StrokeLine customer relationship management system described in study 1, however, highlights potential diversity of callers was not fully captured. The culturally and linguistically diverse (CALD) background of callers to StrokeLine was often assumed by asking what languages the callers spoke which in 70% of remained unknown. No callers required an interpreter during the call and this was captured across all cases included for analysis as either a yes or no response. Leydon et al. (2013) reported that helpline staff find it uncomfortable to ask callers for their ethnic background and this difficulty is often evident in the incomplete or inaccurate nature of information collected for each call. Caller's may often find the question of ethnicity unexpected and confronting in a helpline interaction, especially if asked in an open-ended manner (Leydon et al., 2013). Consequently, providing callers with ethnic categories to choose from may provide more forthcoming responses (Leydon et al., 2013). As such, it's important for staff to be provided appropriate training and data infrastructure redesigned to support better practices. The StrokeLine Advice Services Practice Manual provided to staff to guide their interaction with callers includes a section briefly outlining culturally capable practice, however, more comprehensive resources and training may need to be considered (StrokeLine Advice Services Practice Manual, 2019).

Resource Allocation

Helplines such as StrokeLine aim to function as inbound services and rely on appropriate resource allocation to help them maintain intended service provision. Findings from study 2 in this thesis noted, however, that stroke survivors often received a call-back from StrokeLine staff as they were unable to answer the call on the first try. At the time of this research, the StrokeLine service was managed by one full-time staff member and one part-time staff member. With the increased use of telehealth-based services globally in response to the COVID-19 pandemic, provision of care provided by helplines such as StrokeLine remains timely and relevant. The current staffing model of StrokeLine, however, may prove a hindrance to the future sustainability of the service. There is a need to increase funding to the StrokeLine service to aid in appropriate allocation of resources and ensure the service remains operational well into the future.

5.3 Implications for Health Services and Systems

For health systems in stroke, consideration needs to be given for a more coordinated approach to better integrate interventions designed to support self-management of care within existing health systems (Jordan, Briggs, Brand, & Osborne, 2008). Given some callers contacted StrokeLine while experiencing stroke-like symptoms, a review of current StrokeLine practices is warranted. In particular, improving on instructions provided by StrokeLine to callers while they wait for their call to be attended to by staff may be required. A national survey conducted in 2001, showed that 51% of Australian adults were unable to name warning signs of stroke without being prompted (Sug Yoon, Heller, Levi & Wiggers, 2001**)**. Australian public awareness of stroke warning signs has since improved as a result of significant stroke awareness media campaigns (Bray et al., 2013). For those unaware of these campaigns, however, symptoms of stroke may still not be immediately recognised. It is likely in these instances further clarification is sought from a targeted stroke support service like StrokeLine rather than seeking care in emergency settings. Detailing potential stroke-like symptoms in the StrokeLine introductory message as an extension of general advice relating to the person thinking they are experiencing a stroke may be needed. This may add a level of urgency to seeking more appropriate medical advice for the person calling. Self-management services such as StrokeLine may also benefit from better integration with primary health-care services. Consequently, there may be a need to better equip health care providers in these settings with information about StrokeLine to increase referral and local professional organisations may be a means for facilitating this.

In response to the COVID-19 pandemic, telehealth-based care provision has been prioritised across health systems (Wosik et al., 2020). For telehealth services such as StrokeLine that existed prior to the pandemic, particular consideration needs to be given to the sustainability of service provision that aligns with both evolving needs and the expectations of increased demand. From the data in study 1, it was difficult to fully ascertain whether COVID-19 affected call frequency or reason for calling, as data was collected early on in the pandemic and prior to the rollout of national vaccination initiatives. The pandemic, however, was reported to have a significant impact on a number of other condition-specific health helplines in Australia. The National Kids Helpline reported a 20% increase in calls and calls to the Asthma Australia helpline increased by 77.4% in 2020. The Heart Foundation Helpline in Australia, however, was closed in 2021 as the increased availability of telehealth-based services across the country and the enhanced capacity of the National Healthdirect helpline significantly decreased demand for the service altogether.

The findings from this research also highlight the need for greater transparency in organisational reporting of service outcomes. With the increased focus on data-driven reform in health systems, annual reporting needs to provide deeper insight into the utilisation of telephone-based support. Besides the number of enquiries received each reporting period, helpline data around the reason for contact and consequent action taken by service providers is able to provide real-time insight into health service utilisation. For health services such as StrokeLine to remain sustainable under this model of care, further insight is also required to assess the effectiveness of existing processes. As such, findings from this research have highlighted a need for StrokeLine to provide more comprehensive staff education and training, particularly in the application of culturally competent practices.

The defining characteristic of a health helpline is in providing information, support and advice when someone most needs it, prompting them to initiate contact most often in response to external motivators (Bloch & Antaki, 2019). The sustainability of health services and systems rely on internal and external infrastructure aligned with organisational values (Crisp, 2017). It is important to understand priorities of organisations that implement services and the skills and values of the people involved in their delivery (Kidd, Booth, Lawrence, & Rowat, 2020). Helpline infrastructure can be flexible and adaptable to changing needs and competing priorities. In 2020, for example, the National Coronavirus Helpline in Australia was built on the existing infrastructure of the Healthdirect Helpline, expanding operations in response to changing needs and contexts (Healthdirect Australia, 2020). In the same year, the National Arthritis Infoline in Australia raised funds for an outbound calls program in response to the need for individualised information and support for people with arthritis who were left vulnerable and isolated by the pandemic (Arthritis Australia, 2020). Similarly, the existing capabilities of the StrokeLine service are well-placed to expand and provide an outreach component to the current inbound service model to enhance service delivery, further improving continuity of care in stroke.

An economic evaluation into StrokeLine service provision may clarify how to better allocate resources or provide considerations for relevant service innovation and redesign. Findings in study 2 of this thesis reported calls were often not answered on the first try and having to leave a voicemail message was inconvenient. In turn, the difficulty of managing the documentation of caller data while ensuring person-centred care may benefit from the introduction of more innovative practices by StrokeLine. Helplines often make use of artificial intelligence and pre-recorded messages to automate select aspects of service provision such as capturing relevant user data and helping prioritise callers by placing them in a cue (Bloch & Leydon, 2019). It is important to understand the feasibility of implementing such practices in StrokeLine service provision without compromising on the quality and relevance of the care currently provided by the service. As such, this program of research has consequences for policy makers to help increase the future viability of the StrokeLine service.

5.4 Implications for Policy

Not-for-profit organisation such as the Stroke Foundation in Australia often rely on government funding and philanthropic donations to sustain their initiatives. For policy makers, self-management support services such as StrokeLine must be relevant and scalable in their uptake to justify increased funding and support (Jordan et al., 2008). Services such as StrokeLine, however, continue to exist on the periphery of health systems in Australia due to their limited integration with existing providers, especially in primary care settings. Jordan et al. (2008) highlighted the need for a systematic approach to self-management support in chronic disease. Consequently, integration of self-management support initiatives for stroke within existing health services cannot occur in isolation and requires timely action at the policy level.

As a result of the COVID-19 pandemic and telehealth now being prioritised in all aspects of care provision, telehealth-based self-management support initiatives like StrokeLine cannot be undervalued. Further, the move to implement value-based reform at all levels of healthcare to ensure the future viability of health systems provides a framework for relevant service evaluation given the current climate.

The *National Health Reform Agreement 2020-25 (NHRA)* in Australia was introduced to build health system resilience by transitioning existing systems to focus on key outcomes of value-based care (Australian Government Department of Health, 2021). In particular, better coordination of care across health systems is a long-term focus of the 2020-25 National Health Reform Agreement (NHRA) (Australian Government Department of Health, 2021). The NHRA commits to a long-term vision for health reform where all levels of government share responsibility for health services in Australia. Evaluating and reframing StrokeLine service provision against the six reforms prioritised in the NHRA may provide focussed insight for policy-makers and assist in guiding increased uptake or propose recommendations for service redesign (see Table 1).

Table 1. Critical priorities and reform items prioritised in the 2020-25 National Health Reform Agreement (NHRA)

	Reform Item	Goal
Critical Priority A Improving efficiency and ensuring financial stability	*Unspecified*	Unspecified
Critical Priority B Delivering safe, high-quality care in the right place at the right time through:	*1. Nationally cohesive health technology assessment*	Improving health technology decisions to deliver safe, effective and affordable care
	2. Paying for value and outcomes	Enabling new and flexible ways for governments to pay for health services
	3. Joint planning and funding at a local level	Improving the way health services are planned and delivered at the local level
Critical Priority C Prioritising prevention and helping people manage their health across their lifetime through:	*4. Empowering people through health literacy*	Person-centred health information and support to empower people to manage their own health well and engage effectively with health services
	5. Prevention and wellbeing	To reduce the burden of long-term chronic conditions and improve people's quality of life
Critical Priority D Driving best practice and performance using data and research through	*6. Enhanced health data*	Integrating data to support better health outcomes and save lives

Adapted from Schedule C of the 2020-25 National Health Reform Agreement (NHRA)

5.5 Implications for Future Research

This program of research provides multiple avenues to expand on the current knowledge base around the provision of self-management support for stroke by services such as StrokeLine. Whilst the current program of research provides some insight into the benefit of contacting the StrokeLine for stroke survivors, future research needs to assess the long-term impact of interacting with the service, particularly in identifying measurable benefits of service use. It is also important to understand the facilitators and barriers of seeking care from StrokeLine, particularly investigating the non-use of the service by stroke survivors. Understanding why stroke survivors are not using StrokeLine may provide insight into needing to increase the visibility of the service through more targeted advertising and clear provision of service information. The level of stroke-related impairment of those using StrokeLine is also important to explore, as research into mild stroke and more severe stroke has reported the need for services to cater to differing level of needs (Pereira et al., 2012; Rochette et al., 2010).

Further, the research presented in this thesis focused only on the use of StrokeLine by stroke survivors and their carers. Future research should explore the wider use of the service by health professionals and the general public. Understanding factors prompting the use of the service by health professionals may have implications for improving clinician education around the type of support required for the long-term management of stroke. For the general public, an increased awareness of stroke and its long-term consequences may be warranted. In turn, deeper insight into the use of StrokeLine by carers and their experiences with the service may have implications for reducing carer burden. This program of research also only focussed on calls to StrokeLine and there is a need for future research to explore service provision through email and website-based avenues of contact.

To improve StrokeLine service provision, further evaluating the service using research-based frameworks. Harding, Parker, Hean, and Hemingway (2018) proposed a theoretical framework to aid in assessing the efficacy of telephone-based information and advice services which may be applied to StrokeLine service provision. The efficacy framework considers the context of the service; the specific type of information and advice provided; the effect on individual agency; the outcome of service provision; and the wider impact of service outcomes (Harding et al., 2018). Any future re-design of StrokeLine should also consider a co-design approach, collaborating with service users and integrating their views throughout the improvement process. There also remains a limited understanding of how StrokeLine staff perceive their experience of answering calls and future research should explore this.

Finally, research presented in this thesis investigated calls made to StrokeLine from a retrospective dataset and interviews with stroke survivors who had used StrokeLine recounted only past experiences. Consequently, nothing is known of what occurs during real-time call interactions between those using the service and StrokeLine staff. Conversational analysis has been used in a number of studies reporting on health helpline interactions and is able to provide real-time insight into the call interaction by analysing call recordings (Bloch & Leydon, 2019). A similar approach applied to the StrokeLine service may provide useful insight into the way in which callers and call-takers interact. Insight into how StrokeLine staff handle the interaction may aid with training and quality assessment of the service provided.

5.6 Strengths of the Thesis

Although research into health helplines has existed for years across a number of chronic health conditions, this program of research presented novel findings on the use of a stroke helpline in Australia. This program of research highlighted Stroke Line's existing capabilities through the use of both quantitative and qualitative methods of inquiry. Quantitative methods alone cannot provide comprehensive insight into what is provided by a healthcare service, as most services rely on the individual contexts of those seeking care. As such the use of qualitative methods to elicit personal insight and help contextualise the use of StrokeLine is a further strength of this thesis.

The real-world relevance and implications of this program of research cannot be undervalued. The program of research was undertaken in close partnership with the Stroke Foundation in Australia and findings were reported back to the organisation at multiple points throughout the research process. Feedback provided to StrokeLine staff around limitations in their data capture processes resulted in direct changes to the StrokeLine customer relationship management system infrastructure, notably with the capture of postcodes relating to the location of each contact. Furthermore, findings presented in this thesis help contextualise the StrokeLine service within pre-existing models of stroke are in Australia. Consequently, this thesis highlights the timely role of StrokeLine in Australia for policy-makers to support and further assess the long-term viability of the service within the current digital health landscape.

5.7 Reflections and Limitations of the Thesis

While this program of research adds to new insight into helpline-based provision of self-management support for stroke, some limitations of this thesis need to be acknowledged. Particular limitations for each study have been highlighted in the corresponding results chapters of this thesis, however, broader limitations of the entire program of research will be discussed here.

Firstly, the impact of the COVID-19 pandemic on this thesis needs to be acknowledged, as findings presented are likely to reflect the evolving context in which data was collected for both studies. As telehealth-based delivery was urgently prioritised in all healthcare settings in response to the pandemic, the failings of existing data management processes and structures used to support service provision became increasingly evident across all levels of healthcare (Wosik et al., 2020). As a result, healthcare service providers likely underwent extensive periods of change well into the first few months of the pandemic. Although every attempt was made to maintain transparency between StrokeLine staff during the research process, it is likely the dataset used for analysis and consequent data management processes reported in this thesis are not reflective of the most current practices in place. As such, researchers looking to build on the work presented in this thesis would benefit from a revised understanding of internal StrokeLine processes and current data management practices.

Further, the disjointed nature of data acquired for study 1 had implications on the way in which findings were integrated. The first study did not describe findings of data in free-text boxes in with the corresponding descriptive characteristics and categorical insight of each case captured in the data. Extraction of both datasets occurred separately and repositioning them within a single dataset carried a high risk of error with correctly matching up data for each contact. This thesis also did not explore alternate ways StrokeLine could be accessed (eg. email and website contact). Due the complexity of post-stroke sequelae, it is likely some problems prompting calls to StrokeLine may be too difficult to address over the phone or stroke survivors may experience speech or communication-related impairments such as aphasia. Further, StrokeLine staff may be limited by their scope of practice and a basic understanding of the stroke survivors' context, especially if this is not communicated efficiently. As such, it is likely not all interactions with StrokeLine will have met caller expectations.

Consequently, stroke survivors who have had a positive experience with the StrokeLine service may have been more likely to express an interest in participating in the research included in this thesis and share more favourable experiences. This may have been further compounded by the recruitment strategy employed in study 2. The close reliance on StrokeLine staff directly contacting callers to share information about the study may have discouraged participants with a less favourable experience to participate. In turn, a number of people contacted the research team mistakenly thinking them to be StrokeLine staff. Some further expressed an interest in wanting to be involved with specific internal StrokeLine evaluation initiatives, such as their customer satisfaction survey. It is important to also note that the research reported in this thesis was overall limited in providing insight into the use of StrokeLine by those with communication-related impairments such as aphasia. Although the recruitment strategy involved in study 2 of this thesis did not explicitly exclude those with communication-related stroke impairments, recruitment material was limited in providing aphasia-friendly content and the investigators relied on those with communication-related impairments to request information specific to their needs.

Finally, interviews with stroke survivors were conducted by a relatively novice qualitative researcher (MTC) and questions asked may at times have been leading in nature. Every attempt was made to ensure this was considered during the data analysis process, particularly through the use of a reflexive journal.

5.8 Conclusions

The use of StrokeLine described in this thesis highlights the importance of the service for both stroke survivors and their carers. It centres service provision around providing information and advice, jointly with emotional support to those affected by stroke. This focus aligns with the goal of self-management support initiatives in stroke which aim to increase self-efficacy and reinforce knowledge of an individual's ongoing condition. The thesis has further reported important findings in understanding the range of factors prompting stroke survivors to use StrokeLine and the perceived impact of contacting the service. Through exploring the experiences of stroke survivors using the service, the desperation of stroke survivors experiencing fragmented care in other settings was described. Notably, the individual agency required to initiate timely contact with StrokeLine highlights the unique role helpline-based services play in providing ongoing self-management support in response to evolving needs and contexts. The ability of StrokeLine to empower stroke survivors to take charge of their care and re-engage with existing health services further emphasises the consequence of the service in supporting transitions between care settings.

If stroke survivors are provided with information, advice and support tailored to what they are experiencing at the time they are seeking care themselves, it is likely they will be able to better self-manage their ongoing condition and continue to seek support in response to a change in circumstances. Telehealth-based services such as StrokeLine are well-placed to provide this type of support and existing stroke services need to acknowledge this to best complement standard care. Through further studies using data-driven frameworks, evaluating service design can ensure StrokeLine service provision remains relevant and best aligns with organisational priorities.

The findings from this thesis are timely and important, as the COVID-19 pandemic has exponentially increased the uptake of telehealth-based service provision in Australia. As the number of people living with the long-term consequences of stroke increases, it is essential that existing models of care focus on better supporting stroke survivors through transitions of care in the healthcare system. The role of helpline-based stroke support in facilitating self-management of care should not be undervalued and services such as StrokeLine can enable a better quality of life for stroke survivors in the long-term.

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Chapter 1

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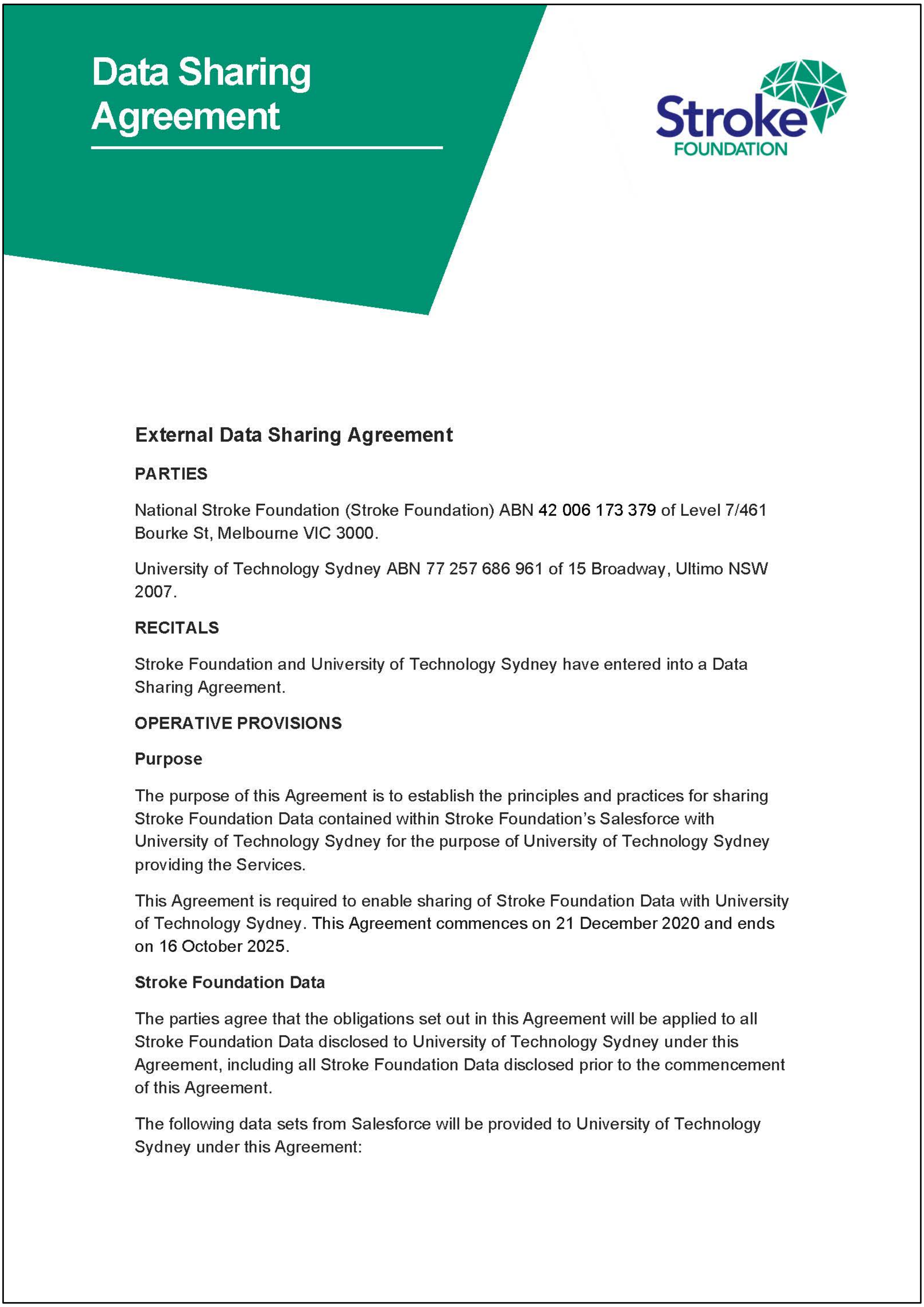
Appendix A: Summary of Data Included for Study 1 Analysis

StrokeLine CRM System Category	Response Options
Constituent type	Advocate Carer/Family/Friend Community fundraiser Consultant Donor General Public My Stroke Journey Secondary Contact Other Person affected by stroke Raffle purchaser Regular giver Survivor StrokeSafe ambassador Volunteer
Gender	Female Male Other
Caller age range	25 or under 26-50 51-64 65+
Stroke survivor age range	0-18 18-25 26-50 51-64 65+
Time since stroke	Less than 1 year 1-2 years 2-5 years 5-9 years 10+ years
Aboriginal or Torres Strait Islander	No Yes Question not asked
Languages spoken	Free-text input
Interpreter required	Yes No
Vulnerability and risk status	Depression Drug and alcohol use Family violence Suicidal ideation
Current stroke symptoms	Yes No
Risk factors present for stroke	Alcohol Use Atrial Fibrillation Cardiovascular Disease Congenital Heart Defect

	Diet Drug Use Exercise Family History of Stroke High Blood Pressure High Cholesterol Other (free text input) Overweight / Obesity Patent Foramen Ovale Prior Stroke History Prior TIA History Risk Factors / Stroke Cause Yet to be Determined Tobacco Use Type II Diabetes	
Reason for Contacting	Prevention	No subcategories
	Health Services Treatment and Care	Access to rehabilitation Advocacy and navigation Concerns about tests and treatment Discharge planning Questions about tests and treatment
	Community Services and Treatment and Care	Access Issues Advocacy & Navigation Aged care Concerns about services NDIS Others Questions about services Rehabilitation Services Stroke Support Group
	Managing Stroke Impairments	Communicating Emotions and mood Fatigue Incontinence Other Pain Personality and behaviour Sleep Swallowing Thinking memory judgement Upper limb Vision and senses Walking and moving Other (free-text input)
	Adjustment/Coping	Family relationships Personal adjustment Roles and occupation
	Practical Issues	Accommodation Driving Finances

		Legal Travel Work
Intervention	Brief intervention Care coordination Information, support, advice, referral type Letter/ call to other	
Mailing State/Province	ACT NSW QLD SA TAS VIC WA NT	
Referred to StrokeLine by	Doctors /Health Professional Enable Me Internet My Stroke Journey Other SF Campaign Word of Mouth Young Stroke Project	
Call duration	<15 mins 15-30 mins 30mins-1hour 1-2 hours 3-4 hours	
Call liaison	<15 mins 1-2 hours 15-30 mins 30mins-1hour 3-4 hours	
Date call received	Automated input	

Appendix B: Stroke Foundation Data Sharing Agreement



Data Sharing Agreement

External Data Sharing Agreement

PARTIES

National Stroke Foundation (Stroke Foundation) ABN 42 006 173 379 of Level 7/461 Bourke St, Melbourne VIC 3000.

University of Technology Sydney ABN 77 257 686 961 of 15 Broadway, Ultimo NSW 2007.

RECITALS

Stroke Foundation and University of Technology Sydney have entered into a Data Sharing Agreement.

OPERATIVE PROVISIONS

Purpose

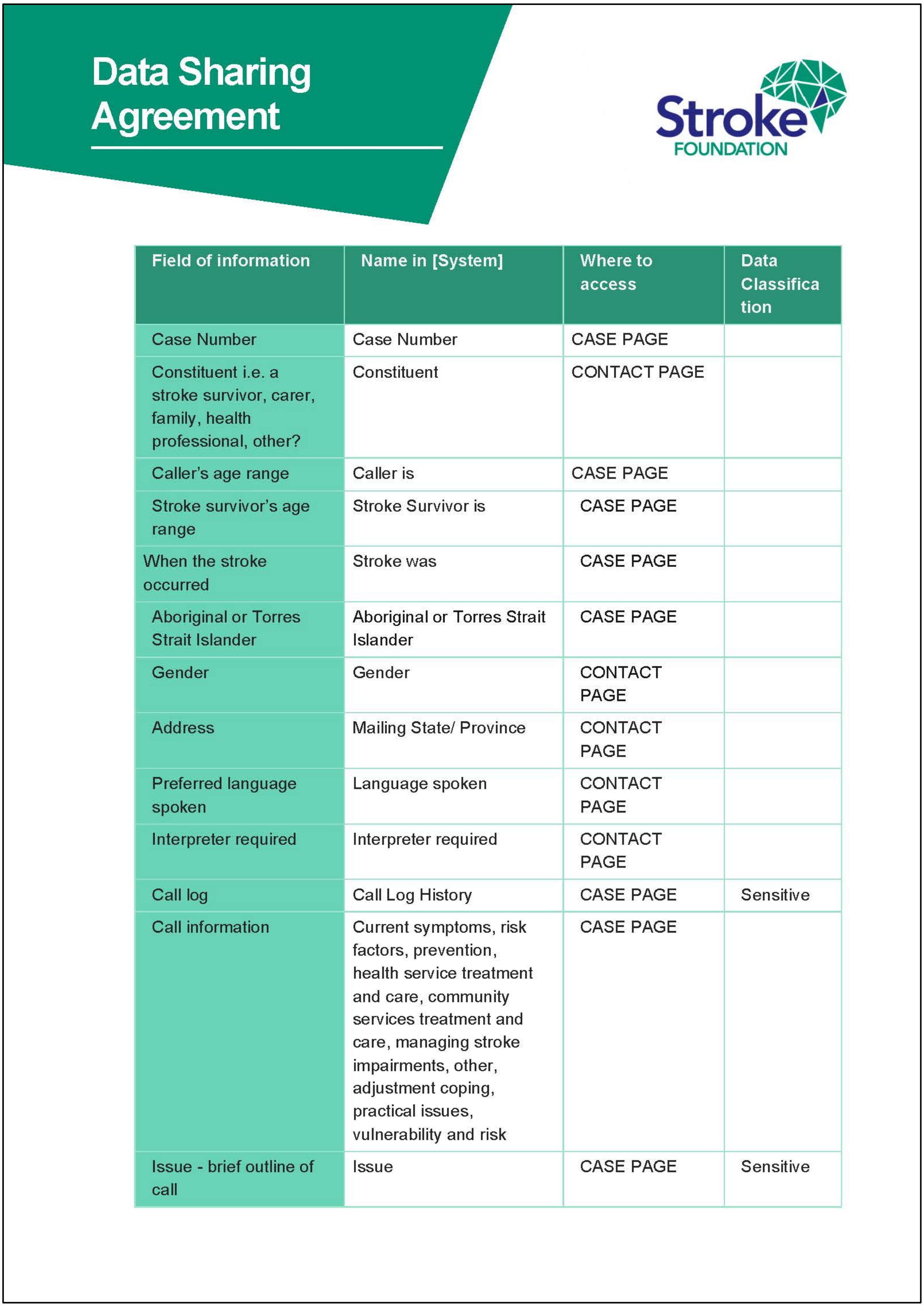
The purpose of this Agreement is to establish the principles and practices for sharing Stroke Foundation Data contained within Stroke Foundation's Salesforce with University of Technology Sydney for the purpose of University of Technology Sydney providing the Services.

This Agreement is required to enable sharing of Stroke Foundation Data with University of Technology Sydney. This Agreement commences on 21 December 2020 and ends on 16 October 2025.

Stroke Foundation Data

The parties agree that the obligations set out in this Agreement will be applied to all Stroke Foundation Data disclosed to University of Technology Sydney under this Agreement, including all Stroke Foundation Data disclosed prior to the commencement of this Agreement.

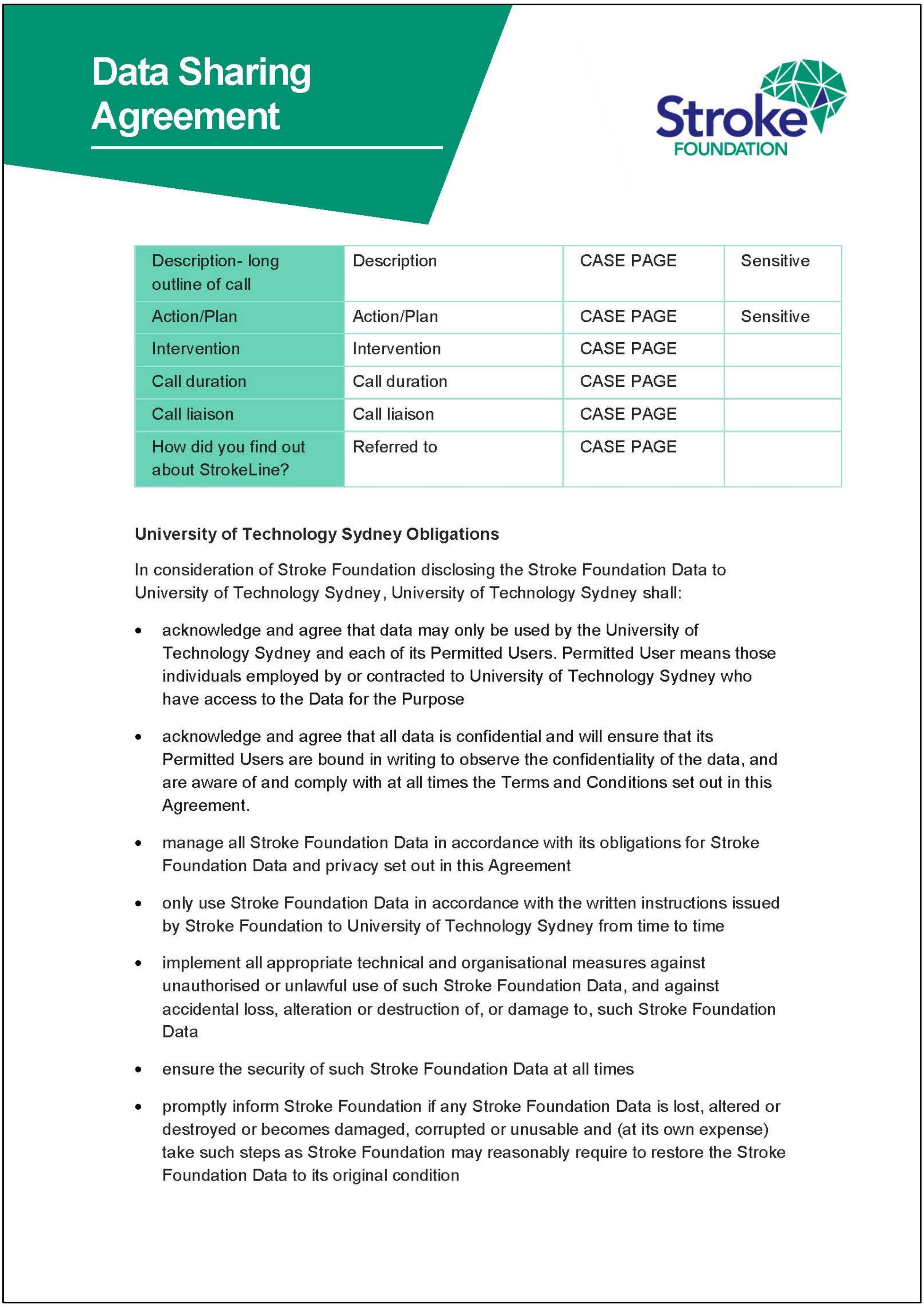
The following data sets from Salesforce will be provided to University of Technology Sydney under this Agreement:



Data Sharing Agreement

Stroke FOUNDATION

Field of information	Name in [System]	Where to access	Data Classification
Case Number	Case Number	CASE PAGE	
Constituent i.e. a stroke survivor, carer, family, health professional, other?	Constituent	CONTACT PAGE	
Caller's age range	Caller is	CASE PAGE	
Stroke survivor's age range	Stroke Survivor is	CASE PAGE	
When the stroke occurred	Stroke was	CASE PAGE	
Aboriginal or Torres Strait Islander	Aboriginal or Torres Strait Islander	CASE PAGE	
Gender	Gender	CONTACT PAGE	
Address	Mailing State/ Province	CONTACT PAGE	
Preferred language spoken	Language spoken	CONTACT PAGE	
Interpreter required	Interpreter required	CONTACT PAGE	
Call log	Call Log History	CASE PAGE	Sensitive
Call information	Current symptoms, risk factors, prevention, health service treatment and care, community services treatment and care, managing stroke impairments, other, adjustment coping, practical issues, vulnerability and risk	CASE PAGE	
Issue - brief outline of call	Issue	CASE PAGE	Sensitive



Data Sharing Agreement

Description- long outline of call	Description	CASE PAGE	Sensitive
Action/Plan	Action/Plan	CASE PAGE	Sensitive
Intervention	Intervention	CASE PAGE	
Call duration	Call duration	CASE PAGE	
Call liaison	Call liaison	CASE PAGE	
How did you find out about StrokeLine?	Referred to	CASE PAGE	

University of Technology Sydney Obligations

In consideration of Stroke Foundation disclosing the Stroke Foundation Data to University of Technology Sydney, University of Technology Sydney shall:

- acknowledge and agree that data may only be used by the University of Technology Sydney and each of its Permitted Users. Permitted User means those individuals employed by or contracted to University of Technology Sydney who have access to the Data for the Purpose
- acknowledge and agree that all data is confidential and will ensure that its Permitted Users are bound in writing to observe the confidentiality of the data, and are aware of and comply with at all times the Terms and Conditions set out in this Agreement.
- manage all Stroke Foundation Data in accordance with its obligations for Stroke Foundation Data and privacy set out in this Agreement
- only use Stroke Foundation Data in accordance with the written instructions issued by Stroke Foundation to University of Technology Sydney from time to time
- implement all appropriate technical and organisational measures against unauthorised or unlawful use of such Stroke Foundation Data, and against accidental loss, alteration or destruction of, or damage to, such Stroke Foundation Data
- ensure the security of such Stroke Foundation Data at all times
- promptly inform Stroke Foundation if any Stroke Foundation Data is lost, altered or destroyed or becomes damaged, corrupted or unusable and (at its own expense) take such steps as Stroke Foundation may reasonably require to restore the Stroke Foundation Data to its original condition

- not modify, amend or alter the contents of such Stroke Foundation Data other than as strictly necessary
- not disclose or permit the disclosure of any such Stroke Foundation Data to any third party (including the individual concerned) unless specifically authorised in writing by Stroke Foundation prior to any such disclosure
- only use such Stroke Foundation Data in accordance with the terms of this Agreement, and only then to the extent necessary for, and in connection with, the provision of the Services to Stroke Foundation, and for no other purpose whatsoever
- on termination of this Agreement or any earlier termination of University of Technology Sydney's right or obligation to use Stroke Foundation Data, and as otherwise directed by the Stroke Foundation, University of Technology Sydney shall either:
  - destroy the Stroke Foundation Data and all copies thereof
  - transfer the Stroke Foundation Data to Stroke Foundation or such other third party as Stroke Foundation may direct, or
  - archive Stroke Foundation Data subject to agreement on terms of archiving including costs
  - not disclose Stroke Foundation Data to any third party.
- notify Stroke Foundation if University of Technology Sydney receives any complaint, notice or communication which relates directly or indirectly to the use of Stroke Foundation Data, and provide Stroke Foundation with full cooperation and assistance in relation to any such complaint, notice or communication
- provide all reasonable assistance to Stroke Foundation, having regard to the nature of the use and Stroke Foundation Data available to University of Technology Sydney, in order to assist Stroke Foundation to comply with its obligations under applicable privacy laws.
- keep and provide to Stroke Foundation on request a record of University of Technology Sydney's use of the Stroke Foundation Data and make available to Stroke Foundation all information necessary (and allow for and contribute to audits or inspections) to demonstrate compliance with University of Technology Sydney's obligations set out in this Agreement
- take reasonable steps to ensure the reliability of all its employees or other representatives who have access to the Stroke Foundation Data and ensure that all such persons:

  - are informed of the confidential nature of the Stroke Foundation Data before they gain access to it, and
  - have committed themselves to confidentiality obligations or are under an appropriate statutory obligation of confidentiality, and
  - agree to indemnify (and keep indemnified) Stroke Foundation against all costs, expenses and liabilities arising from University of Technology Sydney's breach of its obligations under this Agreement.

Stroke Foundation shall:

- ensure that it is entitled to make the relevant Stroke Foundation Data available to University of Technology Sydney so that University of Technology Sydney may lawfully use the Stroke Foundation Data in accordance with this Agreement on behalf of Stroke Foundation.
- transfer Stroke Foundation Data to University of Technology Sydney (categorical data from 1 November 2019 to 30 November 2020, including free text **de-identified data** from 1 to 30 November 2019 and 1 to 30 June 2020) via OneDrive as agreed by the parties
- ensure that the Stroke Foundation Data provided to University of Technology Sydney is accurate to the best knowledge of Stroke Foundation.

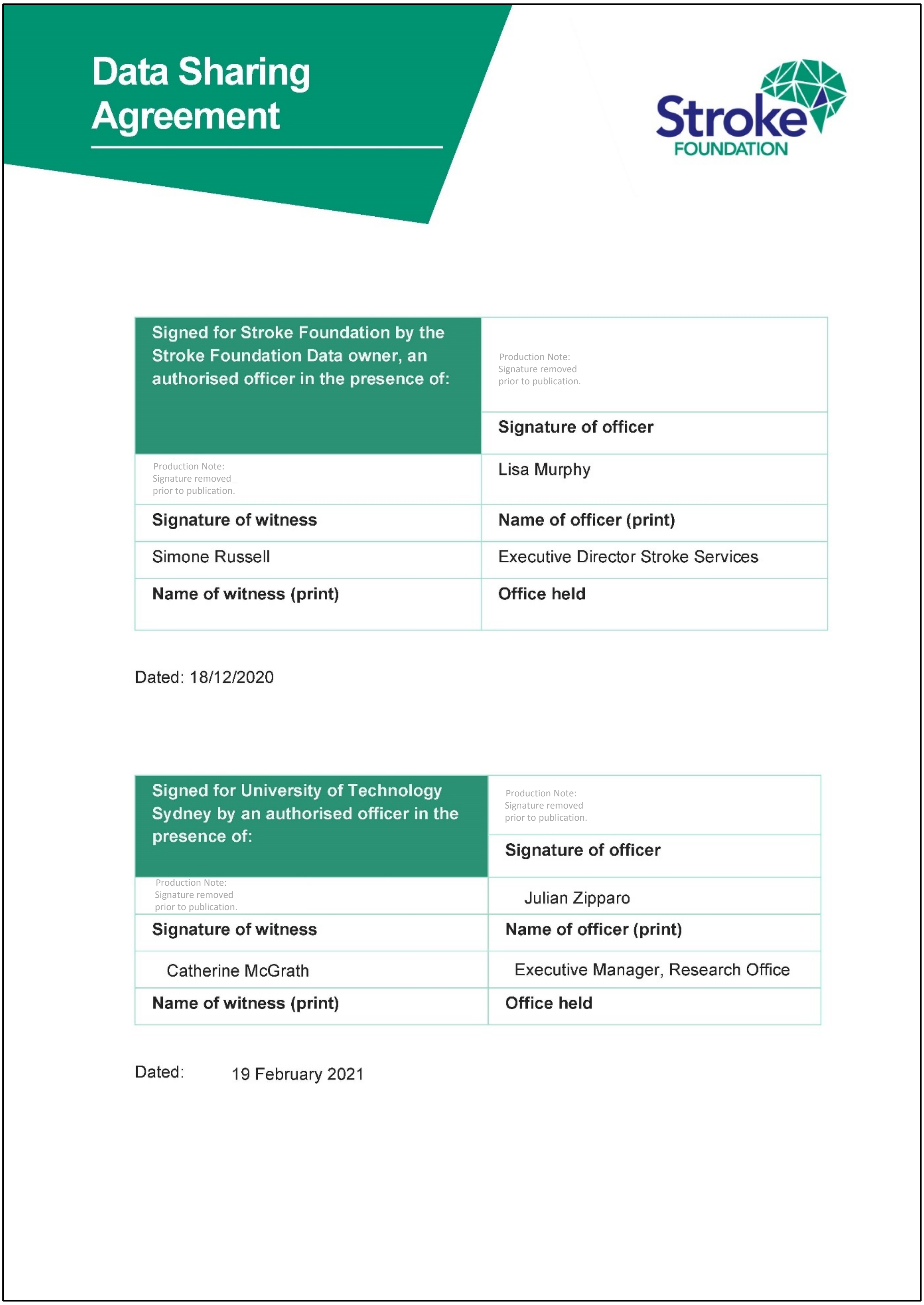
Termination

Stroke Foundation may terminate this Agreement if University of Technology Sydney is in material breach of its obligations under this Agreement, but only where University of Technology Sydney does not cure such material breach within 20 business days of Stroke Foundation notifying University of Technology Sydney of the breach.

General

This Agreement shall be governed by Victorian law.

EXECUTED as an agreement.



Data Sharing Agreement

Stroke FOUNDATION

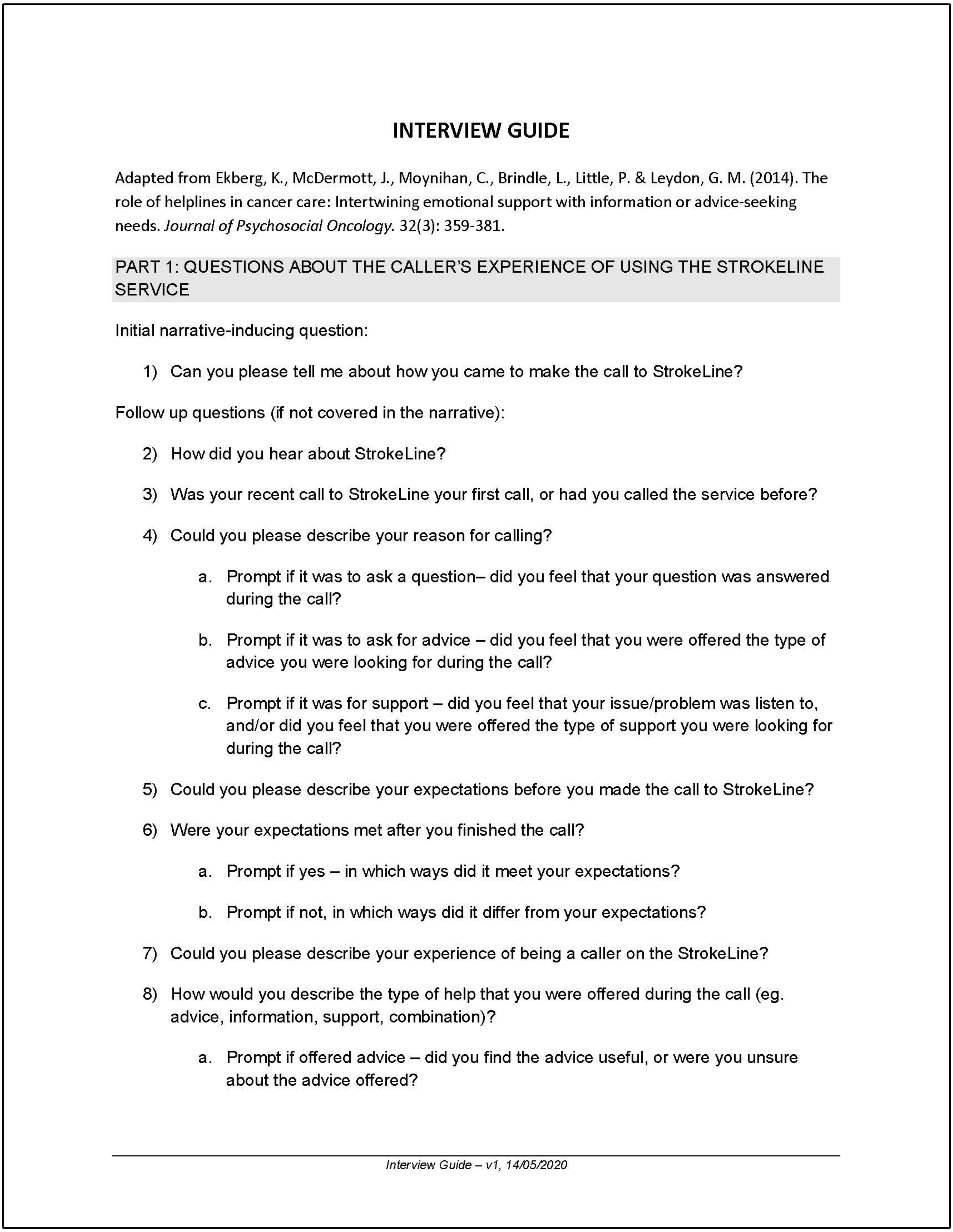
Signed for Stroke Foundation by the Stroke Foundation Data owner, an authorised officer in the presence of:	Production Note: Signature removed prior to publication.
	Signature of officer
Production Note: Signature removed prior to publication.	Lisa Murphy
Signature of witness	**Name of officer (print)**
Simone Russell	Executive Director Stroke Services
Name of witness (print)	**Office held**

Dated: 18/12/2020

Signed for University of Technology Sydney by an authorised officer in the presence of:	Production Note: Signature removed prior to publication.
	Signature of officer
Production Note: Signature removed prior to publication.	Julian Zipparo
Signature of witness	**Name of officer (print)**
Catherine McGrath	Executive Manager, Research Office
Name of witness (print)	**Office held**

Dated: 19 February 2021

Appendix C: Interview Guide for Study 2



INTERVIEW GUIDE

Adapted from Ekberg, K., McDermott, J., Moynihan, C., Brindle, L., Little, P. & Leydon, G. M. (2014). The role of helplines in cancer care: Intertwining emotional support with information or advice-seeking needs. *Journal of Psychosocial Oncology.* 32(3): 359-381.

PART 1: QUESTIONS ABOUT THE CALLER'S EXPERIENCE OF USING THE STROKELINE SERVICE

Initial narrative-inducing question:

1) Can you please tell me about how you came to make the call to StrokeLine?

Follow up questions (if not covered in the narrative):

2) How did you hear about StrokeLine?
3) Was your recent call to StrokeLine your first call, or had you called the service before?
4) Could you please describe your reason for calling?
    a. Prompt if it was to ask a question– did you feel that your question was answered during the call?
    b. Prompt if it was to ask for advice – did you feel that you were offered the type of advice you were looking for during the call?
    c. Prompt if it was for support – did you feel that your issue/problem was listen to, and/or did you feel that you were offered the type of support you were looking for during the call?
5) Could you please describe your expectations before you made the call to StrokeLine?
6) Were your expectations met after you finished the call?
    a. Prompt if yes – in which ways did it meet your expectations?
    b. Prompt if not, in which ways did it differ from your expectations?
7) Could you please describe your experience of being a caller on the StrokeLine?
8) How would you describe the type of help that you were offered during the call (eg. advice, information, support, combination)?
    a. Prompt if offered advice – did you find the advice useful, or were you unsure about the advice offered?

    b. Prompt if offered information – did you find the information useful, or were you unsure about the information offered?

    c. Prompt if offered support – did you feel supported in the issues you discussed with the call-taker during the call?

9) If talking about receiving <u>information</u> – what does receiving information mean to you? As in what type of thing would you consider as information?

10) If talking about receiving <u>advice</u> – what does receiving advice meant to you? As in what type of thing would be considered advice?

11) If talking about receiving <u>support</u>– what does receiving support meant to you? As in what kind of things from the call-take would you consider as support?

12) Did you feel you had good rapport with the call-taker?

    a. Prompt – could you describe how supportive/empathetic you felt they were in regards to your issue/discussion?

13) In your opinion, how would you describe the outcome of the call (eg. support provided, given referral, promised a return call, advice received, etc)?

14) Could you please describe how you felt before you made the call to the StrokeLine?

15) Could you please describe how you felt at the end of the call?

PART 2 : QUESTIONS ABOUT THE CALLER'S EXPERIENCE AFTER EPISODE OF SERVICE

Initial narrative-inducing question:

1) Can you please tell me about any changes in your life that have occurred as a result of contacting the StrokeLine?

Follow up questions (if not covered in the narrative):

2) How did you use the help provided by the StrokeLine after the call ended?

    a. If talking about acting on <u>information</u> – what did you do after the call with the information provided by the StrokeLine?

    b. If talking about acting on <u>advice</u> – what did you do after the call with the advice provided by the StrokeLine?

        c. If talking about acting on support– what did you do after the call with the support provided by the StrokeLine?

3) Have you tried to access any other kinds of help or support since your call to the StrokeLine?
    a. Prompt if yes:
        i. What other kinds of help or support have you tried to access?
        ii. How did they compare to your experience using the StrokeLine?
4) Could you please describe how you feel now about making contact with the StrokeLine?
5) Can you describe the impact you believe the StrokeLine has had on your stroke journey?

PART 3: QUESTIONS ABOUT THE STROKELINE SERVICE

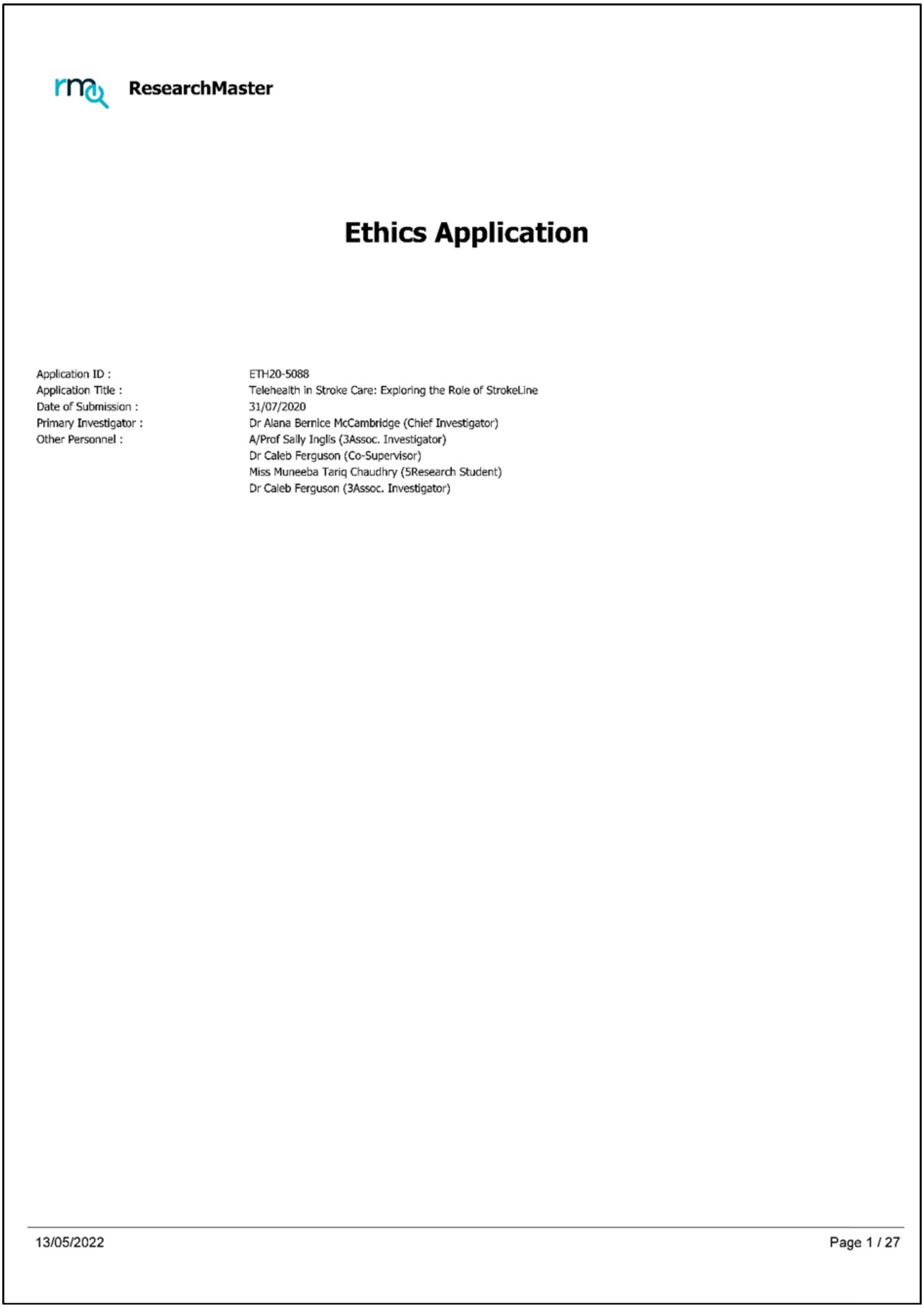
Initial narrative-inducing question:

1) Could you please tell me about your thoughts about the effectiveness of the service you received by the StrokeLine?

Follow up questions (if not covered in the narrative):

2) In your opinion, what do you think are the main aims of the StrokeLine?
3) How satisfied were you with the service provided by the StrokeLine?
4) Can you please describe what you think the main advantages of the StrokeLine are?
5) Do you think there are any disadvantages of the StrokeLine service?
6) Would you use the StrokeLine service again?
    a. Prompt if yes – what are the type of issues for which you might call the StrokeLine in the future?
    b. Prompt if no – can you describe why you don't think you will use the StrokeLine service again?
7) Could you describe ways that you believe the StrokeLine service could be improved?

Appendix D: Ethics Approval Documentation



ResearchMaster

Ethics Application

Application ID : ETH20-5088
Application Title : Telehealth in Stroke Care: Exploring the Role of StrokeLine
Date of Submission : 31/07/2020
Primary Investigator : Dr Alana Bernice McCambridge (Chief Investigator)
Other Personnel : A/Prof Sally Inglis (3Assoc. Investigator)
Dr Caleb Ferguson (Co-Supervisor)
Miss Muneeba Tariq Chaudhry (5Research Student)
Dr Caleb Ferguson (3Assoc. Investigator)

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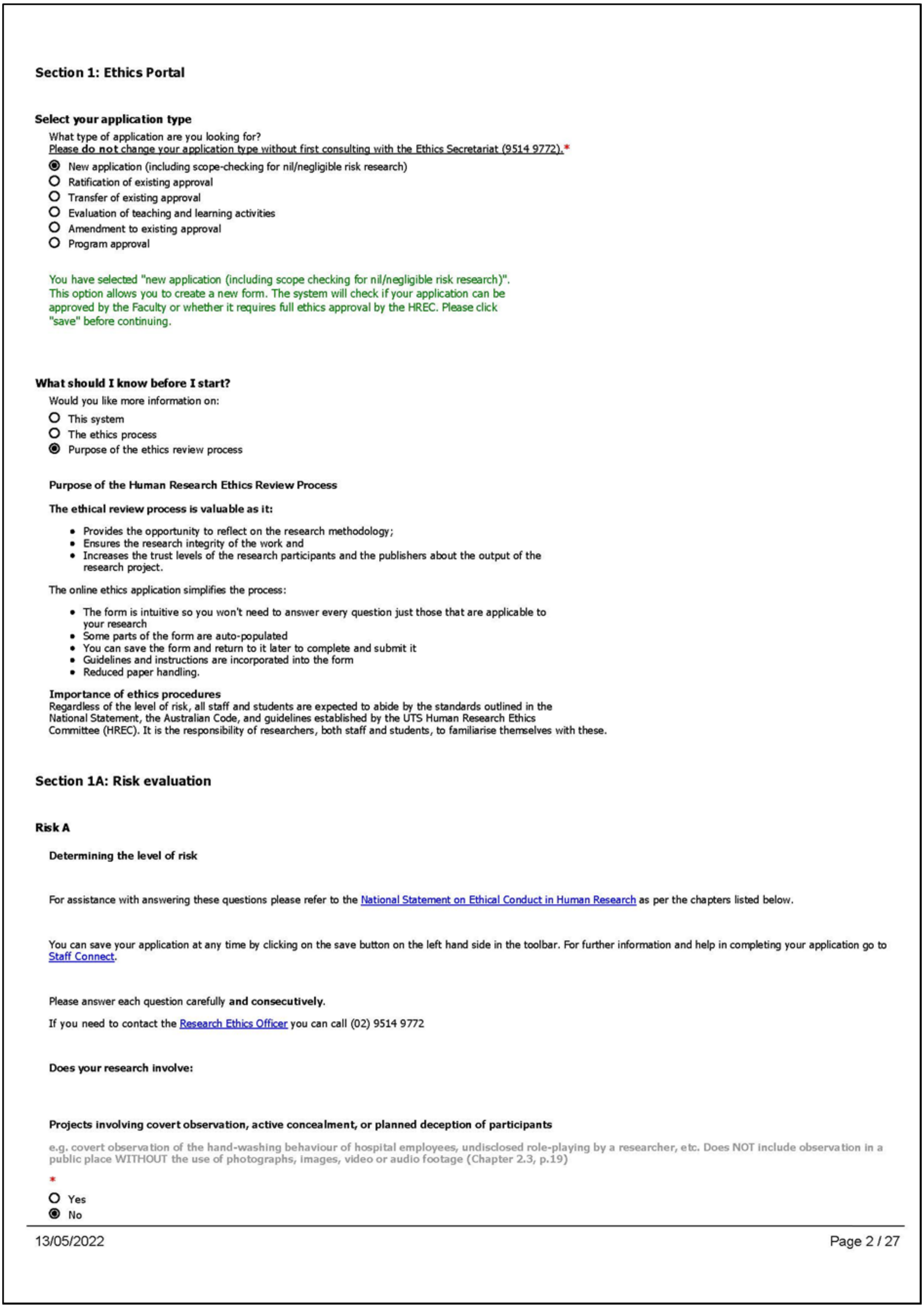

Section 1: Ethics Portal

Select your application type

What type of application are you looking for?
<u>Please **do not** change your application type without first consulting with the Ethics Secretariat (9514 9772).</u>*

● New application (including scope-checking for nil/negligible risk research)
○ Ratification of existing approval
○ Transfer of existing approval
○ Evaluation of teaching and learning activities
○ Amendment to existing approval
○ Program approval

You have selected "new application (including scope checking for nil/negligible risk research)". This option allows you to create a new form. The system will check if your application can be approved by the Faculty or whether it requires full ethics approval by the HREC. Please click "save" before continuing.

What should I know before I start?

Would you like more information on:

○ This system
○ The ethics process
● Purpose of the ethics review process

Purpose of the Human Research Ethics Review Process

The ethical review process is valuable as it:

- Provides the opportunity to reflect on the research methodology;
- Ensures the research integrity of the work and
- Increases the trust levels of the research participants and the publishers about the output of the research project.

The online ethics application simplifies the process:

- The form is intuitive so you won't need to answer every question just those that are applicable to your research
- Some parts of the form are auto-populated
- You can save the form and return to it later to complete and submit it
- Guidelines and instructions are incorporated into the form
- Reduced paper handling.

Importance of ethics procedures
Regardless of the level of risk, all staff and students are expected to abide by the standards outlined in the National Statement, the Australian Code, and guidelines established by the UTS Human Research Ethics Committee (HREC). It is the responsibility of researchers, both staff and students, to familiarise themselves with these.

Section 1A: Risk evaluation

Risk A

Determining the level of risk

For assistance with answering these questions please refer to the National Statement on Ethical Conduct in Human Research as per the chapters listed below.

You can save your application at any time by clicking on the save button on the left hand side in the toolbar. For further information and help in completing your application go to Staff Connect.

Please answer each question carefully **and consecutively.**

If you need to contact the Research Ethics Officer you can call (02) 9514 9772

Does your research involve:

Projects involving covert observation, active concealment, or planned deception of participants

e.g. covert observation of the hand-washing behaviour of hospital employees, undisclosed role-playing by a researcher, etc. Does NOT include observation in a public place WITHOUT the use of photographs, images, video or audio footage (Chapter 2.3, p.19)

*

○ Yes
● No

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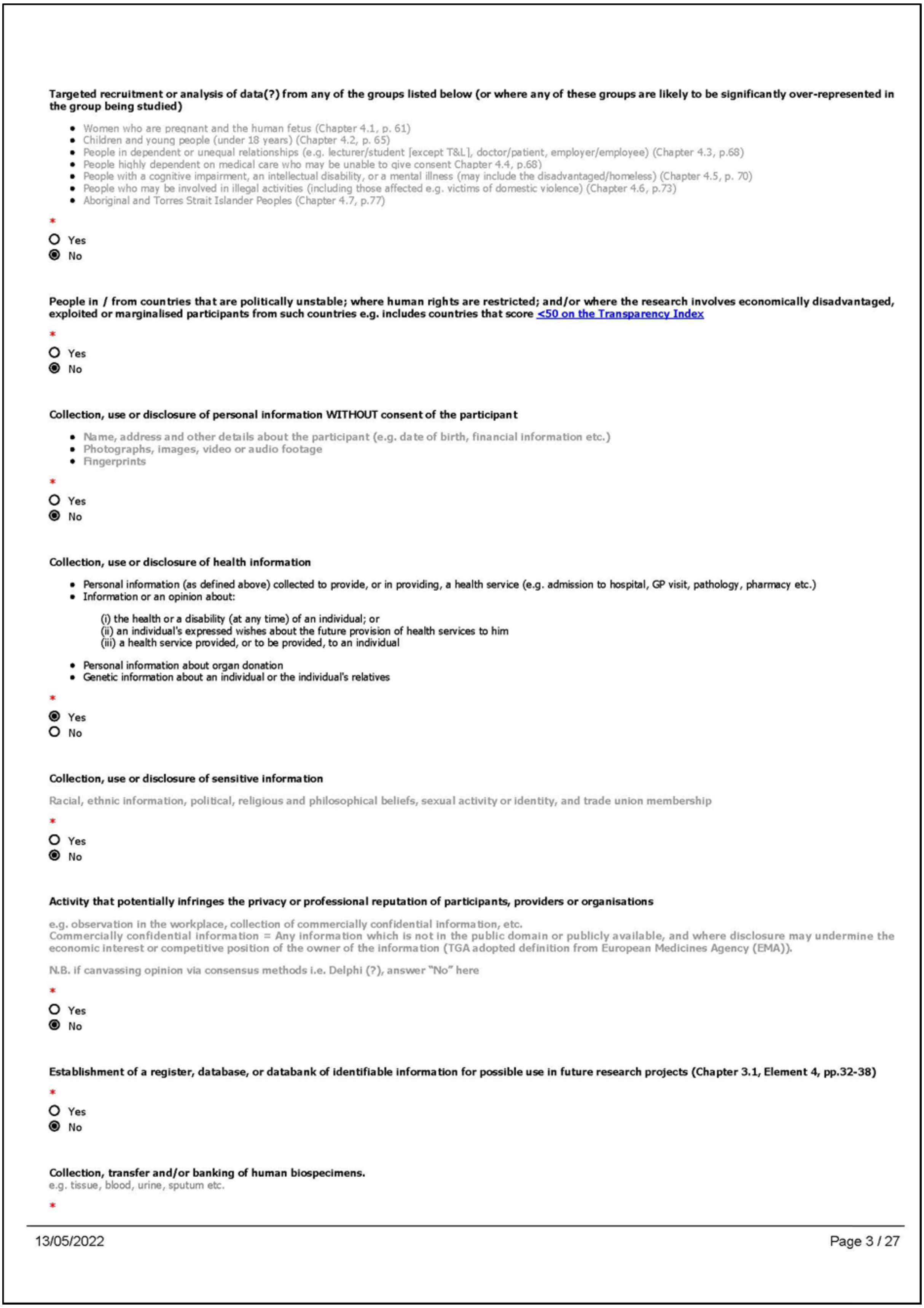

Targeted recruitment or analysis of data(?) from any of the groups listed below (or where any of these groups are likely to be significantly over-represented in the group being studied)

- Women who are pregnant and the human fetus (Chapter 4.1, p. 61)
- Children and young people (under 18 years) (Chapter 4.2, p. 65)
- People in dependent or unequal relationships (e.g. lecturer/student [except T&L], doctor/patient, employer/employee) (Chapter 4.3, p.68)
- People highly dependent on medical care who may be unable to give consent Chapter 4.4, p.68)
- People with a cognitive impairment, an intellectual disability, or a mental illness (may include the disadvantaged/homeless) (Chapter 4.5, p. 70)
- People who may be involved in illegal activities (including those affected e.g. victims of domestic violence) (Chapter 4.6, p.73)
- Aboriginal and Torres Strait Islander Peoples (Chapter 4.7, p.77)

*

○ Yes
● No

People in / from countries that are politically unstable; where human rights are restricted; and/or where the research involves economically disadvantaged, exploited or marginalised participants from such countries e.g. includes countries that score <50 on the Transparency Index

*

○ Yes
● No

Collection, use or disclosure of personal information WITHOUT consent of the participant

- Name, address and other details about the participant (e.g. date of birth, financial information etc.)
- Photographs, images, video or audio footage
- Fingerprints

*

○ Yes
● No

Collection, use or disclosure of health information

- Personal information (as defined above) collected to provide, or in providing, a health service (e.g. admission to hospital, GP visit, pathology, pharmacy etc.)
- Information or an opinion about:

  (i) the health or a disability (at any time) of an individual; or
  (ii) an individual's expressed wishes about the future provision of health services to him
  (iii) a health service provided, or to be provided, to an individual

- Personal information about organ donation
- Genetic information about an individual or the individual's relatives

*

● Yes
○ No

Collection, use or disclosure of sensitive information

Racial, ethnic information, political, religious and philosophical beliefs, sexual activity or identity, and trade union membership

*

○ Yes
● No

Activity that potentially infringes the privacy or professional reputation of participants, providers or organisations

e.g. observation in the workplace, collection of commercially confidential information, etc.
Commercially confidential information = Any information which is not in the public domain or publicly available, and where disclosure may undermine the economic interest or competitive position of the owner of the information (TGA adopted definition from European Medicines Agency (EMA)).

N.B. if canvassing opinion via consensus methods i.e. Delphi (?), answer "No" here

*

○ Yes
● No

Establishment of a register, database, or databank of identifiable information for possible use in future research projects (Chapter 3.1, Element 4, pp.32-38)

*

○ Yes
● No

Collection, transfer and/or banking of human biospecimens.
e.g. tissue, blood, urine, sputum etc.

*

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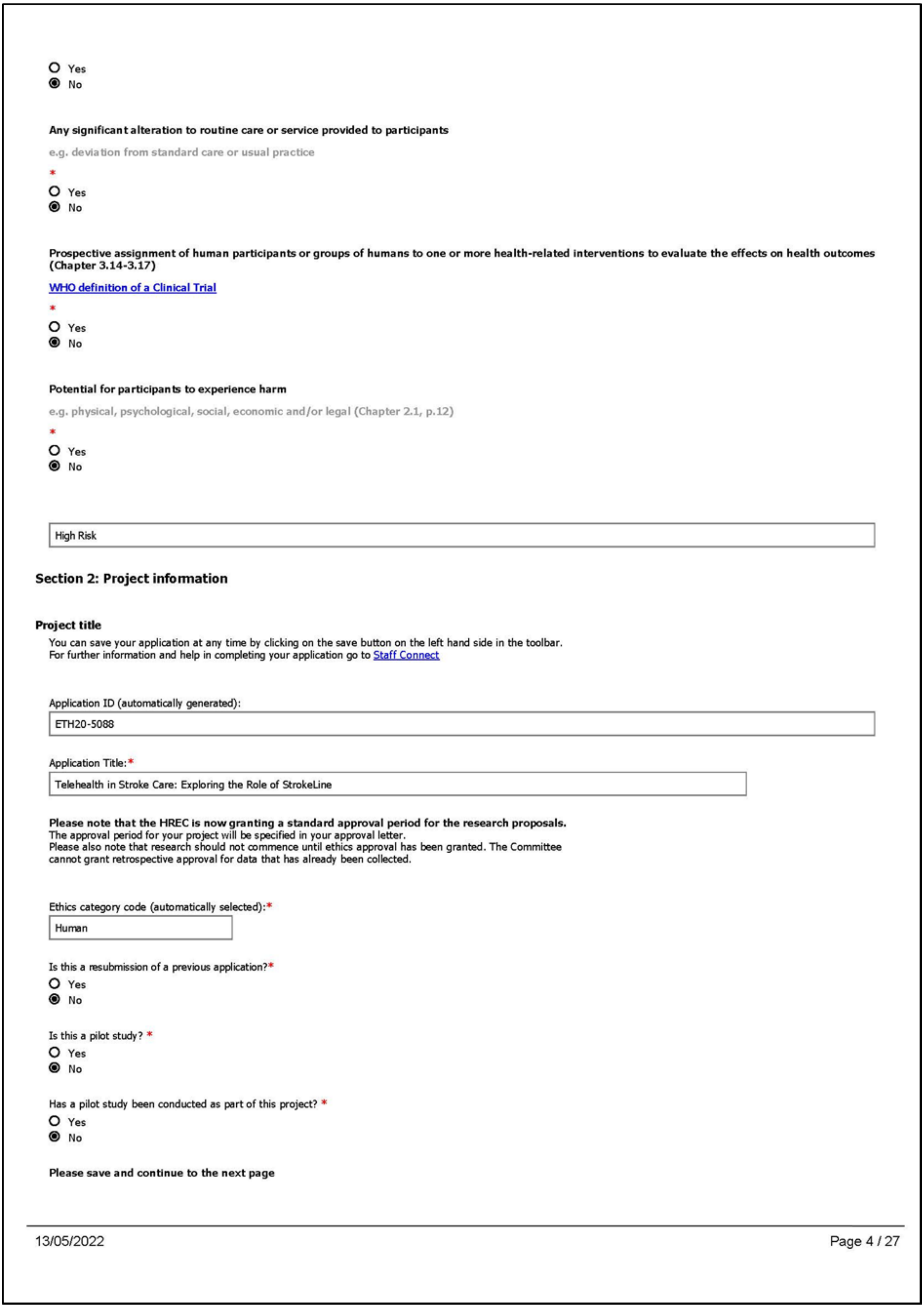

○ Yes
● No

Any significant alteration to routine care or service provided to participants

e.g. deviation from standard care or usual practice

*
○ Yes
● No

Prospective assignment of human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes (Chapter 3.14-3.17)

[WHO definition of a Clinical Trial]

*
○ Yes
● No

Potential for participants to experience harm

e.g. physical, psychological, social, economic and/or legal (Chapter 2.1, p.12)

*
○ Yes
● No

High Risk

Section 2: Project information

Project title

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Application ID (automatically generated):

ETH20-5088

Application Title:*

Telehealth in Stroke Care: Exploring the Role of StrokeLine

Please note that the HREC is now granting a standard approval period for the research proposals.
The approval period for your project will be specified in your approval letter.
Please also note that research should not commence until ethics approval has been granted. The Committee cannot grant retrospective approval for data that has already been collected.

Ethics category code (automatically selected):*

Human

Is this a resubmission of a previous application?*
○ Yes
● No

Is this a pilot study? *
○ Yes
● No

Has a pilot study been conducted as part of this project? *
○ Yes
● No

Please save and continue to the next page

Consultation

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Have you undertaken any consultation in preparing this application?*

● Yes
○ No

Please describe (1500 character limit)*

Supervisors, peers, faculty members, and Stroke Foundation staff members

Please save and continue to the next page

Section 3: Personnel

Investigators

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Are there external investigators or personnel listed on this protocol?*

● Yes
○ No

Is this application for a student project?*

● Yes
○ No

Students - Please note that once your application is submitted it will go directly to your supervisor and not to the Committee. Once your supervisor endorses your application it will come to the Research Ethics Officer for review. Your electronic application must be endorsed by your supervisor by the Research Office (LRO) submission deadline.

Personnel Table

Position type	In the personnel table use the following positions from the drop-down list
Chief Investigator	1Chief Investigator
Co Investigator	3Assoc. Investigator
Supervisor	1Chief Investigator
Co Supervisor	Co-Supervisor
Research Student	5Research Student

Further options are available for Research/Project Managers and Administrators.
The main contact should be marked as 'primary' and should be a UTS staff member.
Please click on 'More Criteria' located on the top right hand side of the table to find personnel.

If any details are incorrect or missing please contact the Ethics Secretariat on (02) 9514 9772 or by email.

Instructions on how to add a person to the personnel table:
1. Click on 'Add'
2. Start typing the details (first name, last name or Staff ID) in the search bar.
3. Click on "Add selected"

4. The extra information panel will open, enter the position. If they are the primary contact (e.g. Chief Investigator/Supervisor), tick "Yes" under 'Primary contact' and then select 'OK.

Students must add their supervisors to their application and must
mark their primary supervisor as a Chief Investigator and as a primary contact.
Students should be listed as "5Research student"

Internal personnel listed on this ethics protocol:

*

1	Primary	
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
2	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
3	Primary	
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.Chaudhry@uts.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	7222

The ResearchMaster database has a very large number of external personnel so please conduct a search for them before adding them in the text box below. Please contact the Ethics Secretariat on 9514 9772 if you cannot find an external investigator through the system.

External personnel listed on this ethics protocol:
*

1	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

If you cannot find a person through the personnel table(s) above, please enter their details here (title, name, organisation, department, phone number, address, email address and their position on this protocol). (4000 character limit)

Name: Ms. Simone Russell
Organisation: Stroke Foundation
Phone number: 03 9918 7267
Address: Level 7, 461 Bourke St, Melbourne, VIC 3000
Email: SRussell@strokefoundation.org.au
Position on Protocol: Associate Investigator (Co-investigator)

Please provide additional (or preferred) contact details of any of the people listed on the project if necessary (4000 character limit)

This question is not answered.

Please provide details of any formal qualifications (REF NS 1.1(e)) of each person listed on the project (4000 character limit)*

Dr. Alana McCambridge - Bachelor of Science (Hons); Doctor of Philosophy (PhD)

Dr. Caleb Ferguson - Bachelor of Science in Nursing; Masters of Health Leadership; Doctor of Philosophy (PhD); Registered Nurse (RN); Fellow of the European Society of Cardiology (FESC); Fellow of the Cardiac Society of Australia and New Zealand (FCSANZ)

Miss Muneeba Chaudhry - Bachelor of Exercise Physiology; Accredited Exercise Physiologist (AEP)

Ms. Simone Russell - Occupational Therapist

A/Prof Sally Inglis - Bachelor of Nursing; Bachelor of Health (Hons); Doctor of Philosophy (PhD); Registered Nurse (RN); Fellow of the Cardiac Society of Australia and New Zealand (FCSANZ)

Please outline the experience of each person listed on this project relevant to this application (4000 character limit)*

Dr. Alana McCambridge is a lecturer in the Discipline of Physiotherapy at UTS and an experienced researcher with interests in neurorehabilitation, neurophysiology, and stroke. She has recently completed a project using big data from the Danish Stroke Registry.

Dr. Caleb Ferguson is an experienced researcher with a research focus on patient-centred approaches to the management of atrial fibrillation, stroke prevention, and digital health. As a Registered Nurse, he has over a decade of clinical experience caring for individuals with stroke, neurological and cardiovascular conditions.

Miss Muneeba Chaudhry is an Accredited Exercise Physiologist with an interest in neurorehabilitation and stroke care.

Ms. Simone Russell works for the Stroke Foundation as the Young Stroke Project Coordinator. She will be the primary liaison between StrokeLine staff and the study investigators.

A/Prof Sally Inglis is an internationally recognized expert on telehealth to improve outcomes and access to evidence-based cardiovascular care. She has completed a large Cochrane review of telemonitoring in heart failure and is also leading Cochrane reviews examining self-management interventions for people with peripheral arterial disease and the use of m-health technology for health education in heart failure.

Primary AOU*

GSH.Graduate School of Health

Managing Unit

Faculty of Health

Please save and continue to the next page

Student details

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Degree being undertaken (500 character limit)*

Master of Physiotherapy (Research)

Have you been successful in your doctoral/masters assessment? *

● Yes
○ No

Please make sure you attach a copy of your DA/Stage one confirmation in the attachments section.

Students, please read carefully: Your application should be reviewed by the Ethics Secretariat prior to submitting to the Committee. Once you have completed this application and followed the submission instructions, your application will go to your supervisor for review. Once your supervisor has endorsed the application it will come to the Ethics Secretariat for a pre-review. This pre-review process is necessary to ensure that your application is complete, has all necessary attachments, and that the quality of responses to the questions meets the Committee¿s expectations. Your application should therefore be submitted at least one week prior to the closing date. If you do not submit your application in time, it may be delayed and held off until the next closing date.

Section 4: Funding

Funding details

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Have you received funding in relation to this research?*

○ Yes
● No

Do you intend to apply for funding in the future?*

○ Yes
● No

Please save and continue to the next page

Section 5: Methodology

Description

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The purpose of this section is to place your research in context for the HREC and demonstrate your ability to conduct the research. The HREC may only approve research which is methodologically sound. Remember to use simple language that can be understood by people from a variety of backgrounds. Avoid jargon and acronyms.

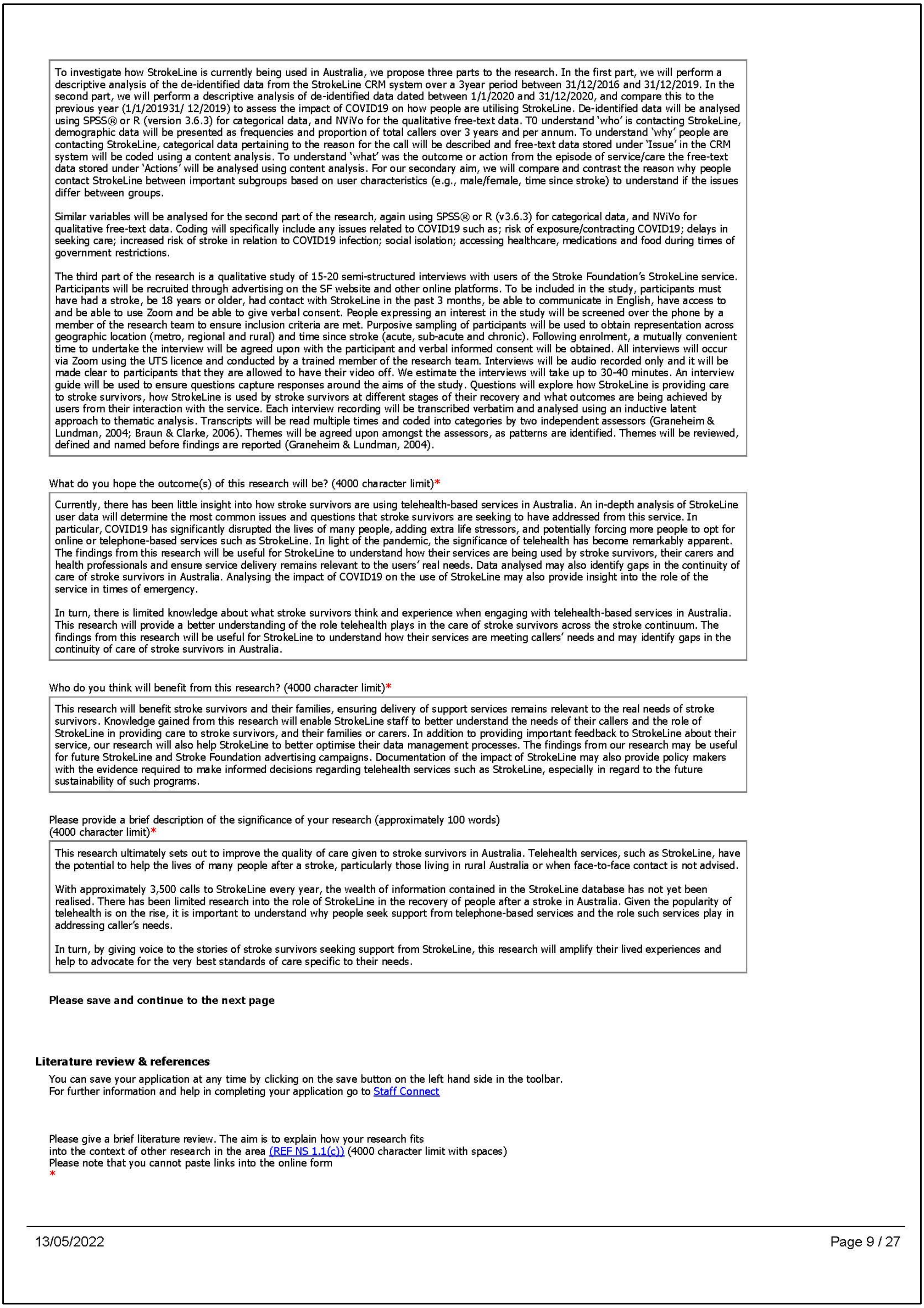
What are the hypotheses/goals/aims/objectives of your research? Please include a brief description using plain English explaining your research aims (approximately 100 words) (4000 character limit)*

In Australia, StrokeLine exists as an in-bound telehealth stroke support service provided by the Stroke Foundation (SF). StrokeLine allows users to make contact with a qualified health professional via phone, email or social media. Call data is categorically logged by staff into a customer relationship management (CRM) system after each episode of care.

The goal of this research is to explore the StrokeLine database and investigate how the service is currently being used to support the lives of people living with stroke in Australia. The first part of this research aims to understand who is contacting StrokeLine, why they contacted the service and what care was provided by the service. We will also investigate if the reason why a person contacted StrokeLine differs between key characteristics in the user data. The second part of the research aims to evaluate the impact of COVID19 on the number and type of enquiries received by StrokeLine. The third part of the research aims to explore the lived experience of people who have used StrokeLine and the perceived impact of seeking care through the service. Factors that prompt people to seek care through StrokeLine will also be explored.

Note: Clinical Trials, Recruitment of Participants and Data Collection are dealt with later so you will not need to describe them in detail below

Please provide a brief description of the research design including research questions and proposed methods for conducting the research (approximately 250 words) (4000 character limit)*



To investigate how StrokeLine is currently being used in Australia, we propose three parts to the research. In the first part, we will perform a descriptive analysis of the de-identified data from the StrokeLine CRM system over a 3year period between 31/12/2016 and 31/12/2019. In the second part, we will perform a descriptive analysis of de-identified data dated between 1/1/2020 and 31/12/2020, and compare this to the previous year (1/1/201931/ 12/2019) to assess the impact of COVID19 on how people are utilising StrokeLine. De-identified data will be analysed using SPSS® or R (version 3.6.3) for categorical data, and NViVo for the qualitative free-text data. T0 understand 'who' is contacting StrokeLine, demographic data will be presented as frequencies and proportion of total callers over 3 years and per annum. To understand 'why' people are contacting StrokeLine, categorical data pertaining to the reason for the call will be described and free-text data stored under 'Issue' in the CRM system will be coded using a content analysis. To understand 'what' was the outcome or action from the episode of service/care the free-text data stored under 'Actions' will be analysed using content analysis. For our secondary aim, we will compare and contrast the reason why people contact StrokeLine between important subgroups based on user characteristics (e.g., male/female, time since stroke) to understand if the issues differ between groups.

Similar variables will be analysed for the second part of the research, again using SPSS® or R (v3.6.3) for categorical data, and NViVo for qualitative free-text data. Coding will specifically include any issues related to COVID19 such as; risk of exposure/contracting COVID19; delays in seeking care; increased risk of stroke in relation to COVID19 infection; social isolation; accessing healthcare, medications and food during times of government restrictions.

The third part of the research is a qualitative study of 15-20 semi-structured interviews with users of the Stroke Foundation's StrokeLine service. Participants will be recruited through advertising on the SF website and other online platforms. To be included in the study, participants must have had a stroke, be 18 years or older, had contact with StrokeLine in the past 3 months, be able to communicate in English, have access to and be able to use Zoom and be able to give verbal consent. People expressing an interest in the study will be screened over the phone by a member of the research team to ensure inclusion criteria are met. Purposive sampling of participants will be used to obtain representation across geographic location (metro, regional and rural) and time since stroke (acute, sub-acute and chronic). Following enrolment, a mutually convenient time to undertake the interview will be agreed upon with the participant and verbal informed consent will be obtained. All interviews will occur via Zoom using the UTS licence and conducted by a trained member of the research team. Interviews will be audio recorded only and it will be made clear to participants that they are allowed to have their video off. We estimate the interviews will take up to 30-40 minutes. An interview guide will be used to ensure questions capture responses around the aims of the study. Questions will explore how StrokeLine is providing care to stroke survivors, how StrokeLine is used by stroke survivors at different stages of their recovery and what outcomes are being achieved by users from their interaction with the service. Each interview recording will be transcribed verbatim and analysed using an inductive latent approach to thematic analysis. Transcripts will be read multiple times and coded into categories by two independent assessors (Graneheim & Lundman, 2004; Braun & Clarke, 2006). Themes will be agreed upon amongst the assessors, as patterns are identified. Themes will be reviewed, defined and named before findings are reported (Graneheim & Lundman, 2004).

What do you hope the outcome(s) of this research will be? (4000 character limit)*

Currently, there has been little insight into how stroke survivors are using telehealth-based services in Australia. An in-depth analysis of StrokeLine user data will determine the most common issues and questions that stroke survivors are seeking to have addressed from this service. In particular, COVID19 has significantly disrupted the lives of many people, adding extra life stressors, and potentially forcing more people to opt for online or telephone-based services such as StrokeLine. In light of the pandemic, the significance of telehealth has become remarkably apparent. The findings from this research will be useful for StrokeLine to understand how their services are being used by stroke survivors, their carers and health professionals and ensure service delivery remains relevant to the users' real needs. Data analysed may also identify gaps in the continuity of care of stroke survivors in Australia. Analysing the impact of COVID19 on the use of StrokeLine may also provide insight into the role of the service in times of emergency.

In turn, there is limited knowledge about what stroke survivors think and experience when engaging with telehealth-based services in Australia. This research will provide a better understanding of the role telehealth plays in the care of stroke survivors across the stroke continuum. The findings from this research will be useful for StrokeLine to understand how their services are meeting callers' needs and may identify gaps in the continuity of care of stroke survivors in Australia.

Who do you think will benefit from this research? (4000 character limit)*

This research will benefit stroke survivors and their families, ensuring delivery of support services remains relevant to the real needs of stroke survivors. Knowledge gained from this research will enable StrokeLine staff to better understand the needs of their callers and the role of StrokeLine in providing care to stroke survivors, and their families or carers. In addition to providing important feedback to StrokeLine about their service, our research will also help StrokeLine to better optimise their data management processes. The findings from our research may be useful for future StrokeLine and Stroke Foundation advertising campaigns. Documentation of the impact of StrokeLine may also provide policy makers with the evidence required to make informed decisions regarding telehealth services such as StrokeLine, especially in regard to the future sustainability of such programs.

Please provide a brief description of the significance of your research (approximately 100 words)
(4000 character limit)*

This research ultimately sets out to improve the quality of care given to stroke survivors in Australia. Telehealth services, such as StrokeLine, have the potential to help the lives of many people after a stroke, particularly those living in rural Australia or when face-to-face contact is not advised.

With approximately 3,500 calls to StrokeLine every year, the wealth of information contained in the StrokeLine database has not yet been realised. There has been limited research into the role of StrokeLine in the recovery of people after a stroke in Australia. Given the popularity of telehealth is on the rise, it is important to understand why people seek support from telephone-based services and the role such services play in addressing caller's needs.

In turn, by giving voice to the stories of stroke survivors seeking support from StrokeLine, this research will amplify their lived experiences and help to advocate for the very best standards of care specific to their needs.

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Literature review & references

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Please give a brief literature review. The aim is to explain how your research fits into the context of other research in the area (REF NS 1.1(c)) (4000 character limit with spaces)
Please note that you cannot paste links into the online form
*

Telephone-based services are thought to play an integral role for the on-going care of people living with chronic health conditions, though further research into the services provided in Australia is required (Knight et al, 2010). In the literature, evaluation of telephone-based services for heart failure, cancer, rheumatology and stroke have been reported (Dickerson & Forster, 2015; Inglis et al., 2015; Boltong et al., 2017; Arvidsson et al., 2019). An analysis of the UK Stroke Association Helpline reported 19,674 inquiries were received in 2013, more than 3 times the number of annual inquiries from 1990 (Dickerson & Forster, 2015). Although an increase in inquiries was reflective of the positive changes to stroke care over the years, there was little difference in the types of inquiries received with questions about stroke recovery and rehabilitation remaining common in both 1990 and 2013 (Hanger & Mulley, 1993; Dickerson & Forster, 2015). A review of telehealth initiatives in heart failure reported findings from 25 studies evaluating structured telephone support, noting improvements in knowledge of heart failure and self-care behaviours of the callers (Inglis et al., 2015). In cancer, studies of callers' experiences with seeking care using telephone-based support found that callers were able to better understand their situation, encouraging further engagement with other cancer services (Boltong et al., 2017). In addition, after having problems obtaining answers to questions from the internet or health care professionals, a telephone-based service for people with rheumatology was found to be effective at enabling constructive dialogue and motivational support to users seeking care from their service (Arvidsson et al., 2019). Such studies highlight the importance of evaluating telehealth-based services to better understand how telehealth services are used and what role they play in attaining a successful outcome for the caller (Harding et al., 2018). Analysis of why people engage with telephone-based support could reveal common issues people living with chronic health conditions experience, and whether these issues are able to be resolved using telehealth services.

The impact of telehealth-based services for stroke survivors in Australia is not well understood. In particular there is a need to improve transitions of care, and the ongoing support needed by stroke survivors and their families after discharge from hospital (Ferguson et al., 2016). Stroke survivors discharged into the community report low levels of satisfaction with post-discharge information provision, especially around long-term management of disability and accessing support services (O'Connell et al., 2009; Ferguson et al., 2016). A feeling of abandonment exists amongst stroke survivors who require support to navigate between transitions of care through the healthcare system (Wissel et al., 2013; Ghazzawi et al., 2016). Telehealth-based stroke care may be key to addressing this void and the implications of on-going, immediate telephone-based support needs to be further investigated.

In Australia, StrokeLine exists as a nationwide stroke support service provided by the Stroke Foundation (SF). To understand how StrokeLine is being used by stroke survivors, continual evaluation of user data is required to optimise service operation. In 2014, an internal evaluation report aimed to investigate the appropriateness, effectiveness, and efficiency of StrokeLine (National StrokeFoundation, 2014). Overall, the report provided a general overview of StrokeLine. However, to ensure service delivery remains relevant to the real needs of stroke survivors using the service, continual evaluation using robust research methods is required. Understanding how stroke survivors seek and act on the advice provided to them by StrokeLine is an important factor for evaluating the impact telehealth services can have on the lives of stroke survivors and their carers.

Please list the references only used in the literature review and cited in your application
NOTE: Do not include references you have not used in this application (4000 character limit)
*

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Methods and methodologies

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In order to consider your research, the HREC will need to know what it will involve for your participants (REF NS 3.1)

What kinds of methods and methodologies will you use in your research? (More than one box may be checked)*

☑ Quantitative
☑ Qualitative

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Quantitative

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Section 1: Quantitative Methodologies*

☐ Experimental
☐ Quasi-experimental
☑ Correlational research
☐ Survey Design
☐ Meta analysis
☐ Other *(Please describe below)

Section 2: Quantitative methods*

☐ Written survey
☐ Online survey/research
☐ Pre-post/testing
☐ Telephone survey
☐ Questionnaires
☑ Access to records
☐ Clinical trial
☑ Statistical analysis
☑ Content analysis
☐ Physiological testing/assessment
☐ Other* (please describe below)

What **quantitative** methodology and methods will you be using in this research? More than one box may be checked.

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Qualitative

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What **qualitative** methodology and methods will be using in this research?

Section 1: Qualitative methodology*

☐ Auto-ethnography
☐ Historical research
☐ Action research
☐ Narrative enquiry
☐ Biographical research
☐ Case study
☑ Phenomenology
☐ Indigenous research paradigm
☐ Discourse analysis
☐ Grounded theory
☐ Other *(Please describe below)

Section 2: Qualitative methods*

☐ Participants observation
☐ Covert observation
☐ On-line research
☐ Psychological testing/assessment
☐ Verbal protocol
☐ Journaling
☐ Artifact analysis
☐ Document/Policy analysis
☐ Access to records
☑ Audio/video recording
☐ Life story or oral history
☐ Focus groups
☐ Structured interviews
☑ Semi-structured interviews
☐ Unstructured interviews
☐ Other * (Please describe below)

Please describe how interviews will be conducted, including how many participants will be involved (from each participant group if there is more than one group/cohort), the amount of time required of participants for this, whether it will be recorded, and any other information applicable (4000 character limit)*

We aim to conduct approximately 15-20 semi-structured interviews with users of the Stroke Foundation's StrokeLine service. All interviews will occur via Zoom using the UTS licence, be audio-recorded, and conducted by a trained member of the research team. For people unfamiliar with Zoom, detailed instructions and assistance will be provided to set up the call prior to the interview.

We estimate the actual interviews will take up to 30-40 minutes, and break periods can be provided as needed. Interviews will be semi-structured and use open-ended questions designed around the aims of the study as follows: Part 1 – Questions about the caller's experience of using the StrokeLine service; Part 2 – Questions about the caller's experience after episode of care; and Part 3 – Questions about the StrokeLine service.

Interviews will initially be directed by participant narratives around their experiences of using StrokeLine, with follow-up questions to be asked if research aims are not covered in the narrative as outlined in the interview guide.

Interviews will be piloted on three participants and alterations to the interview guide will be made accordingly to cater for any unexpected themes that emerge. These interviews will not be included in the final data analysis. Each interview recording will be transcribed verbatim for analysis. Written field notes will be kept to aid with transparency of data collection and to add validity to interpretations made. Interview transcripts will also sent to participants for review.

Please describe how audio/video recording will be used in the research, including how many participants will be involved (from each participant group if there is more than one group/cohort), the amount of time required of participants for this, whether it will be recorded, and any other information applicable (4000 character limit)*

As stated above, all interviews will occur via Zoom using the UTS licence and will be audio-recorded, by the research team. This will be done to allow for interviews to be transcribed verbatim for analysis.

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Section 6: Research participants/subjects part 1

Recruitment of participants

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In line with the National Statement, the definition of participants includes not only those humans who are the primary focus of the research but also those who will be affected by the research. The HREC regards the principle of respect for persons as of paramount importance.
(REF NS 1.1 (d), 1.6-1.9, 1.10, 2.1).

How will you initially select and contact your participants? More than one box may be checked, if appropriate*

- ☑ Advertisement/flyer
- ☑ E-mail
- ☑ Telephone
- ☑ Internet
- ☑ Organisation
- ☐ Personal contact
- ☐ Letter
- ☐ Other contact method to be used

Outline how you will obtain participants' contact details and what your recruitment process will be (4000 character limit)*

Participants' contact details will be obtained when they first make contact with the research team themselves. Details for contacting the research team will be included on all advertising material.
Callers to the StrokeLine will be asked at the end of their call if they would like to be contacted by the research team and/or would like to be given the details of the research team. This will only be done by StrokeLine staff who are not involved in the research study/team.

Please describe your recruitment plan/strategy

Participants will be recruited using one or more of the following methods: 1) Recruitment flyer sent out to all callers with the Stroke Foundation StrokeLine follow-up satisfaction email; 2) Callers asked at the end of service of care if they would like to be contacted by the research team and/or research team details given to caller; 3) Recruitment flyer advertised on appropriate social media platforms such as Stroke Foundation Twitter and Facebook communities; 4) Recruitment flyer included in Stroke Foundation newsletters and shared on the EnableMe platform, an online community for those affected by stroke.

How many participants do you intend to recruit? (If you are intending to recruit different groups of participants, please answer all relevant questions for each group, e.g. control group, test group, etc)
(4000 character limit)*

We intend to recruit 15-20 participants in total. Purposive sampling will be used to recruit a minimum of 5 participants for each group categorising time since stroke (acute, sub-acute and chronic). To obtain a representation across geographic location, a minimum of 5 participants each will also be recruited from metro, regional and rural areas.

Explain how and why you have chosen this number (If the research is quantitative, explain the power calculations; if the research is qualitative, explain why the proposed number is likely to result in adequate data) (4000 character limit). For guidance, see how to address sample size here.*

The intent to recruit 15-20 participants is based on recommendations of similar qualitative studies (Vasileiou, et al., 2018). Participants will be recruited until data saturation occurs, with the same comments made across multiple interviews, indicating no new themes are emerging and the collection of new data would only yield similar results (Saunders, et al., 2018).

Describe your inclusion and exclusion criteria for participants (4000 character limit)*

To be included in the study, participants must have had a stroke, be 18 years or older, had contact with StrokeLine in the past 3 months, be able to communicate in English, have access to and be able to use Zoom and be able to give verbal consent. For those with a communication disorder, we will source appropriate support persons (e.g., carer, family, UTS speech pathologist) to aid in the consent and interview process. Including participants who have contacted StrokeLine in the last 3 months will increase the likelihood of participants being able to recall their encounter. We will exclude people from outside Australia, people who have experienced a transient ischemic attack (TIA), people who are not able to communicate in English, and health professionals or members of the general public who contact the service.

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Participant involvement

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What time commitment will the research involve for your participants?
NOTE: This information must be included in any information to participants
(4000 character limit)*

We estimate screening participants over the phone will take up to 15 minutes. Any assistance needed to help participants set up Zoom may take 20 minutes. The interview itself will take up to 30-40 minutes, excluding any break periods that may need to be provided. We also estimate it will take participants 30 minutes to review their interview transcripts. Therefore the total time commitment is approximately 2 hours.

In what location will the research/data collection take place?
NOTE: This information must be included in any information to participants
(4000 character limit)*

All interviews will occur using the video-conferencing platform Zoom. As such, all data will be collected remotely.

What travel, if any, does the research involve for your participants?
NOTE: This information must be included in any information to participants
(4000 character limit)*

There is no travel involved for our research participants.

Please include any additional information relating to participants that you think relevant
NOTE: This information must be included in any information to participants
(4000 character limit)*

If required, participants will be allowed to take breaks during the interview. At the end of the interview, the participant will be provided an opportunity to debrief and ask any questions.

Describe and justify any benefit, payment or compensation the participants will receive. For research being conducted with Aboriginal and Torres Strait Islander People, the described benefits from research should have been discussed with and agreed to by the Aboriginal or Torres Strait Islander research stakeholders. (REF NS 2.1) and 4.7.8 & 4.7.9)
(4000 character limit)*

Although there may not be any immediate benefits for participants, we will be offering participants a $30 e-gift card for participating in the third part of our research. This will be offered to thank participants for their involvement in the study and to compensate them for the time involved in being part of the interview process. The gift card will be emailed to participants once the interview process has concluded and will be redeemable at participating retailers, both online and in-store.

Participants will help contribute to the limited understanding we currently have of the role telehealth plays in the care of stroke survivors across the stroke continuum. The findings from this research will be useful for StrokeLine to understand how their services are meeting callers' needs and may identify gaps in the continuity of care of stroke survivors in Australia. In the long run, participants may also benefit from any consequent improvements in service delivery.

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Consent

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Will you be obtaining written consent?*

○ Yes
● No

Please explain why and describe how you will obtain and record consent (4000 character limit)*

Informed consent will be obtained verbally using audio recordings on Zoom and the UTS verbal consent transcript. The participant will be read a verbal consent transcript and asked to respond verbally if they understand and thereby consent to the study. If there is difficulty obtaining verbal consent due to a communication disorder, we will source appropriate support (e.g. family, UTS speech pathologist A/Prof Emma Power) to aid in the consent and participation in the research.

Do you believe there will be any special issues relating to consent in your research? (REF NS 1.13, 2.2, 2.3, Chapter 4)*

● Yes
○ No

Please describe what special issues may be related to consent in your research (4000 character limit)*

There may be difficulty in obtaining consent from stroke survivors whose speech has been affected. Stroke survivors with communication disorders such as Aphasia may find it difficult to communicate with the research team and understand the informed consent process. This issue can be overcome by including carers, family members, and/or speech pathologists during the process.

Are the participants able to consent fully? (REF NS Chapter 2, 4.4, 4.5)*

● Yes
○ No

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Limited disclosure

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Does this research involve limited disclosure to participants? (REF NS 2.3)*

○ Yes
● No

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Ethical considerations specific to participants

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Indicate if your research will involve the following populations (as per the National Statement) other than as incidental participants (i.e. they are not included in the design of the project but may be participants) (REF NS Chapter 4)
*

☐ Women who are pregnant and the human foetus
☐ Children and young people
☐ People in dependent or unequal relationships
☐ People highly dependent upon medical care who may be unable to give consent
☐ People with a cognitive impairment, an intellectual disability or a mental illness
☐ People who may be involved in illegal activities
☐ People who are incarcerated
☐ Aboriginal and Torres Strait Islander Peoples
☐ People in other countries
☑ None of the above

If your research is being conducted in Australia, does it involve Culturally and Linguistically Diverse (CALD) People (other than incidentally)?*

○ Yes
● No

Does your research involve Defence or the Department of Veteran Affairs in any way?*

○ Yes
● No

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Section 7: Research participants/subjects part 2

Risk/harm

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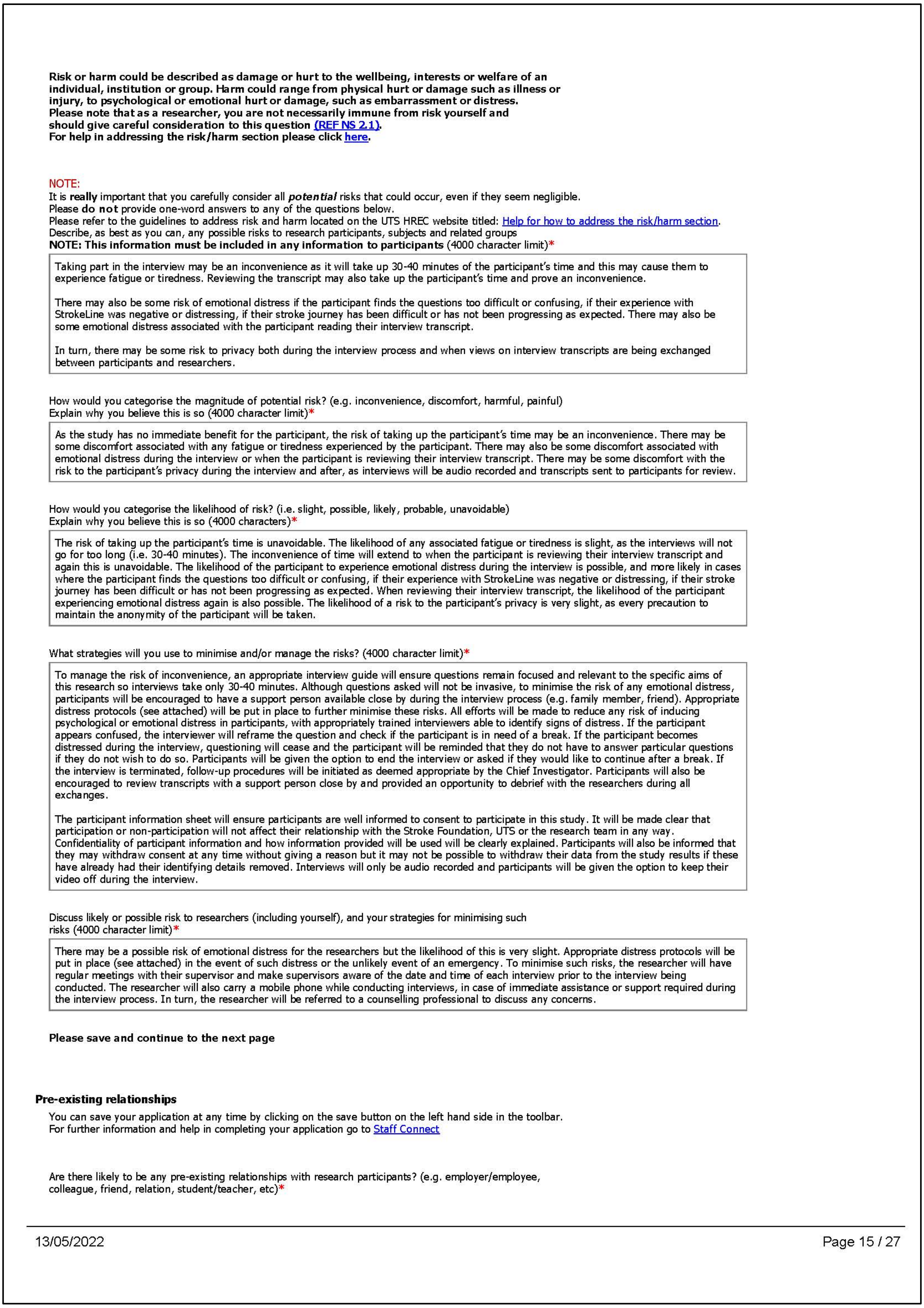


Risk or harm could be described as damage or hurt to the wellbeing, interests or welfare of an individual, institution or group. Harm could range from physical hurt or damage such as illness or injury, to psychological or emotional hurt or damage, such as embarrassment or distress.
Please note that as a researcher, you are not necessarily immune from risk yourself and should give careful consideration to this question (REF NS 2.1).
For help in addressing the risk/harm section please click here.

NOTE:
It is **really** important that you carefully consider all ***potential*** risks that could occur, even if they seem negligible.
Please **do not** provide one-word answers to any of the questions below.
Please refer to the guidelines to address risk and harm located on the UTS HREC website titled: Help for how to address the risk/harm section.
Describe, as best as you can, any possible risks to research participants, subjects and related groups
NOTE: This information must be included in any information to participants (4000 character limit)*

Taking part in the interview may be an inconvenience as it will take up 30-40 minutes of the participant's time and this may cause them to experience fatigue or tiredness. Reviewing the transcript may also take up the participant's time and prove an inconvenience.

There may also be some risk of emotional distress if the participant finds the questions too difficult or confusing, if their experience with StrokeLine was negative or distressing, if their stroke journey has been difficult or has not been progressing as expected. There may also be some emotional distress associated with the participant reading their interview transcript.

In turn, there may be some risk to privacy both during the interview process and when views on interview transcripts are being exchanged between participants and researchers.

How would you categorise the magnitude of potential risk? (e.g. inconvenience, discomfort, harmful, painful)
Explain why you believe this is so (4000 character limit)*

As the study has no immediate benefit for the participant, the risk of taking up the participant's time may be an inconvenience. There may be some discomfort associated with any fatigue or tiredness experienced by the participant. There may also be some discomfort associated with emotional distress during the interview or when the participant is reviewing their interview transcript. There may be some discomfort with the risk to the participant's privacy during the interview and after, as interviews will be audio recorded and transcripts sent to participants for review.

How would you categorise the likelihood of risk? (i.e. slight, possible, likely, probable, unavoidable)
Explain why you believe this is so (4000 characters)*

The risk of taking up the participant's time is unavoidable. The likelihood of any associated fatigue or tiredness is slight, as the interviews will not go for too long (i.e. 30-40 minutes). The inconvenience of time will extend to when the participant is reviewing their interview transcript and again this is unavoidable. The likelihood of the participant to experience emotional distress during the interview is possible, and more likely in cases where the participant finds the questions too difficult or confusing, if their experience with StrokeLine was negative or distressing, if their stroke journey has been difficult or has not been progressing as expected. When reviewing their interview transcript, the likelihood of the participant experiencing emotional distress again is also possible. The likelihood of a risk to the participant's privacy is very slight, as every precaution to maintain the anonymity of the participant will be taken.

What strategies will you use to minimise and/or manage the risks? (4000 character limit)*

To manage the risk of inconvenience, an appropriate interview guide will ensure questions remain focused and relevant to the specific aims of this research so interviews take only 30-40 minutes. Although questions asked will not be invasive, to minimise the risk of any emotional distress, participants will be encouraged to have a support person available close by during the interview process (e.g. family member, friend). Appropriate distress protocols (see attached) will be put in place to further minimise these risks. All efforts will be made to reduce any risk of inducing psychological or emotional distress in participants, with appropriately trained interviewers able to identify signs of distress. If the participant appears confused, the interviewer will reframe the question and check if the participant is in need of a break. If the participant becomes distressed during the interview, questioning will cease and the participant will be reminded that they do not have to answer particular questions if they do not wish to do so. Participants will be given the option to end the interview or asked if they would like to continue after a break. If the interview is terminated, follow-up procedures will be initiated as deemed appropriate by the Chief Investigator. Participants will also be encouraged to review transcripts with a support person close by and provided an opportunity to debrief with the researchers during all exchanges.

The participant information sheet will ensure participants are well informed to consent to participate in this study. It will be made clear that participation or non-participation will not affect their relationship with the Stroke Foundation, UTS or the research team in any way. Confidentiality of participant information and how information provided will be used will be clearly explained. Participants will also be informed that they may withdraw consent at any time without giving a reason but it may not be possible to withdraw their data from the study results if these have already had their identifying details removed. Interviews will only be audio recorded and participants will be given the option to keep their video off during the interview.

Discuss likely or possible risk to researchers (including yourself), and your strategies for minimising such risks (4000 character limit)*

There may be a possible risk of emotional distress for the researchers but the likelihood of this is very slight. Appropriate distress protocols will be put in place (see attached) in the event of such distress or the unlikely event of an emergency. To minimise such risks, the researcher will have regular meetings with their supervisor and make supervisors aware of the date and time of each interview prior to the interview being conducted. The researcher will also carry a mobile phone while conducting interviews, in case of immediate assistance or support required during the interview process. In turn, the researcher will be referred to a counselling professional to discuss any concerns.

Please save and continue to the next page

Pre-existing relationships

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Are there likely to be any pre-existing relationships with research participants? (e.g. employer/employee, colleague, friend, relation, student/teacher, etc)*

○ Yes
● No

Will you be recruiting UTS staff and/or students as research participants?*

○ Yes
● No

Please save and continue to the next page

External organisations

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Indicate if your research will involve any of the following:*

☐ Institution
☑ Organisation
☐ Community Group
☐ None of the above

Please describe what type(s) of institution / organisation / community group will be involved and how many will be involved (4000 character limit)*

The Stroke Foundation in Australia will be the only organisation involved with this research. The Stroke Foundation is a national charity that aims to support and advocate for stroke survivors, their families, healthcare professionals and researchers. They also raise awareness on the prevention and treatment of stroke in the wider community.

Was the research generated from within the institution / organisation / community group?*

○ Yes
● No

Please save and continue to the next page

External organisation consent

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Have you sought appropriate approval or support from the institution / organisation / community group involved?*

● Yes
○ No

Please attach a copy of any letter of approval/agreement at the end of this form

Do you intend to feed the research results back to the institution / organisation /community group?*

● Yes
○ No

Please describe how (4000 character limit)*

We will report research findings back to the Stroke Foundation and StrokeLine staff through written reports and/or presentations. These will include reports/presentations about the impact StrokeLine has had on stroke survivors' recovery. Examples of the positive outcomes that stroke survivors have gained by seeking support from the StrokeLine could be helpful in informing future policy or funding decisions, or news type stories and advertisements for StrokeLine.

Does this research involve any contracts, including confidentiality agreements? (REF NS 3.2.12, 3.5.6) (Section 2.5 and 4, The Code)*

● Yes
○ No

Is your contract finalised?*

○ Yes
● No

Please indicate when you believe it will be finalised*

31/07/2020

Please save and continue to the next page

Section 8: Data

Data collection

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

The collection, storage and use of data involve important considerations of privacy. When collecting data, researchers should show due sensitivity and respect for persons. It is also important that data be reliable, authentic, and where appropriate, replicable. This section will provide the HREC with information as to how you intend to deal with these issues.
(REF NS 2.2.6(f), 3.2) (Section 2, The Code)

Who will collect the data? (More than one box may be checked) (Section 2, The Code)*

☐ External contract researcher
☐ External associate researcher
☐ External student
☑ Internal (UTS) academic researcher
☐ Internal (UTS) research assistant
☑ Internal (UTS) student
☐ Research Assistant
☐ Volunteers
☐ Other

Will you be attaching a sample of your data recording/measurement instrument(s) to this application (e.g. survey, interview format, etc?)*

● Yes
○ No

Please save and continue to the next page

Information database or personal records

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Do your data collection or recruitment methods include access to an information database or personal records?
(Section 95 and 95A, Privacy Act) (REF NS 3.2)
*

● Yes
○ No

Indicate the source of data you will be obtaining (more than one box may be checked):*

☐ Medical Records
☑ Database
☐ Student Records
☐ Records relating to employment
☐ Court records or data
☐ Other

Please describe what type of database records, how many will be involved, and how you will obtain approval or consent (4000 character limit)*

The StrokeLine CRM system collects data over the course of a total episode of care. For each episode of care, the StrokeLine staff member records demographic details about the caller and reasons for the call using predefined categorical variables. We are seeking to extract de-identified data from StrokeLine episodes of service logged between 31/12/2016 and 31/12/2020. The process of de-identification will happen prior to the researchers receiving the data. StrokeLine staff will export the data from their CRM system, de-identify the data and transfer this de-identified dataset to the researchers. StrokeLine will remove all contact details of callers and each episode of care will only be labeled with a number.

Data we are seeking to analysis will include date of service, demographics of users (e.g. gender, age), origin of contact (e.g., email, phone, web) and type of caller (e.g., health professional, stroke survivor, carer). Other user characteristics will also be analysed such as time since stroke (early <1 year, late >1 year), location (metro, regional, rural), or indigenous/non-indigenous status if the data permits. Predefined categorical data related to why a person is seeking care will also be used including variables such as practical issues (e.g.,accommodation, driving, finances); adjusting/coping issues (e.g., family relationships, occupation); and the type of health service treatment and care being sought (e.g., Questions about tests and treatments, access to rehabilitation). A summary of the episode of care outlining the issues discussed & actions taken is also entered by the staff member using free text. We are seeking to also extract this data for coding using a content analysis.

After consultation with the StrokeLine, we have been made aware that the 'summary' field (which indicates what was discussed during the phone consultation) may in some instances include the first name or surname of the caller (e.g. 'Bob' or 'Mr. Smith'); the name of a carer/family member (eg. 'his wife Anna'); or hospital associated with care. The free-text field is similar to what a medical record would contain in an initial interview by a health professional. We have agreed with StrokeLine that they will have a volunteer permanently delete any incidental identifiable information prior to the transfer of data to UTS researchers (Dr Alana McCambridge, Ms Muneeba Chaudhry).

Attached is email correspondence of this agreement, and currently a formal data sharing agreement is being devised by the Stroke Foundation to support this agreement. Please also see attached variables list for a more detailed outline of the proposed variables to be analysed and a confirmation email from the Stroke Foundation that approves our protocol.

StrokeLine provides a disclaimer over the phone to callers before each episode of service. The disclaimer does not specifically mention the use of data for research purposes, however as per the Stroke Foundation's Privacy Policy (https://strokefoundation.org.au/Privacy) regarding implied consent the research does act to further the Stroke Foundation's mission and an opt-out option was provided. The privacy policy which is referred to in the disclaimer states that inference of an individual's consent (i.e., implied consent) will be appropriate where the Contributor (i.e., the caller) could reasonably expect the shared content to be used to further Stroke Foundation's Mission and the ability to opt-out was clearly communicated and easy to access.

As the disclaimer does not specifically state "research", we ask for a waiver of consent based on the National Statement (2.3.10). Please see attached.

Please save and continue to the next page

Data type

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

The HREC is required to report on privacy to the Federal and NSW Privacy Commissioners

Indicate the category of data you will be obtaining at the point of data collection (More than one box may be checked):*

☐ Individually identifiable data
☑ Re-identifiable data
☐ Non-identifiable data

Are you obtaining consent for individually identifiable or re-identifiable information?*

● Yes
○ No

Please select how you will be obtaining consent from the list below*

Other

Please describe what other method you will use to obtain consent (4000 character limit)*

Informed consent will be obtained verbally using audio recordings on Zoom and the UTS verbal consent transcript. The participant will be read a verbal consent transcript and asked to respond verbally if they understand and thereby consent to the study. If there is difficulty obtaining verbal consent due to a communication disorder, we will source appropriate support (e.g. family, UTS speech pathologist A/Prof Emma Power) to aid in the consent and participation in the research.

Why do you need to have access to individually identifiable and/or re-identifiable data? (4000 character limit)*

The interview component of the study requires identifiable participant details (mainly contact details) to be collected and stored for the purposes of conducting screening prior to the interview, to conduct the interview itself, and to send and receive transcribed interviews between participants and researchers.

Audio recordings and interview transcripts will have identifiers removed and will be stored using a study enrolment number. Identifiable data (eg. contact details) will be stored separately to these and password protected. Although identifiers will have been removed from all recordings and consequent transcripts, it may remain possible to re-identify a specific individual by linking the different data sets.

Will you be seeking identifiable information from a Commonwealth agency, without the consent from the individuals to which the data refer?*

○ Yes
● No

Please save and continue to the next page

Data storage

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Data must be stored and secured for a minimum of 5 years after publication (Some data are required for longer periods of time and the storage will need to take this into account). For further details on retention requirements, refer to the UTS Records Management Policy http://www.records.uts.edu.au/policies/index.html The data should be stored so as to ensure maximum privacy for participants, reliability and retrievability of data.

Indicate the format(s) the data will be stored in (Choose as many categories as applicable)
NOTE: This information must be included in any information to participants
*

☑ Electronic/digital recording
☑ Handwritten notes
☐ Microfilm
☐ Non-identifiable(anonymous)data
☑ On-line data storage
☐ Paper questionnaires/Surveys
☑ Transcripts of tapes/recordingd
☐ Video tapes
☐ Other

Who will have access to the raw data? (Choose as many categories as applicable)
NOTE: This information must be included in any information to participants
*

☑ UTS academic researcher(s)
☑ UTS student(s) and supervisors
☑ External researcher(s)
☐ Research assistant(s)
☐ Funding body/organisation
☐ Partner organisation(s)
☐ Other

Please save and continue to the next page

Use & publication of data

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

How do you intend to use and/or publish the data? (Choose as many categories as applicable)
NOTE: This information must be included in any information to participants
*

☐ Book
☐ Client Report
☑ Conference paper
☑ Electronic publication
☑ Media
☑ Report
☑ Thesis
☑ Journal articles
☐ Other

Do you envisage any additional use of data in future research projects?*

○ Yes
● No

Please save and continue to the next page

Privacy principles

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

As a general principle, privacy and confidentiality should be respected at all stages of the research (raw data, analysis, published or archived), and by all those involved in the research (including the researcher, research assistants, administrative assistants, students, interpreters, translators, data processors, members of focus groups, etc.)

Note: Privacy and confidentiality is complicated in NSW because it is governed by a number of separate Acts. From 12 March 2014, the new Australian Privacy Principles (APPs) were introduced to regulate the handling of personal information by Australian government agencies and some private sector organisations.

The privacy fact sheet providing the text of the 13 APP can be accessed here.

The 13 APP apply to all research conducted by staff and students of this University.

Will this research be undertaken in conformity to ALL the Privacy Principles?*

● Yes
○ No

Please save and continue to the next page

Privacy & confidentiality

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

How will you ensure the security of the data? (4000 character limit)*

All data will be stored on Cloudstor, a secure online file storage platform. Access to Cloudstor is password protected and all passwords will only be made available to members of the research team. The Data Manager and Data Steward as nominated in the project Research Database Management Plan (RDMP) will be tasked with the management of the research data. In the unlikely event of a data breach, any necessary action to prevent any further data breaches from occurring will be taken. Appropriate procedures outlined in the UTS Guide for Research Integrity Breaches will be followed.

How will you protect the confidentiality/privacy of your participants? (4000 character limit)*

Interviews will only be audio recorded and participants will have the option of keeping their video off during the interview. The researchers will make every attempt to conduct interviews remotely from a private setting, with no personal interruptions.

All participants will receive a study enrolment number and this will be used to de-identify them on all study documents and files. A password protected master list will be compiled containing a record of each participant and their contact details. The contact details and any electronic forms (e.g. screening questionnaire) will be stored separately from participant data. Interview recordings, transcripts and all associated data will be stored on CloudStor. In any publication or dissemination of the study data, participant quotes will be presented in a way that does not reveal identifying information to ensure the anonymity of participants. All data and records generated during the study will be kept confidential in accordance with UTS institutional policies on subject privacy. The data will only be used by members of the research team for the purposes of conducting the study itself.

To what extent will you or anyone else be able to identify the research participants from the published or unpublished data? Please describe: (4000 character limit)*

Although all data will be stored using study enrolment numbers allocated to each participant, there is a slight possibility that research participants may be re-identifiable from the unpublished data only by members of the research team who conducted the interviews. Audio recordings may contain re-identifiable information but when transcribed, all identifiable data will be removed by the researchers.

Research participants, however, will not be identifiable from published data. In any publication or dissemination of the study data, participant quotes will be presented in a way that does not reveal identifying information to ensure the anonymity of participants.

Please save and continue to the next page

Interpretation/analysis/disposal

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

Regardless of whether data collected is qualitative or quantitative, how do you plan to analyse these data into material that is valid and reliable? (Include a brief summary of your Analysis Plan) (4000 character limit)*

Interview transcripts will be sent to participants for review to validate the data collected and empower participants by giving them control of what is written (Mero-Jaffe, 2011). Data from transcribed interviews will be analysed using an inductive latent approach to thematic analysis based on phenomenology, with the assistance of NVivo. Transcripts will be read multiple times and coded into categories (Graneheim & Lundman, 2004; Braun & Clarke,2006). Data will be coded by two independent assessors from the research team and themes will be agreed upon amongst the assessors, as patterns are identified. Themes will be reviewed, defined and named before findings are reported (Graneheim & Lundman, 2004).

Will the data be archived or destroyed? *

☑ Archived
☐ Destroyed

Where will the data be archived, who will have access to it, and will there be any conditions attached?
(4000 character limit)*

On completion of the project, data will be stored in the eResearch Store within an archival data record created in Stash. Data will be archived for 5 years and then destroyed. The data steward nominated in the Research Data Management Plan (RDMP) is responsible for the retention of the research data during this time and will be charged with disposing the data once the archival period has lapsed.

Please save and continue to the next page

Section 9: Additional information

Other ethical issues

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

If there are any additional ethical issues which you do not believe have been covered by this form, please explain them for the HREC: (4000 character limit)*

We do not believe there are any additional ethical issues to consider.

Please save and continue to the next page

Section 10: Attachments

Attachments

You can save your application at any time by clicking on the save button on the left hand side in the toolbar.
For further information and help in completing your application go to Staff Connect

I have attached the following supporting documents

Doctoral or Masters assessment*

● Yes
○ N/A

Participant Information Sheet(s)*

● Yes
○ No

Survey(s)/questionnaire(s)/outline of question(s)*

● Yes
○ N/A

Evidence of approval for access to information database or records*

● Yes
○ N/A

Evidence of approval from external institution, organisation or community group*

○ Yes
● N/A

Explanations of any technical terms used*

○ Yes
● N/A

Standard Operating Procedures

N.B. May include a distress or disclosure protocol [see UTS HREC Disclosure Guidelines], Faculty of Health Low Risk protocol; procedures for participant screening, physiological, or biological sampling and/or laboratory or safety procedures where relevant.

*

● Yes
○ No

Please explain why any of the above items have not been attached (either softcopy/hardcopy) and when they will be provided (4000 character limit)*

No technical terms have been used in this application. We are currently in the process of finalising approvals with the Stroke Foundation and we will provide evidence of this by 15/08/2020.

Documents attached to this application:

How to attach documents

1. Click on 'Add'
   Ensure the fields are as follows:
   - Document type- soft copy
   - Name- as is
   - Description- fill in if you wish
2. You can then either select the file you want to upload OR drag and drop it where it says 'Drop file here'
3. Click on 'OK'

Note: Please use the following HREC templates when creating an information sheet, consent form, verbal script, etc.: HREC templates*

1	Document type	Soft copy
	Name	Interview Guide
	Reference (Document Title)	Interview Guide_v1.pdf
	Description	
2	Document type	Soft copy
	Name	Verbal Consent Script
	Reference (Document Title)	Verbal Consent Script_v1.pdf
	Description	
3	Document type	Soft copy
	Name	Distress Protocol
	Reference (Document Title)	Distress Protocol_v1.pdf
	Description	
4	Document type	Soft copy
	Name	Participant Information Sheet
	Reference (Document Title)	Participant Information Sheet_v1.pdf
	Description	
5	Document type	Soft copy
	Name	Recruitment Flyer
	Reference (Document Title)	Recruitment Flyer_v1.pdf
	Description	
6	Document type	Soft copy
	Name	ETH20-5088 -MCCAMBRIDGE (for CHAUDRY) - MREC outcome and comments
	Reference (Document Title)	Final_Responses_ETH20-5088 -MCCAMBRIDGE (for CHAUDHRY) - MREC outcome and comments.docx
	Description	
7	Document type	Soft copy
	Name	Responses to MREC Comments
	Reference (Document Title)	Final_Responses_ETH20-5088 -MCCAMBRIDGE (for CHAUDHRY) - MREC outcome and comments.docx
	Description	Responses to MREC Comments
8	Document type	Soft copy
	Name	v2_Distress Protocol_Study3
	Reference (Document Title)	v2_Distress Protocol_Study3.docx
	Description	Amended Distress Protocol, as per MREC comments (see tracked changes)
9	Document type	Soft copy
	Name	v2_Participant Information Sheet_Study3
	Reference (Document Title)	v2_Participant Information Sheet_Study3.docx
	Description	Amended Participant Information Sheet, as per MREC comments (see tracked changes)
10	Document type	Soft copy
	Name	v2_Verbal Consent Script_Study3
	Reference (Document Title)	v2_Verbal Consent Script_Study3.docx
	Description	Amended Verbal Consent Script, as per MREC comments (see tracked changes)
11	Document type	Soft copy
	Name	Stage 1 Assessment Outcome

	Reference (Document Title)	CHAUDHRY, Muneeba - GRSP Stage 1 Review Outcome Letter.pdf
	Description	Outcome of Stage 1 Master's Assessment
12	Document type	Soft copy
	Name	NHMRC Waiver of Consent (for study 1 and 2)
	Reference (Document Title)	Waiver of Consent_Study1and2.pdf
	Description	NHMRC Waiver of Consent based on the National Statement (2.3.10) for study 1 and 2
13	Document type	Soft copy
	Name	Data De-indentification Correspondence with Stroke Foundation (study 1 and 2)
	Reference (Document Title)	Data De-indetification Correspondence with Stroke Foundation (study 1 and 2).pdf
	Description	Data De-identification Correspondence with Stroke Foundation for study 1 and 2.
14	Document type	Soft copy
	Name	Evidence of Stroke Foundation Support for Research Protocol
	Reference (Document Title)	Evidence of Stroke Foundation Support for Research Protocol.pdf
	Description	Evidence of Stroke Foundation Support for Research Protocol
15	Document type	Soft copy
	Name	List of Variables (study 1 and 2)
	Reference (Document Title)	List of Variables (study 1 and 2).pdf
	Description	List of Variables for study 1 and 2

Please read the submission instructions carefully at the end of this application form.
Please save and continue to the next page

Declaration

Declaration

I have answered all questions in the risk assessment truly and completely to the best of my knowledge

I will notify the UTS Human Research Ethics Committee of any variation to this research that may alter the level of risk associated with it

This research will be undertaken in compliance with the UTS Research Ethics and Integrity Policy or any replacement or amendment thereof

This research will be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research

please click on the "Submit" button in the Actions menu.

Confirmation

Confirmation by Local Research Office High Risk

Application type*

Research (student project)

Internal personnel listed on this ethics protocol*

1	Primary	
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
2	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
3	Primary	
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.Chaudhry@uts.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	7222

External personnel listed on this ethics protocol*

1	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

Checked by:*

Ed Dharmadji

Date of review:*

27/07/2020

The Research Office has confirmed that: All information in this application and supporting documentation is correct and as complete as possible *

● Yes
○ No

Confirmation by ADR

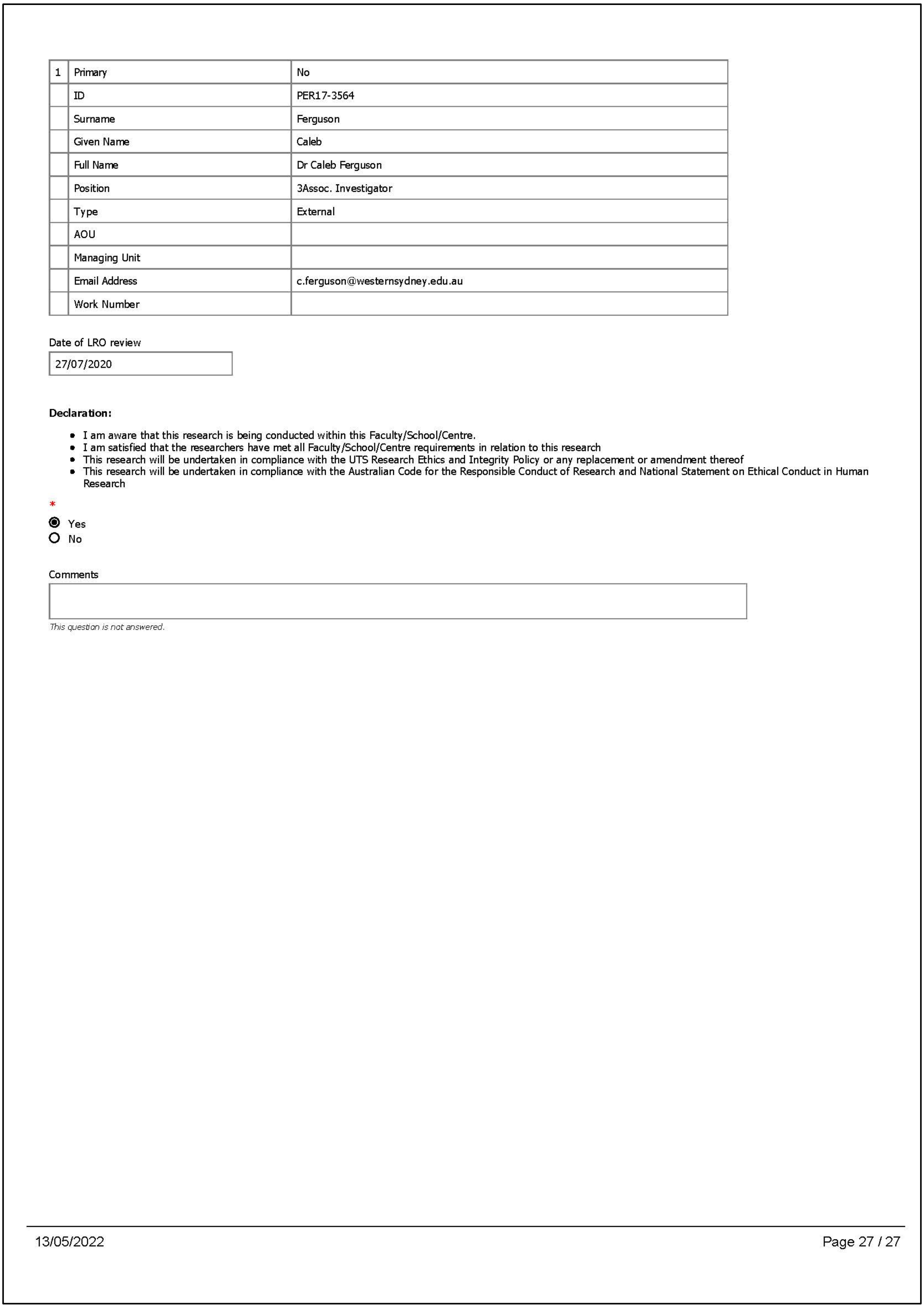
Application type

Human

Internal personnel listed on this ethics protocol

1	Primary	
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
2	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
3	Primary	
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.Chaudhry@uts.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	7222

External personnel listed on this ethics protocol



1	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

Date of LRO review

27/07/2020

Declaration:

- I am aware that this research is being conducted within this Faculty/School/Centre.
- I am satisfied that the researchers have met all Faculty/School/Centre requirements in relation to this research
- This research will be undertaken in compliance with the UTS Research Ethics and Integrity Policy or any replacement or amendment thereof
- This research will be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research

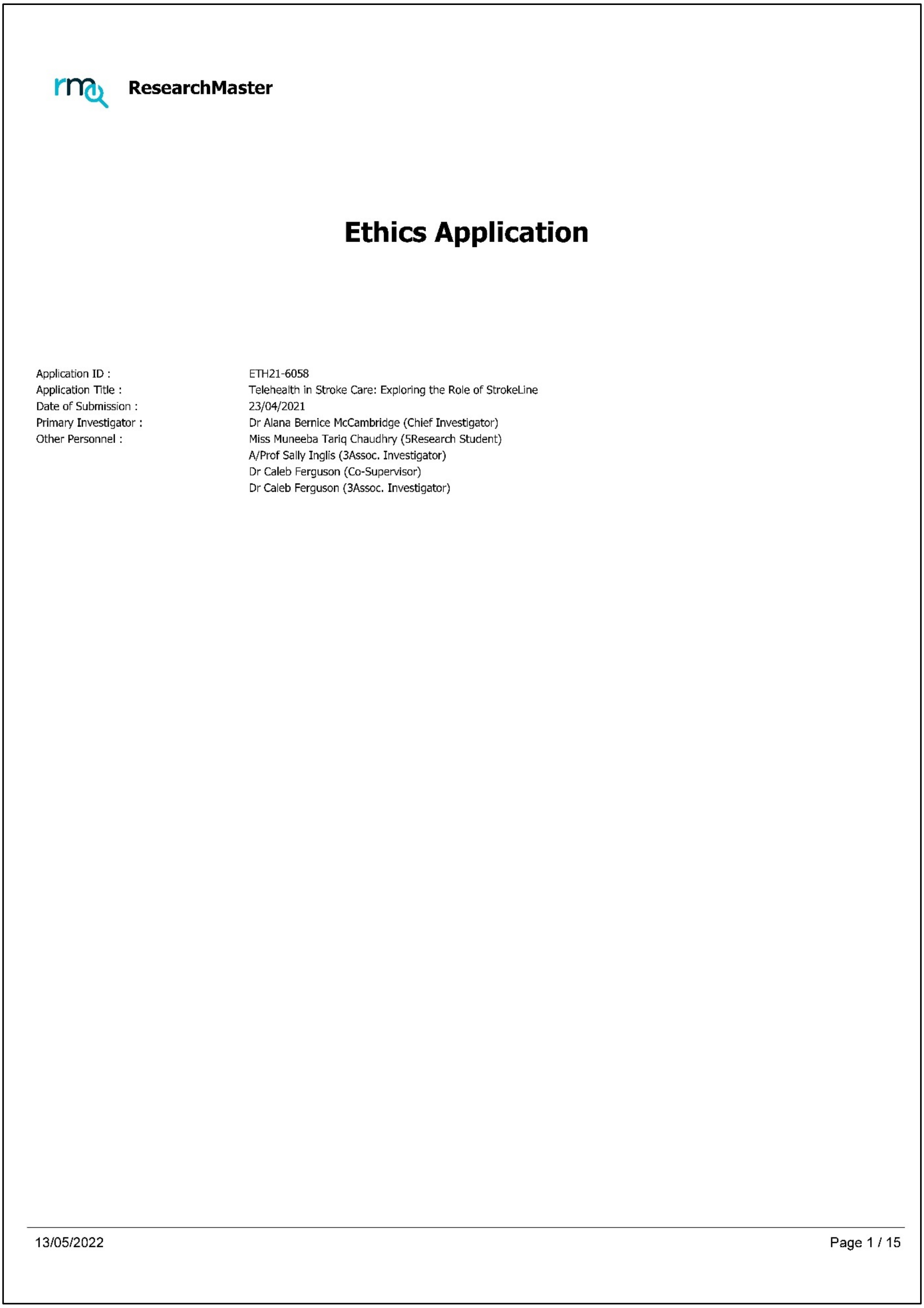
*

● Yes
○ No

Comments

This question is not answered.

Amendment to Existing Approval



ResearchMaster

Ethics Application

Application ID :	ETH21-6058
Application Title :	Telehealth in Stroke Care: Exploring the Role of StrokeLine
Date of Submission :	23/04/2021
Primary Investigator :	Dr Alana Bernice McCambridge (Chief Investigator)
Other Personnel :	Miss Muneeba Tariq Chaudhry (5Research Student) A/Prof Sally Inglis (3Assoc. Investigator) Dr Caleb Ferguson (Co-Supervisor) Dr Caleb Ferguson (3Assoc. Investigator)

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Section 1: Ethics Portal

Select your application type

What type of application are you looking for?

Please **do not** change your application type without first consulting with the Ethics Secretariat (9514 9772).*

○ New application (including scope-checking for nil/negligible risk research)
○ Ratification of existing approval
○ Transfer of existing approval
○ Evaluation of teaching and learning activities
● Amendment to existing approval
○ Program approval

You have selected "amendment application". This option allows you to amend
an existing UTS HREC approved protocol. Please click "save" before continuing.

Please refer to the amendment table on our website regarding the requirements for amendments to existing approval before continuing.

Please indicate the risk classification of the original ethics approval?*

○ Nil/Neg risk
○ Low risk
● High risk

What should I know before I start?

Would you like more information on:

● This system
○ The ethics process
○ Purpose of the ethics review process

This system

The purpose of this online system is to streamline the ethics application process.

Mandatory questions in the application form are marked with a red asterisk (*) and must be answered before submitting this form. If a question is left unanswered on a page the form menu will show a red exclamation mark (!) on the left side of the page name and the question will be highlighted in pink.

The navigation menu allows you to view all sections and pages of the application, and also keeps track of what pages have been visited and/or completed and which pages are incomplete.

Action buttons (located on the right) shows the actions that the person viewing the form can make, and will differ between each role, e.g. student, supervisor, staff member, faculty member, HREC member, Research Ethics Officer, etc.

'Next page': Each time you click on the blue 'next page' button, your application is saved automatically.

Save: This button allows you to save the page before moving to other pages.

Comments: This allows you to make comments on the application.

Reports: Allows you to view or print a PDF the application form.

Section 1A: Risk evaluation

Risk A

Determining the level of risk and review

- Please answer each question carefully **and consecutively**.
- For assistance with answering these questions please refer to the National Statement on Ethical Conduct in Human Research as per the chapters listed below.
- If you need to contact the Research Ethics Officer you can call (02) 9514 9772
- Click on the help buttons (?) for more information
- You can save your application at any time by clicking on the save button on the left hand side in the toolbar. For further information and help in completing your application go to our website.

Does your research involve:

Projects involving covert observation, active concealment, or planned deception of participants

e.g. covert observation of the hand-washing behaviour of hospital employees, undisclosed role-playing by a researcher, etc. Does NOT include observation in a public place WITHOUT the use of photographs, images, video or audio footage (Chapter 2.3, p.19)

*

○ Yes
● No

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Targeted recruitment or analysis of data(?) from any of the groups listed below (or where any of these groups are likely to be significantly over-represented in the group being studied)

- Women who are pregnant and the human fetus (Chapter 4.1, p. 61)
- Children and young people (under 18 years) (Chapter 4.2, p. 65)
- People in dependent or unequal relationships (e.g. lecturer/student [except T&L], doctor/patient, employer/employee) (Chapter 4.3, p.68)
- People highly dependent on medical care who may be unable to give consent Chapter 4.4, p.68)
- People with a cognitive impairment, an intellectual disability, or a mental illness (may include the disadvantaged/homeless) (Chapter 4.5, p. 70)
- People who may be involved in illegal activities (including those affected e.g. victims of domestic violence) (Chapter 4.6, p.73)
- Aboriginal and Torres Strait Islander Peoples (Chapter 4.7, p.77)

*

○ Yes
● No

Targeted recruitment of people in / from countries that score <50 on the Corruption Perception Index (CPI) (check here)
This includes any cohorts from these countries, i.e. it is not restricted to marginalised groups within these countries*

○ Yes
● No

Collection, use or disclosure of personal information without consent of the participant(?)

- a record which may include your name, address and other details about the participant (e.g. date of birth, financial information etc.)
- photographs, images, video or audio footage
- fingerprints, blood or DNA samples

*

○ Yes
● No

Collection, use or disclosure of health information(?)

- personal information that is information or an opinion about
  - the physical or mental health or a disability (at any time) of an individual; or
  - an individual's expressed wishes about the future provision of health services to him or her, or
  - a health service provided, or to be provided, to an individual or
- other personal information collected to provide, or in providing, a health service, or
- other personal information about an individual collected in connection with the donation, or intended donation, of a individual's body parts, organs, body substances, or
- other personal information that is genetic information about an individual arising from a health service provided to the individual in a form that is or could be predictive of the health (at any time) of the individual or of a genetic relative of the individual, or
- healthcare identifiers

N.B Includes information collected through physiological testing or assessment. Examples include but are not limited to EEG, EMG, BMI, blood pressure, DEXA, etc.*

● Yes
○ No

Collection, use or disclosure of sensitive information
Racial, ethnic information, political, religious and philosophical beliefs, sexual activity or identity, and trade union membership
*

○ Yes
● No

Activity that potentially infringes the privacy or professional reputation of participants, providers or organisations
e.g. observation in the workplace, collection of commercially confidential information, etc.
Commercially confidential information = Any information which is not in the public domain or publicly available, and where disclosure may undermine the economic interest or competitive position of the owner of the information (TGA adopted definition from European Medicines Agency (EMA)).

N.B. if canvassing opinion via consensus methods i.e. Delphi (?), answer "No" here
*

○ Yes
● No

Establishment of a register or databank of identifiable data for possible use in future research projects (Chapter 3.2, p.27) (?)

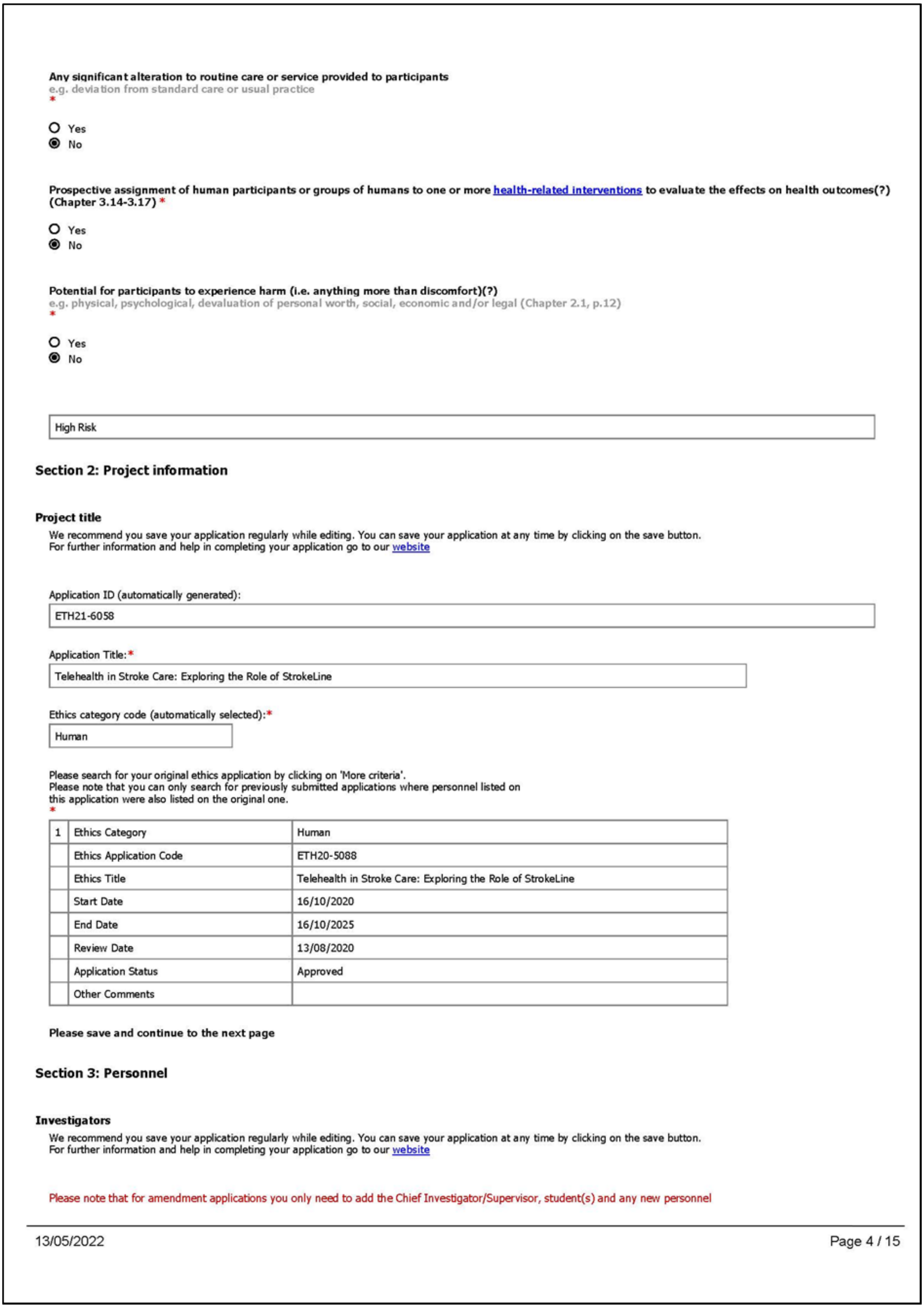
*

○ Yes
● No

Collection, transfer(?) and/or banking of human biospecimens.
e.g. tissue, blood, urine, sputum etc.(?)

*

○ Yes
● No



Any significant alteration to routine care or service provided to participants
e.g. deviation from standard care or usual practice
*

○ Yes
● No

Prospective assignment of human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes(?) (Chapter 3.14-3.17) *

○ Yes
● No

Potential for participants to experience harm (i.e. anything more than discomfort)(?)
e.g. physical, psychological, devaluation of personal worth, social, economic and/or legal (Chapter 2.1, p.12)
*

○ Yes
● No

High Risk

Section 2: Project information

Project title

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

Application ID (automatically generated):
ETH21-6058

Application Title:*
Telehealth in Stroke Care: Exploring the Role of StrokeLine

Ethics category code (automatically selected):*
Human

Please search for your original ethics application by clicking on 'More criteria'.
Please note that you can only search for previously submitted applications where personnel listed on this application were also listed on the original one.
*

1	Ethics Category	Human
	Ethics Application Code	ETH20-5088
	Ethics Title	Telehealth in Stroke Care: Exploring the Role of StrokeLine
	Start Date	16/10/2020
	End Date	16/10/2025
	Review Date	13/08/2020
	Application Status	Approved
	Other Comments	

Please save and continue to the next page

Section 3: Personnel

Investigators

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

Please note that for amendment applications you only need to add the Chief Investigator/Supervisor, student(s) and any new personnel

Are there external investigators or personnel listed on this protocol?*

● Yes
○ No

Is this application for a student project?*

● Yes
○ No

Student applicants:

1. Please note that once your application is submitted it will go directly to your supervisor and not to the Committee.
2. We **strongly** recommend notifying your supervisor that you have submitted your application in case of any technical issues, to avoid potential delays in the review process.
3. Once your supervisor endorses your application it will go to your Local Research Office for endorsement before coming to the Ethics Secretariat for review.
4. Your electronic application must be endorsed by your supervisor by the Local Research Office (LRO) submission deadline.
5. Please also ensure that the Primary AOU at the end of this page is updated to your supervisor's AOU. This will show in the table under 'Internal personnel listed below', once you add them. If you need any assistance with this please contact Research.Ethics@uts.edu.au or call 9514 9772. Please note that this is particularly important if you have a dual role as a staff/student as your application could go to the wrong faculty for review through the automated process.

Are the student(s) listed on this protocol new to the protocol? (e.g. being added as part of the amendment application)*

○ Yes
● No

Positions in the personnel table

Position type:	In the personnel table use the following positions from the drop-down list:
Chief Investigator/Supervisor	1Chief Investigator (students must **not** be listed as Chief Investigator)
Co Investigator	3Assoc. Investigator
Co Supervisor	Co-Supervisor
Research Student	5Research Student
Project Administrator	7Project Administrator

Note: Further options are available in the drop down list.

Instructions on how to add a person to the personnel table:

1. Click on "Add"
2. Start typing the details (first name, last name or Staff ID) in the search bar.
3. Click on "Add selected"
4. The extra information panel will open, select their position from the drop-down list. If they are the primary contact (e.g. Chief Investigator/Supervisor), tick "Yes" under 'Primary contact' and then select "OK"

- **Student research:** Students must add their supervisors to their application and must mark their primary supervisor as a Chief Investigator and as a primary contact. Students must be listed as "5Research student" under the column 'Position' to ensure the application is properly submitted to their supervisor.
- **Ratifications/Transfers:** If this list differs from that of the original application, you must provide evidence that any additional investigators have been added via amendment to the lead/external HREC [attach relevant amendments and evidence of approval].

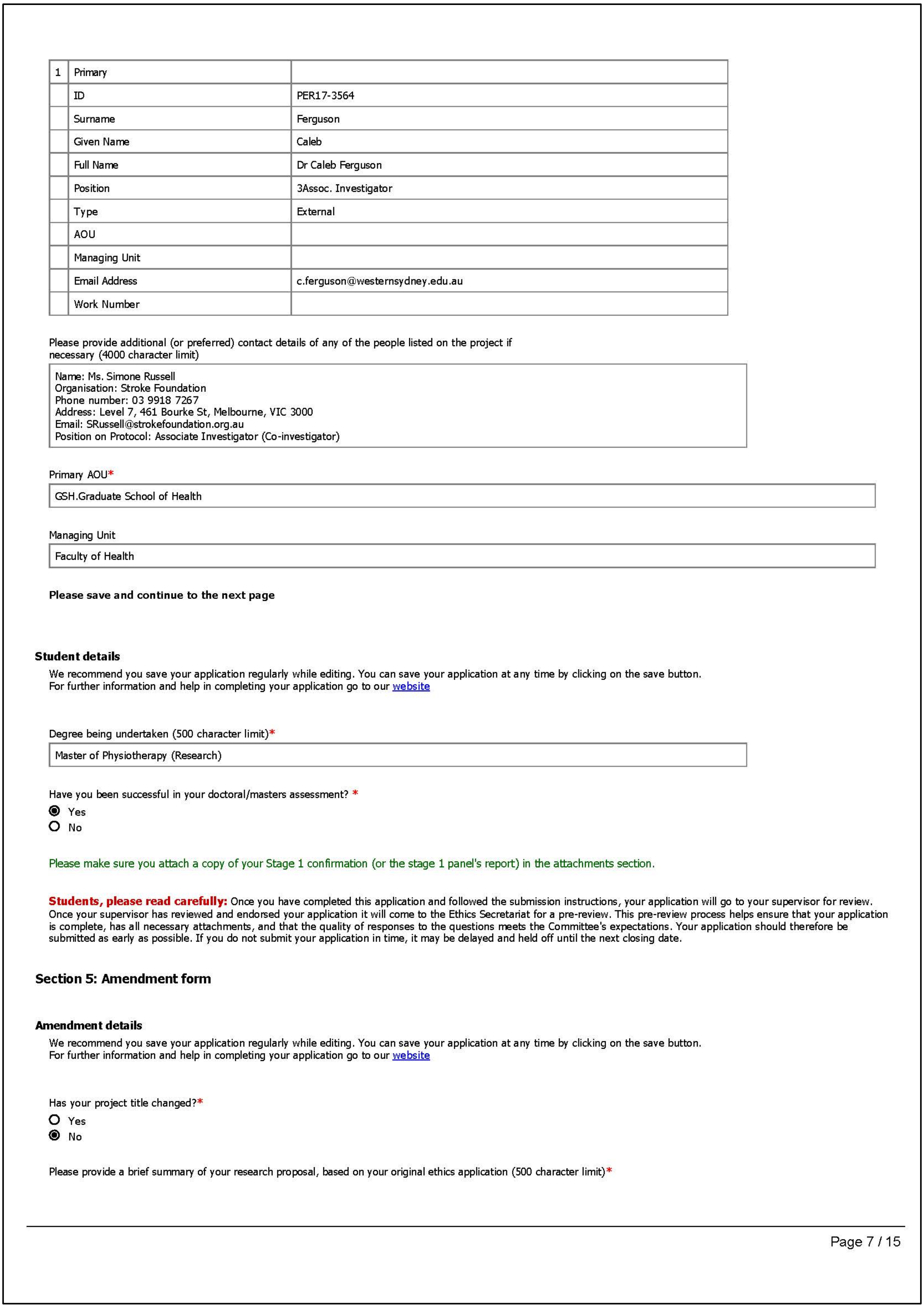
Internal personnel listed on this ethics protocol:*

1	Primary	No
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.T.Chaudhry@student.uts.edu.au
	Work Number	
2	Primary	No
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
3	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	+61 2 95147222

If any details are incorrect or missing please contact the Ethics Secretariat on (02) 9514 9772 or by email.

The ResearchMaster database has a very large number of external personnel so please conduct a search for them before adding them in the text box below. Please contact the Ethics Secretariat on 9514 9772 if you cannot find an external investigator through the system.

External personnel listed on this ethics protocol:
*



1	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

Please provide additional (or preferred) contact details of any of the people listed on the project if necessary (4000 character limit)

Name: Ms. Simone Russell
Organisation: Stroke Foundation
Phone number: 03 9918 7267
Address: Level 7, 461 Bourke St, Melbourne, VIC 3000
Email: SRussell@strokefoundation.org.au
Position on Protocol: Associate Investigator (Co-investigator)

Primary AOU*

GSH.Graduate School of Health

Managing Unit

Faculty of Health

Please save and continue to the next page

Student details

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

Degree being undertaken (500 character limit)*

Master of Physiotherapy (Research)

Have you been successful in your doctoral/masters assessment? *

● Yes
○ No

Please make sure you attach a copy of your Stage 1 confirmation (or the stage 1 panel's report) in the attachments section.

Students, please read carefully: Once you have completed this application and followed the submission instructions, your application will go to your supervisor for review. Once your supervisor has reviewed and endorsed your application it will come to the Ethics Secretariat for a pre-review. This pre-review process helps ensure that your application is complete, has all necessary attachments, and that the quality of responses to the questions meets the Committee's expectations. Your application should therefore be submitted as early as possible. If you do not submit your application in time, it may be delayed and held off until the next closing date.

Section 5: Amendment form

Amendment details

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

Has your project title changed?*

○ Yes
● No

Please provide a brief summary of your research proposal, based on your original ethics application (500 character limit)*

The part of the research we are requesting an amendment for aims to qualitatively explore the experiences of stroke survivors who have used the Stroke Foundation's StrokeLine service and the perceived impact of seeking care on their stroke journey. We are aiming to conduct 15-20, 30-40 minute semi-structured interviews on Zoom with stroke survivors who have used StrokeLine in the past 3 months. Participants will be recruited through advertising on the SF website and other online platforms. Interviews will be audio-recorded and transcribed verbatim for thematic analysis. This research will help support services remain relevant to the real needs of stroke survivors.

Does your amendment involve any of the following changes:*

☐ Change to completion date
☐ Change to personnel
☐ Change to research instruments/participant material
☐ Change to research methodology
☑ Change to recruitment of participants
☐ Other

Approximate new completion date

This question is not answered.

Does your amendment involve the addition of children as participants? (not as incidental)*

○ Yes
● No

Will changes include research be conducted using UTS staff and/or students? (not previously approved for)*

○ Yes
● No

What changes to your original ethics application are you proposing? (1500 character limit)*

We would like to add an additional recruitment avenue for our study. This would include emailing recent users of the StrokeLine service to notify them of the opportunity to participate in our research study. We have been given approval from the StrokeLine of the Stroke Foundation to send an email to users of the StrokeLine service in the past 3 months that have provided their email addresses to the StrokeLine. The email will be sent from StrokeLine and will direct interested people to get in contact with the research team, therefore maintaining an arms-length approach from the research team.

Attached is correspondence from StrokeLine staff Simone and Jude Czerenkowski - the National Manager of the Stroke Foundation's StrokeConnect Program of which StrokeLine is a part confirming that this approach will be suitable for them also. The email is currently being drafted and we will submit that to the Ethics Secretariat once it is completed and approval for this additional approach has been given.

Why do you wish to make these changes?*

We are requesting this amendment to our recruitment process, following 3-4 months of slow recruitment. We expect this strategy will greatly boost recruitment.

Please save and continue to the next page

Impact of amendment on research participants part 1

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

This section requires you to consider the ways in which your proposed amendments may impact upon the ethical issues raised on your original application. Specifically, we ask you to outline the effects (if any) of your amendments on the following areas, and how you intend to deal with them. Does your amendment affect any of the following:

Outcome of your research?*

○ Yes
● No

Current or future applications for funding?*

○ Yes
● No

Recruitment of participants (quantity, methods)*

● Yes
○ No

Please provide further information on how your amendment effects the recruitment of participants (quality, methods) (1500 character limit)*

We expect the new strategy added to our recruitment plan will help greatly boost recruitment. The new recruitment strategy will involve StrokeLine staff sending an email to all users of the StrokeLine service in the past 3 months who have agreed to provide their email address to StrokeLine for future correspondence. As the email will be sent from StrokeLine and only direct interested people to contact the research team, an arm-length approach will be maintained by the Research Team.

The new strategy will see StrokeLine staff involved only in screening potential participants within the timeframe for inclusion (ie. 3 months since contacting StrokeLine). All further screening for inclusion for the study (ie. stroke survivor, 18 years or older, able to communicate in English, have access to and be able to use Zoom and be able to give verbal consent) will be done only by members of the research team. Any follow-up correspondence from the emails sent out by StrokeLine will be answered by StrokeLine staff and again direct people to contact the research team for more information. The Stroke Foundation will not be aware of who has been consequently included in the study.

Anticipated risk or harm to participants and/or researchers?*

○ Yes
● No

Relationships (if any) between researchers and participants?*

○ Yes
● No

Please continue to the next page

Impact of amendment on research participants part 2

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

This section requires you to consider the ways in which your proposed amendments may impact upon the ethical issues raised on your original application. Specifically, we ask you to outline the effects (if any) of your amendments on the following areas, and how you intend to deal with them. Does your amendment affect any of the following:

Consent from Participants? *

○ Yes
● No

Data collection, interpretation, storage and/or disposal? *

○ Yes
● No

Privacy and confidentiality of participants?*

○ Yes
● No

Are you required to submit requests for amendment to any external bodies to UTS? (e.g. an Area Health Service, other university)*

● Yes
○ No

Please indicate how this will/has been be done*

We have gained approval for the new recruitment strategy from the Stroke Foundation. Attached is correspondence from StrokeLine staff Simone and Jude Czerenkowski - the National Manager of the Stroke Foundation's StrokeConnect Program of which StrokeLine is a part confirming that this new recruitment approach will be suitable for them also. The email to be used is currently being drafted by StrokeLine and we will submit that to the Ethics Secretariat once it is completed and HREC approval for this additional approach has been given.

Are there any other relevant ethical issues in relation to the proposed amendment? *

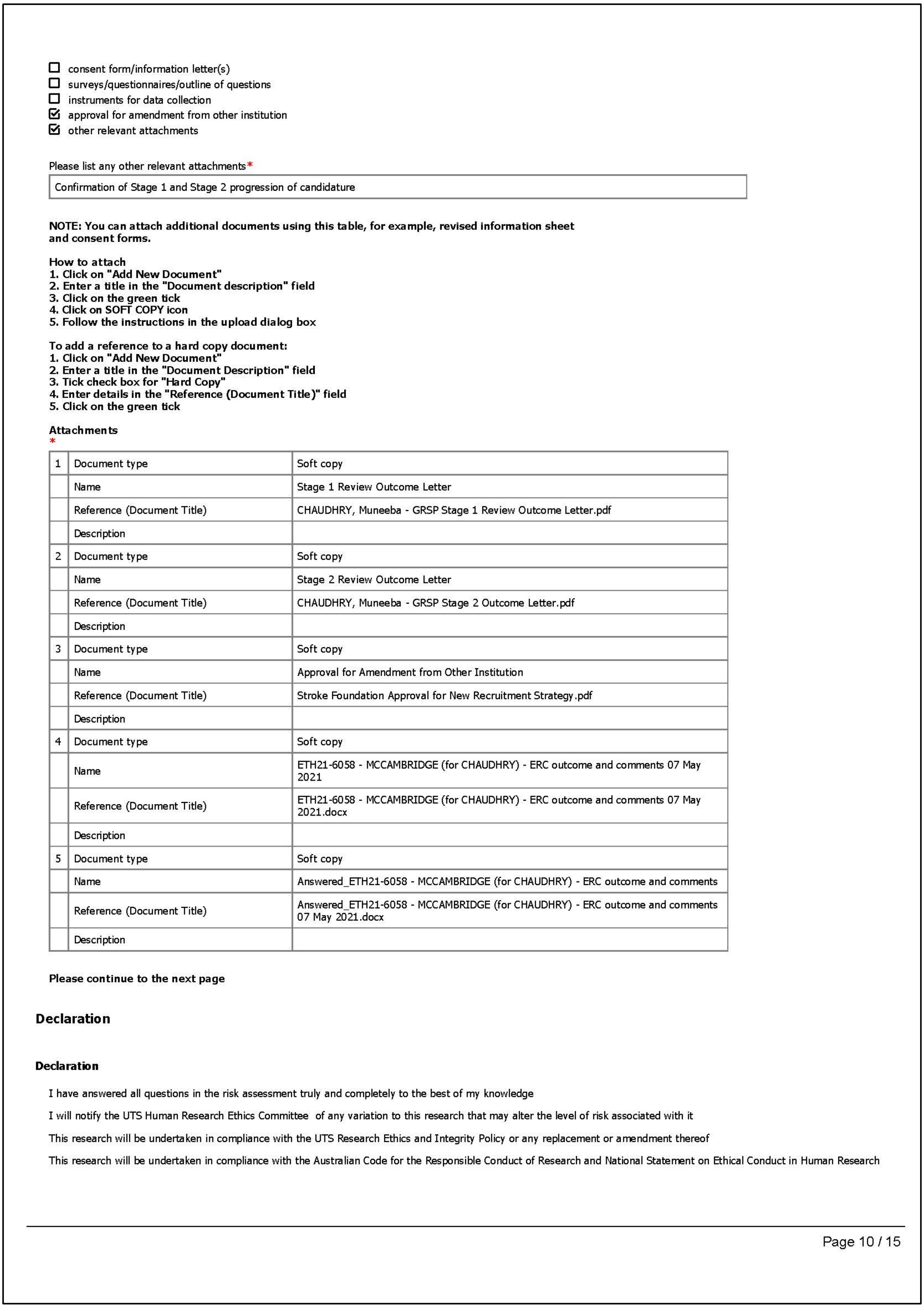
○ Yes
● No

Please continue to the next page

Amendment attachments

We recommend you save your application regularly while editing. You can save your application at any time by clicking on the save button.
For further information and help in completing your application go to our website

I have attached the following supporting documents that require amendment from the approval of my original application:*



☐ consent form/information letter(s)
☐ surveys/questionnaires/outline of questions
☐ instruments for data collection
☑ approval for amendment from other institution
☑ other relevant attachments

Please list any other relevant attachments*

Confirmation of Stage 1 and Stage 2 progression of candidature

NOTE: You can attach additional documents using this table, for example, revised information sheet and consent forms.

How to attach
1. Click on "Add New Document"
2. Enter a title in the "Document description" field
3. Click on the green tick
4. Click on SOFT COPY icon
5. Follow the instructions in the upload dialog box

To add a reference to a hard copy document:
1. Click on "Add New Document"
2. Enter a title in the "Document Description" field
3. Tick check box for "Hard Copy"
4. Enter details in the "Reference (Document Title)" field
5. Click on the green tick

Attachments
*

1	Document type	Soft copy
	Name	Stage 1 Review Outcome Letter
	Reference (Document Title)	CHAUDHRY, Muneeba - GRSP Stage 1 Review Outcome Letter.pdf
	Description	
2	Document type	Soft copy
	Name	Stage 2 Review Outcome Letter
	Reference (Document Title)	CHAUDHRY, Muneeba - GRSP Stage 2 Outcome Letter.pdf
	Description	
3	Document type	Soft copy
	Name	Approval for Amendment from Other Institution
	Reference (Document Title)	Stroke Foundation Approval for New Recruitment Strategy.pdf
	Description	
4	Document type	Soft copy
	Name	ETH21-6058 - MCCAMBRIDGE (for CHAUDHRY) - ERC outcome and comments 07 May 2021
	Reference (Document Title)	ETH21-6058 - MCCAMBRIDGE (for CHAUDHRY) - ERC outcome and comments 07 May 2021.docx
	Description	
5	Document type	Soft copy
	Name	Answered_ETH21-6058 - MCCAMBRIDGE (for CHAUDHRY) - ERC outcome and comments
	Reference (Document Title)	Answered_ETH21-6058 - MCCAMBRIDGE (for CHAUDHRY) - ERC outcome and comments 07 May 2021.docx
	Description	

Please continue to the next page

Declaration

Declaration

I have answered all questions in the risk assessment truly and completely to the best of my knowledge

I will notify the UTS Human Research Ethics Committee of any variation to this research that may alter the level of risk associated with it

This research will be undertaken in compliance with the UTS Research Ethics and Integrity Policy or any replacement or amendment thereof

This research will be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research

Please click on the "Submit" button in the Actions menu.

Confirmation

Confirmation by Local Research Office High Risk

Application type*

Research (student project)

Internal personnel listed on this ethics protocol*

1	Primary	No
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.T.Chaudhry@student.uts.edu.au
	Work Number	
2	Primary	No
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
3	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	+61 2 95147222

External personnel listed on this ethics protocol*

1	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

Please indicate the risk classification of the original ethics approval?*

○ Nil/Neg risk
○ Low risk
● High risk

Please contact the Ethics Secretariat.

Checked by:*

Ed Dharmadji

Date of review:*

20/04/2021

The Research Office has confirmed that: All information in this application and supporting documentation is correct and as complete as possible *

● Yes
○ No

Confirmation by ADR

Application type

Human

Internal personnel listed on this ethics protocol

1	Primary	No
	ID	139831
	Surname	Chaudhry
	Given Name	Muneeba
	Full Name	Miss Muneeba Tariq Chaudhry
	Position	5Research Student
	Type	External
	AOU	GSH.Graduate School of Health
	Managing Unit	Faculty of Health
	Email Address	Muneeba.T.Chaudhry@student.uts.edu.au
	Work Number	
2	Primary	No
	ID	111643
	Surname	Inglis
	Given Name	Sally
	Full Name	A/Prof Sally Inglis
	Position	3Assoc. Investigator
	Type	Internal
	AOU	FoH.IMPACCT
	Managing Unit	Faculty of Health
	Email Address	Sally.Inglis@uts.edu.au
	Work Number	+61 2 95144819
3	Primary	No
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	Co-Supervisor
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	
4	Primary	Yes
	ID	128398
	Surname	McCambridge
	Given Name	Alana
	Full Name	Dr Alana Bernice McCambridge
	Position	Chief Investigator
	Type	Internal
	AOU	GSH.Physiotherapy
	Managing Unit	Faculty of Health
	Email Address	Alana.McCambridge@uts.edu.au
	Work Number	+61 2 95147222

External personnel listed on this ethics protocol

1	Primary	
	ID	PER17-3564
	Surname	Ferguson
	Given Name	Caleb
	Full Name	Dr Caleb Ferguson
	Position	3Assoc. Investigator
	Type	External
	AOU	
	Managing Unit	
	Email Address	c.ferguson@westernsydney.edu.au
	Work Number	

Date of LRO review

20/04/2021

Declaration:

- I am aware that this research is being conducted within this Faculty/School/Centre.
- I am satisfied that the researchers have met all Faculty/School/Centre requirements in relation to this research
- This research will be undertaken in compliance with the UTS Research Ethics and Integrity Policy or any replacement or amendment thereof
- This research will be undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research

*

● Yes
○ No

Comments

This question is not answered.

Appendix E: Study 1 Journal Publication

Contemporary Nurse, 2023
https://doi.org/10.1080/10376178.2023.2262619

User profile of people contacting a stroke helpline (StrokeLine) in Australia: a retrospective cohort study

Muneeba T. Chaudhry[a], Alana B. McCambridge[a], Simone Russell[b], Katherine Yong[b], Sally C. Inglis[a], Arianne Verhagen[a] and Caleb Ferguson[c,d]*

[a]*Faculty of Health, University of Technology Sydney, Sydney, NSW, Australia;* [b]*Stroke Foundation, Melbourne, Victoria, Australia;* [c]*School of Nursing, University of Wollongong, NSW 2522, Australia;* [d]*Western Sydney Local Health District, Blacktown Hospital, Sydney, NSW, Australia*

(*Received 30 May 2023; accepted 17 September 2023*)

Background: StrokeLine is a specialised telephone helpline led by health professionals in Australia.
Aims: (i) To describe the profile of StrokeLine callers; (ii) to understand the reasons people engage with the service and (iii) how StrokeLine responded to the caller's needs.
Methods: Routine call data were obtained from the StrokeLine between November 2019 and November 2020. Data were extracted and descriptive analyses performed. De-identified free-text data were obtained separately for November 2019 and June 2020 and analysed using qualitative content analysis.
Results: Of the 1429 calls most were from carers, family and friends (38%) or the stroke survivor themselves (34%). Most calls were made by women (64%) and the average age of the stroke survivor was ≥65 years (33%) with the time since the stroke occurred <1 year. The main reason for calling was to manage stroke-related impairments (40%). Providing information, support and advice was the most common action provided by StrokeLine staff (25%). Content analysis of 225 calls revealed most stroke survivors called for emotional support, while carers sought more practical guidance. StrokeLine provided information for referral to relevant services and guidance on what to do next.
Conclusions: Most calls were received from family and carers, as well as stroke survivors. They contacted StrokeLine for information and advice, practical solutions, emotional support, and referral advice to other services.

Keywords: telestroke; helpline; stroke; telehealth; selfcare

Impact statement

StrokeLine provides a critical helpline for stroke survivors, their carers, family and friends. StrokeLine staff provide information, emotional support, practical advice and referral advice to other services. The main reason for calling was to seek advice on managing stroke-related impairments.

Plain language summary

This study describes the use of a stroke-specific helpline, collected from callers to StrokeLine (a national stroke helpline). The study found StrokeLine staff provide information, emotional

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*Corresponding author. Email: calebf@uow.edu.au support, practical advice and referral advice to other services. The main reason for calling was to seek advice on managing stroke-related impairments.

Introduction

Stroke is a leading cause of long-term disability worldwide with more than 80 million stroke survivors globally (Johnson et al., 2019). In 2012, the Stroke Foundation (Australia) reported that by 2032, an estimated 700,000 Australians will be living with a stroke-related disability. The impact of stroke is significant and long-term management is often challenging (Boehme et al., 2021). Stroke survivors experience a range of motor, cognitive and psychosocial impairments that persist into the chronic stages of recovery (Hawkins et al., 2017). Approximately two-thirds of stroke survivors will live with residual cognitive or functional impairment, including limitations to mobility, sensation, balance and communication (Arienti et al., 2019; Broussy et al., 2019). Other residual effects such as depression, fatigue and pain further reduce quality of life (Broussy et al., 2019).

Care needs change and evolve, at each stage of recovery (Chen et al., 2019). As with most chronic conditions, sustainable recovery relies on engaging stroke survivors and their family caregivers to promote self-management of their condition (Taylor et al., 2014; Walsh et al., 2015). Stroke survivors report low satisfaction with post-discharge education and information provision, especially addressing long-term management of disability and accessing support services (Ferguson et al., 2016; O'Connell et al., 2009). Stroke survivors express feelings of abandonment, when they require navigate between complex transitions of care through the often-fragmented healthcare system (Ghazzawi et al., 2016; Wissel et al., 2013). Improvements should be made to the continuity of care provided to stroke survivors and their families after being discharged from hospital (Ferguson et al., 2016). focusing on patient-centred support, and interventions that support transition (Pearce et al., 2015).

Telehealth-based models of stroke care may be key to supporting stroke survivors in transitioning between care settings (Schwamm, 2019). Phone-based services are thought to play an integral role in the ongoing care of people living with chronic health conditions, especially in facilitating cost-effective support for self-management of care (Hanlon et al., 2017; Taylor et al., 2014). Specialised helplines allow healthcare professionals to provide timely and relevant information and advice to support a caller's immediate needs (Ekberg et al., 2014). It is therefore important to understand the role of such services in addressing the needs of the caller.

In Australia, the Stroke Foundation is a not-for-profit organisation that provides information and advice services to people affected by stroke, as well as advocacy for prevention, management and support for people affected by stroke. Among these services, StrokeLine has existed since 2002, as a nationwide stroke-specific helpline that allows users to make inbound contact with a qualified registered health professional (such as nursing or allied health professional), via phone, email, or social media. The helpline supports stroke survivors, their families and friends and aims to educate the wider community on stroke detection and prevention.

Research into phone-based services aims to improve our understanding of how telehealth services are currently being used to obtain information and advice, and what role the service plays in attaining a successful outcome for the caller (Harding et al., 2018). Analysis of phone-based support services could reveal common issues people living with stroke experience, and whether these issues can be resolved using phone-based intervention. Few studies have described how callers use stroke-specific phone services (Dickerson & Forster, 2015; Hanger & Mulley, 1993). and no previous study has described an Australian service. Therefore our aim is (1) to describe the callers engaging with StrokeLine; (2) their reasons why they contacted the service; (3) and to describe the actions taken by StrokeLine in response to the callers' needs.

Methods

Design

A retrospective cohort study using routine call data from the StrokeLine customer relationship management (CRM) system. Ethical approval was provided by the Human Research Ethics Committee at the University of Technology Sydney (Ref: ETH20-5088). Data transfer was approved by the Stroke Foundation (Australia) (19/02/2021).

Database

The CRM system collects data throughout a total episode of a caller's care. An episode of care was defined as one or more episodes of service provided by StrokeLine to address a caller's needs, with an episode of care ending only when no further service delivery is expected by the caller. An episode of service was any occasion of service delivery and can include other methods of delivery such as email follow-up. For each episode of care, demographic details about the caller and reasons for the call are recorded using pre-defined categorical variables by StrokeLine staff. A combination of predefined responses and free-text boxes capture user information such as constituent type (i.e. a stroke survivor, carer, family etc.), caller's age range, gender, when the stroke occurred, language spoken, where the caller is calling from and if the caller identifies as Aboriginal or Torres Strait Islander. Call information about reasons for calling was logged under predefined categories such as current symptoms, risk factors, prevention, health service treatment and care, community services treatment and care, managing stroke impairments, adjustment coping, practical issues, vulnerability, and risk. The pre-defined categorical variables related to why a person was seeking care included practical issues (e.g. accommodation, driving, finances), adjusting/coping issues (e.g. family relationships, occupation) and the type of health service treatment and care being sought (e.g. questions about tests and treatments, access to rehabilitation). A summary of the episode of care was entered by the staff member using free text outlining the issues discussed and actions taken. Evidence of any email follow-up provided to the caller is also attached to each call record. The total duration spent on each case was noted as the combined total of one or more episodes of service associated with the episode of care. The total time spent on other tasks (e.g. follow-up emails, calls to others) associated with each episode of care was recorded under 'call liaison'. We obtained categorically logged calls from the StrokeLine CRM system between 1 November 2019 and 30 November 2020. Free-text call data from the StrokeLine CRM system was supplied for two separate months: November 2019 and June 2020. All data were provided by StrokeLine as an Excel file and organised under variable labels and codes. We excluded cases from people living outside of Australia, public enquiries not related to the support of a stroke survivor and enquiries from health professionals. All identifying information was de-identified by a volunteer of the Stroke Foundation prior to data transfer to researchers.

Analysis

Microsoft Excel was used to analyse categorical variables and NVivo to analyse the free-text data. Data cleaning was undertaken to detect and remove duplicates, incorrect or unexpected data that could not be verified. The proportion of missing data for each variable was calculated and reported.

To understand 'who' was contacting StrokeLine, demographic data were presented as frequencies and proportion of total calls over months. To understand 'why' people were contacting StrokeLine, categorical data about the reason for the call was described and free-text data stored under 'Issue' in the CRM system was coded using content analysis (Graneheim & Lundman, 2004). To understand 'what' was provided by StrokeLine, the type of action provided was determined using content analysis of the free-text data stored under 'Description' and 'Actions/Plans' (Graneheim & Lundman, 2004). Finally, the 'Call Log History' outlining the summary of interaction between the caller and StrokeLine staff was analysed using content analysis to understand the number of interactions required to resolve the issue.

Results

Dataset

The StrokeLine data set contained 1429 individual cases and 159 variables. Unfortunately, many of the categories contained no data at all (missing data), some categories contained repeated data and several categories had only a few cases (Supplementary 1).

The number of calls received varied between 80 and 140 calls per month (an average of 109 per month). Most calls originated from Victoria, Queensland and New South Wales (Figure 1). Call duration ranged from 15 to 30 minutes (*n*=352, 25%), less than 15 minutes (*n*=263, 18%), 30 minutes to an hour (*n*=218, 15%), an hour to two hours (*n*=23, 2%) and 1 call (0.07%) taking over 3 hours.

Population

Most calls received were from carers, family members or friends (*n* = 545; 38%) or stroke survivors (*n* = 482; 34%). Only 86 calls (6%) were received from a person not having a stroke, but indirectly affected by stroke and 6% (*n* = 86) from donors to the foundation. Three percent of calls (*n* = 43) were recorded as volunteers and advocates and were excluded from analyses. Callers were 31% (*n* = 443) female and 11% (*n* = 152) male, and 51% (*n* = 734) of calls had no record of gender.

There were 778 calls (54%) where the age of a stroke survivor was recorded. Most of the callers were aged over 50 years (*n* = 618; 79%) and only 3 calls concerned a person under 18 years. Time since the stroke had occurred was reported for 822 calls (58%), with most callers concerned about a stroke that occurred less than a year ago (*n* = 566; 69%). There were also 67 calls (5%) where the caller was potentially experiencing stroke symptoms with further medical attention required.

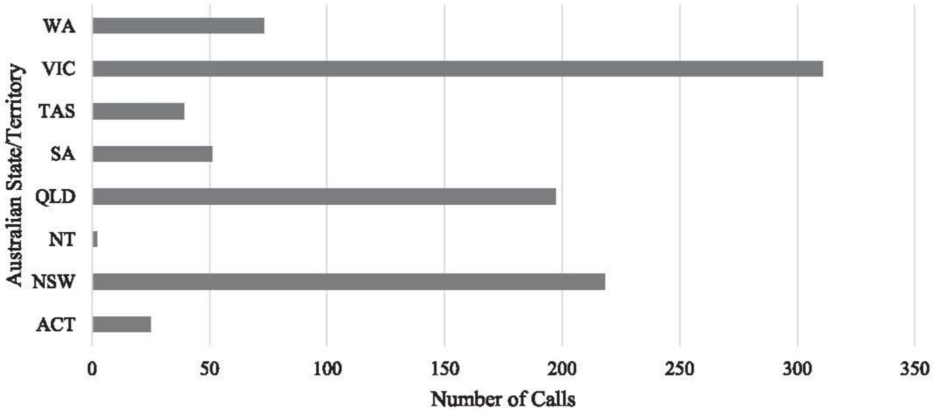

Figure 1. State-wise distribution of StrokeLine calls between 1 November 2019 and 30 November 2020.

Only 88 calls (6%) indicated whether a caller identified themselves as Aboriginal or Torres Strait Islander. Of 425 calls (30%) the data provided information about languages spoken at home, including English (29%), Russian (0.14%), Greek (0.14%), Dutch (0.07%) and Korean (0.07%).

There were 394 calls (28%) that provided information on pre-existing risk factors for stroke categorised under 19 variables, including high blood pressure (5%), high cholesterol (4%), cardiovascular disease (4%) and atrial fibrillation (1.5%). Vulnerability and risk for depression, drug and alcohol use, family violence and suicidal ideation were captured for only 67 calls (5%).

Reasons for calling

The reason for calling were captured under seven different categories (Supplementary 2). Most calls were categorised as ‘Managing stroke impairments’ and ‘Community services treatment and care’.

Actions provided by StrokeLine

The type of actions provided were reported for 404 calls (28%). These included 362 calls where information, support, advice, or referral was provided, for 20 calls a ‘brief intervention’ (such as informal counselling for health promotion or disease prevention) was provided, and for 17 calls a letter or call to someone else was provided and for 4 calls (0.3%) provided with care coordination (Supplementary 3).

Free-text data

The free-text dataset included 103 calls from November 2019 and 122 calls from June 2020, with a similar number of calls received by stroke survivors and carers/family across the two months (Supplementary 4 and 5). Data were categorised into four themes:

Issue

Most calls from stroke survivors across both months included seeking emotional support, especially in seeking reassurance of post-stroke-related impairments, including both ongoing physical and cognitive symptoms. Most calls from carers/family included seeking practical guidance on how best to support a stroke survivor, especially regarding managing a stroke survivor’s cognitive decline and transition from acute hospital care.

Description

Calls from both stroke survivors and carers were often prompted by a lack of information or when all other avenues of seeking guidance had been exhausted.

Action plan

For both November 2019 and June 2020, most calls received by stroke survivors concerned providing information on how to best manage their stroke-related impairments, along with providing reassurance and validation of the individual’s experience with managing these. For carers/family, StrokeLine staff most often provided guidance and advice on what to do next regarding stroke survivors’ care.

Emails and comments

Calls answered on the first try included 90 calls (87%) in November 2019 and 15 calls (12%) in June 2020. In November 2019, a voicemail or message left with reception was the first point of contact for 13 calls (13%), with a call-back provided by StrokeLine to initiate further episodes of service to resolve the issue. This was similarly the case for 107 calls (88%) in June 2020. Email follow-up after the call was provided for 38 calls (37%) in November 2019 and 29 calls (24%) in June 2020. Most email follow-ups provided included links to resources discussed during the call (eg. information sheets, websites or video links about stroke-related impairments and community services).

Discussion

Most calls received were from stroke survivors and carers, family members or friends. Most callers were female, 65 years or over, and related to a recent stroke. However, those who identify as Aboriginal or Torres Strait Islander descent may have been under-recorded in these data. The need for an interpreter was also the main method of identifying culturally diverse callers, which again are assumed to be underrepresented in these data. The main reasons to call StrokeLine were related to health or community services for treatment and care and how to manage stroke-related impairments. A lack of direction around '*what to do*' and '*where to go*' were common motivating factors prompting someone to call StrokeLine. In most instances, people contacted StrokeLine, when previous avenues for seeking information were exhausted, or they were dissatisfied with the quality of care provided in other settings. Most often, StrokeLine staff provided both stroke survivors and carers with actionable items to discuss with their GP or specialist and helped formulate a plan of how to do this. For stroke survivors, StrokeLine provided reassurance and validation of the individual's experience with managing stroke-related impairments.

The geographic location of the caller was limited to only the state/territory the call was received from, with most calls received from Victoria and New South Wales (NSW). The strength and relevance of telehealth services lie in their cost-effectiveness and ease of accessibility. As such, it is important to understand the specific remote, regional, or metro locations of callers to provide better insight into what concerns are prompting enquiries both in the absence or presence of other healthcare services in each area.

Interpretation

StrokeLine's ability to provide practical guidance is well aligned with studies reporting on the importance of social support from friends, family or stroke support groups in helping to normalise experiences (Jones et al., 2013). Such informal methods of accessing support emphasise the importance of self-management as a collective experience rather than one undertaken in isolation. One study found that when services designed to aid in self-management of care in stroke fail to account for individual needs and circumstances, the relevance of the information provided is unconducive to real behaviour change and addresses only basic educational needs (Jones et al., 2013). The real underpinning of supporting self-management relies on organisational structures that facilitate a relationship between individuals and health care professionals, allowing for the time and flexibility to enable active problem solving and shared decision-making. In many ways, the StrokeLine database is reflective of the complexities of stroke and the multi-faceted ways it can affect an individual. This study has highlighted the complexities of balancing person-centred care provision in a telehealth setting with data-driven processes that are needed to best support this.

Limitations

A major limitation of our study was the volume of missing data. Although all information under each category should be collected during an episode of care, in most instances it appeared a data summary for each call was recorded instead using free text and much of the categorical data was left blank. This resulted in a considerable amount of missing data under most categories, but some of this data was able to be retained through content analysis of the free-text summary. Secondly, it was only feasible for StrokeLine to provide us with two months of de-identified free-text data for analysis and this may have influenced our findings, due to seasonal variation for example. Thirdly, we also did not include enquiries received via email or social media in analyses. Despite these limitations, a major strength of this study is the ability to provide a unique user profile and evaluation of the StrokeLine service in Australia.

Implications

Clinical implications

Findings from this study can be used to improve service delivery of StrokeLine and other comparable health care services. Exploring retrospective data collected routinely as part of service provision allows for an insight into the way a helpline works and can benefit the callers as well as their carers/family.

For StrokeLine, the current study highlights the express need for better processes to capture data and data infrastructure capabilities to support these. In turn, the need for appropriate staffing and training remains paramount. As the StrokeLine CRM system continues to evolve and the data entry procedures become more streamlined, improvements in the quality of the service are likely to better inform strategic planning and increase outreach. An ongoing challenge will be ensuring that the StrokeLine data infrastructure remains well supported by appropriate staffing and data-management procedures. With the remarkable growth of telehealth-based innovation in recent years, translating this to existing services to better adapt their role within a changing digital landscape should not be neglected. Building on StrokeLine's existing capabilities, further work may look at service redesign to better capture those not actively seeking support to self-manage their condition, especially in the earlier stages of transitioning between care settings. Incorporating a greater outreach component to the current inbound service model may enhance the role StrokeLine plays in providing continuity of care.

Research implications

Appropriate funding and support from policymakers are needed to improve the quality of the data collection and improve the validity and generalisability of the findings. Several changes in data collection procedures have been implemented by StrokeLine following this study. As such, routinely reviewing caller information is an important component of improving service delivery and ensuring the service remains relevant to those affected by stroke. Further research is needed to understand how people are using the information and advice provided by StrokeLine and whether there are measurable benefits of contacting the service.

Conclusion

This study describes the utilisation of a stroke-specific support helpline by people affected by stroke. Understanding the issues prompting callers to seek care and what can currently be offered by StrokeLine staff, provided insight into the needs of survivors and potential gaps within stroke care in Australia. Inbound helplines such as StrokeLine are well-placed in disseminating timely and person-centred information and advice across the trajectory of stroke care.

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Disclosure statement

CF is a member of the Stroke Foundation (Australia) Research Advisory Committee. SR and KY are employed by the Stroke Foundation (Australia).

Guarantor: CF.

Contributor statement

MTC, AM and CF contributed to the conceptualisation and design of the study. MTC, AM, CF, SR and KY contributed to the acquisition and collection of data. MTC, AM, CF, SR, KY, SCI and AV contributed to the analyses of data and report writing. All authors approved the final version of the manuscript.

Data availability statement

Due to the sensitive nature of the data collected for this study, requests to access the dataset from qualified researchers trained in human subject confidentiality protocols may be sent to the corresponding author.

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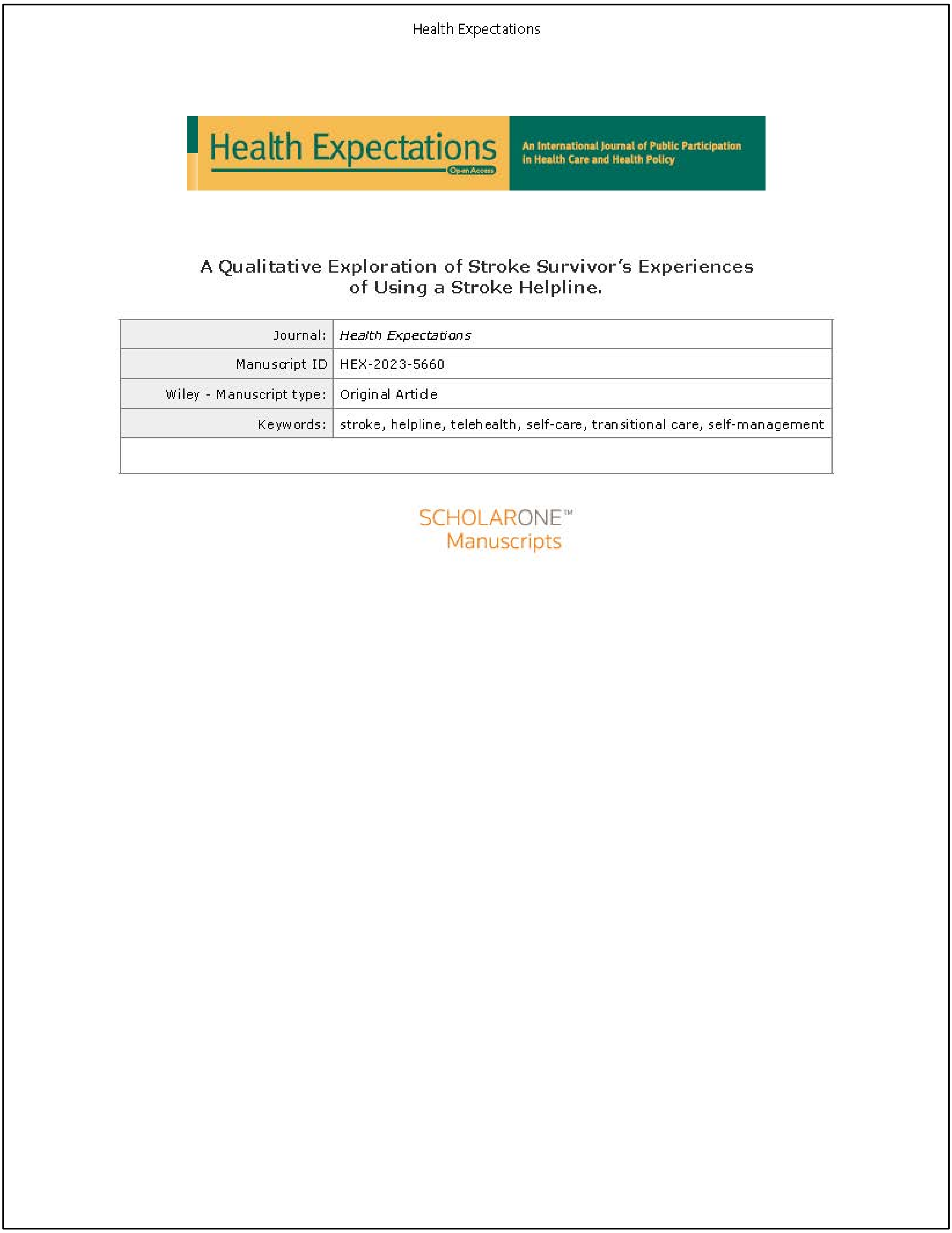
Appendix F: Study 2 Journal Publication



Health Expectations

Health Expectations

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A Qualitative Exploration of Stroke Survivor's Experiences of Using a Stroke Helpline.

Journal:	*Health Expectations*
Manuscript ID	HEX-2023-5660
Wiley - Manuscript type:	Original Article
Keywords:	stroke, helpline, telehealth, self-care, transitional care, self-management

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ABSTRACT

Background: StrokeLine is a stroke-specific helpline used by stroke survivors and their families in Australia to access professional support. There has been little research that explored stroke survivors' experiences of using helplines and their perceived impact on their stroke recovery.

Aim: To explore the reasons prompting stroke survivors to call StrokeLine , their experiences, and describe the perceived impact of calling StrokeLine on their recovery.

Methods*:* An exploratory descriptive qualitative study was undertaken using thematic analysis of data collected through semi-structured interviews of stroke survivors between December 2020 and May 2022. Participants were recruited using purposive. Interviews were conducted via audio recorded Zoom conference calling and transcribed verbatim for thematic analysis.

Results: A total of eight callers (4 men and 4 women) participated, with the time since stroke ranging from between 3.5 months to 5 years. Four major themes were identified, including 17 sub-themes. Key themes included; 1) factors prompting use of StrokeLine; 2) experience of using StrokeLine; 3) perceived impact of using StrokeLine; and 4) conceptualising StrokeLine service provision.

Conclusions*:* Participants perceived their experience of contacting StrokeLine as having a positive impact on their stroke recovery, leaving them feeling empowered and motivated to self-manage their condition.

Patient or Public Contribution: Stroke survivors with lived experience influenced the conceptualisation of this study through conversations with consumers and the Stroke Foundation. Eight stroke survivors were involved as participants in the research study.

INTRODUCTION

In Australia alone, the number of people living with the long-term sequelae of stroke will increase to an estimated 700,000 people by 2032 (1). The physical and psychosocial impacts of stroke are significant, with care needs evolving at every stage of recovery (2, 3). As with most chronic conditions, facilitating self-management in stroke is essential to empower survivorship and reduce the burden on health-systems (4, 5). Currently, there remains a low-level of satisfaction with information provided after discharge from formal care in acute settings, particularly around long-term management of disability and accessing follow-up services (6, 7). Stroke survivors who require support to navigate between transitions of care through the healthcare system report a feeling of abandonment (2, 3). Telehealth-based care may be helpful in providing effective self-management support to stroke survivors across the continuum of stroke recovery.

Telephone-based services, such as helplines, are able to provide access to timely support (8). Specialised helplines led by qualified health professionals exist globally for chronic conditions such as cancer, mental health and heart disease, helping to facilitate self-management of care (4). An international study exploring the rationale, experience and impact of seeking care using telephone-based support for cancer found that callers were able to better understand their situation, facilitating further engagement with other cancer services (9). In addition, a Swedish rheumatology helpline was effective at enabling constructive dialogue and providing motivational support for callers who had problems obtaining answers from other care settings (10). Ensuring telehealth-based care is relevant to the needs of the user is important to ensuring services remain sustainable in the future (11). Globally, Stroke helplines exist in the United States of America and as part of the NHS in the United Kingdom. However, research into helplines for stroke survivors remains scarce.

In Australia, StrokeLine operates nationwide and is a free inbound phone-delivered stroke support service provided by the Stroke Foundation, a not-for-profit organisation (and Australia's peak body and national voice of stroke), providing resources for those affected by stroke. The service operates from a single site (based in Melbourne, Australia) between routine business hours on weekdays and is staffed by qualified health professionals from a nursing or allied health background who can be contacted via phone, email, or social media. StrokeLine staff offer advice and support to stroke survivors and their families, health professionals and the public. The role of telehealth-based support services for stroke survivors is not well understood and the impact of telephone-based stroke care in needs further investigation. To date, research into stroke helplines is extremely limited, focusing only on user characteristics and a limited understanding of how they are used (12, 13). There is no research that has explored caller experiences of contacting a stroke helpline and little is known about how stroke survivors perceive their encounter with such a service.

The aims of this study were to i) explore the reasons that prompt stroke survivors to use a stroke helpline and secondly; and ii) to examine the perceived impact of the encounter on their stroke journey.

METHODS

Design

This study followed a qualitative exploratory design and was guided by the consolidated criteria for reporting qualitative research (COREQ) (14). Data were collected using semi-structured interviews with stroke survivors between December 2020 and June 2022 to explore their experiences of using StrokeLine, a telehealth-based support service. Informed consent from participants was obtained verbally using a scripted checklist at the beginning of each interview. Ethical approval for this study was granted by the Human Research Ethics Committee at the [redacted] (no.: ETH20-5088).

Participants and Recruitment

Inclusion criteria: Participants must have had a stroke at any time, be 18 years or older, had contact with StrokeLine in the past 3 months, be able to communicate in English, have access to and be able to use conference calling and be able to provide verbal consent. *Exclusion criteria:* People who had contacted StrokeLine and were health professionals, members of the general public, and those not affected by stroke including carers and family members.

Stroke survivors with aphasia were not explicitly excluded from this study, as suitability for inclusion would be determined on a case-by-case basis in conjunction with an expert Speech Pathologist familiar with qualitative interviewing strategies for people with aphasia.

The Stroke Foundation in Australia assisted with recruitment of participants for the study, through study advertisements included in monthly Stroke Foundation newsletters, on Stroke Foundation and authors' social media channels (e.g. Twitter and Facebook) and online forum posts associated with the Stroke Foundation's EnableMe (stroke survivor platform) service for stroke survivors and their carers. StrokeLine staff also sent pre-scripted emails directly to callers who were stroke survivors in two recruitment cycles, capturing only callers who had called StrokeLine in the preceding 3 months.

Potential participants contacted the researchers and an information sheet about the study was emailed to them prior to being screened over the phone for inclusion. If a participant was deemed eligible, an interview time with the researcher was scheduled within a week.

Procedures

Prior to each interview, the participant informed the researchers of their age, location, time since stroke, if they lived alone and whether they identified as an Aboriginal or Torres Strait Islander. Due to the COVID-19 pandemic and recruitment of participants across Australia, all interviews with participants were conducted online using audio recorded Zoom conference calling. Interviews were conducted by a qualified member of the research team with a duration of 25 to 40 minutes. The interviewer ([redacted]) was a female, Accredited Exercise Physiologist (AEP) experienced in working clinically with stroke survivors, during their recovery and rehabilitation. The interviewer was also supervised and mentored in the conduct of qualitative interviewing by a more experienced member of the research team ([redacted]). A standardised interview guide was followed to ensure key questions remained consistent across participants. Interviews were semi-structured and directed by participant narratives around their experiences of using StrokeLine. The interview guide is supplied as supplementary materials.

Purposive sampling was used. Time since stroke was categorised as either acute, sub-acute or chronic as defined by Bernhardt, Hayward (15). Geographic location was categorised as either metro, rural or remote based on the Australian Statistical Geography Standard (ASGS) – Remoteness Area framework (16).

Data Analysis

Each interview was audio-recorded and later transcribed verbatim for analysis. All identifying features of the data were removed before being shared amongst the research team. Written field notes were kept to aid with transparency of data collection. Interview transcripts were sent to participants for review to validate the data collected (17).

Data from transcribed interviews were analysed using a data-driven inductive latent approach to thematic analysis. Transcripts were read multiple times to aid familiarisation and coded into categories using Excel (18). Next, data were broadly coded by two independent assessors (MC & ER) themes were agreed by consensus. Themes were reviewed, defined and named (18). For each theme, sub themes were also named and identified. The two assessors discussed the analysis to ensure participant views were interpreted through multiple perspectives at each step (18). Data were coded as the interviews and the interviews were transcribed immediately after each interview.

RESULTS

Study Population

Eight callers (4 men and 4 women), ranging in ages from 28 to 82 years were included **– see Table** 1. The time since stroke ranged from between 3.5 months to 5 years, with callers either in the chronic (n=4) or sub-acute stage of recovery (n=4). Callers were from 4 different states in Australia with callers located in either a metro area (n=4) or regional area (n=4) at the time of the call. None of the participants identified themselves as being Aboriginal or Torres Strait Islander (**Table 1**).

Table 1. Characteristics of Participants

Participant	Age at the Time of Interview	Gender	Time Since Stroke	Stroke Recovery Stage*	State	Geographical Classification±	Living Alone
1	62	Male	5 months	Sub-acute	QLD	Metro	Yes
2	82	Female	3 years	Chronic	SA	Regional	Yes
3	79	Female	8 months	Chronic	SA	Metro	No
4	54	Male	4 months	Sub-acute	NSW	Regional	Yes
5	57	Male	5 years	Chronic	VIC	Metro	Yes
6	44	Male	3.5 months	Sub-acute	SA	Regional	No
7	28	Female	6 months	Sub-acute	NSW	Metro	No
8	47	Female	4 years	Chronic	QLD	Regional	No

*As defined by Bernhardt, Hayward (15) based on time since stroke

±Based on the Australian Statistical Geography Standard (ASGS) – Remoteness Area framework (16)

Thematic Analysis

Findings from a systematic review suggest that interview studies necessarily require large sample sizes to reach saturation. Furthermore, a homogenous study cohort may require lower sample sizes to reach saturation with participants ranging from 9 to 17 interviews. This is more likely to occur within an objectively defined scope of exploration (19). Four major themes were identified, including 17 sub-themes. Key themes included 1) factors prompting use of StrokeLine, 2) experience of using StrokeLine, 3) perceived impact of using StrokeLine and 4) conceptualising StrokeLine service provision (**Figure 1**).

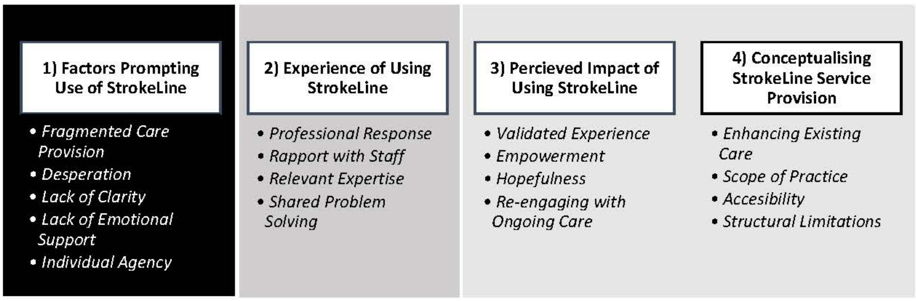

Figure 1. Themes and sub-themes across the call process

Theme 1: Factors Prompting Use of StrokeLine

[Sub-theme: Fragmented Care Provision] Participants discussed a lack of follow-up from health professionals following discharge from hospital. Responses often noted very little direction given by healthcare professionals or other stroke services of what to do and where to go next. Participants also felt neglected by the healthcare system.

> *"...I spent about an hour and a half with the specialist and that's it. That was the end of my care in relation to my stroke. So there was no follow-up. They gave me a mobile phone number to call the stroke clinic and made it very clear that if I ever had any questions, any concerns, I was to call that number, and if I didn't get through, I was to leave a message and they would get back to me. I must have rung that number 10, 15 times and never had a response. No one's ever picked it up, and no one has ever returned the phone call." (P6, male, sub-acute)*

Participants, however, noted receiving an information pack when discharged from the hospital. Most called StrokeLine only after finding the number for the service in an information pack (such as MyStrokeJourney), after some time had passed once they were home.

> *"The only information they gave me at the hospital when I left was a leaflet." (P6, male, sub-acute)*

[Sub-theme: Desperation] Participants often contacted StrokeLine as a 'last resort', only after exhausting all other known avenues of seeking solutions to their problems or after no longer knowing where to turn.

> *"...and it was a call of last resort because I still can't work out who I'm meant to talk to. I have no mechanism of getting in contact with anyone that can provide me with advice at all." (P6, male, sub-acute)*

> *"I think I rang on both occasions because I had exhausted my own mental and psychological resources - that's the point that I was at to make that phone call." (P5, male, chronic)*

[Sub-theme: Lack of Clarity] Participants contacted StrokeLine seeking clarity around their concerns. Concerns themselves were often complex, compounded by conflicting information, advice and support needs. As such, there was never a singular reason for contacting the service.

> *"I felt that I wasn't getting enough information from the medical profession that I felt made sense for me. And I'm one of these people, that I'm on a need to know basis. If I understand as best one can what's happening for you, then you can manage the situation. But if you don't know what's happening, you can't manage it because it's sort of a blind spot. And so to me it was logical because it was sort of to do with the stroke...that they were the logical people to perhaps give me some answers or at least point me in a direction that will be useful in terms of managing what was happening for me at the time." (P1, female, chronic)*

[Sub-theme: Seeking Emotional Support] Along with seeking clarity and practical guidance, StrokeLine calls were often driven by participants' emotional states. Often calls were prompted with no real direction and very limited expectations, as participants sought out the service to make sense of their changed circumstances, under heightened emotional distress.

> *"I was quite keen to talk to someone who might have some level of understanding of what I've experienced and what is normal and what isn't normal." (P6, male, sub-acute)*

[Sub-theme: Individual Agency] Participants all revealed individual agency in their active involvement in seeking control of their current situation, prompting them to call StrokeLine and initiate continuity of their own care.

> *"It wasn't until it became quite evident that there was no support whatsoever in the process that I had experienced that I thought, well, I better be proactive here and I rang the StrokeLine." (P6, male, sub-acute)*

Theme 2: Experience of Using StrokeLine

[Sub-theme: Professional Response] Participants valued the way in which StrokeLine responded to their first contact. In particular, participants appreciated the timely and professional response of StrokeLine staff, even when their call was not answered on the first try.

> *"So, I rang up and there was no one to answer my call and I left a message. And on both occasions the person got back really quickly. Like impressively quickly, as in when you leave a message you rarely get a call back in any... and on the first occasion - I got a call back from the lady, from one of them. And then another one of the ladies called back at the same time and I said, "Well, I think I'm already talking..." The response was impressive and the response was impressive like twice over." (P6, male, sub-acute)*

[Sub-theme: Rapport with Staff] Participants experienced good rapport with StrokeLine staff during their contact. They felt comfortable sharing sensitive information about their experiences and perceived a sense of familiarity when interacting with StrokeLine staff. Most participants emphasised how they did not feel patronised when sharing their concerns and instead felt listened to.

> *"I didn't feel like I was ringing up and there was a script that was being followed to provide me with guidance. I felt it was quite personal experience to what I experienced and it felt like... so the effectiveness of it, I think it was quite effective from that perspective." (P6, male, sub-acute)*

[Sub-theme: Relevant Expertise] Participants not only understood StrokeLine staff to be experienced enough to provide advice based on their professional qualifications and expertise, but also appreciated they had knowledge relevant to all aspects of their stroke care.

> *"I think the balance that you've got with the people that you have on the stroke hotline for me was ideal. It wasn't someone who had had a stroke, but I felt that they had - well, maybe they have, I have no idea, I couldn't tell - and they were able to provide me with caring advice." (P6, male, sub-acute)*

[Sub-theme: Shared Problem-Solving] Participants appreciated the way in which their concerns were addressed by StrokeLine staff, particularly in being included in the process and not simply being given the answers someone else thought they needed.

> *"...she gave me direction and a sense of purpose. I think which was...there was another person saying, "I now have heard what you're experiencing and I think that what you're experiencing warrants you should go and see your GP and you should go and take this course of action". And I think that was an important thing to gain from that conversation, which I haven't got anywhere else, not even from the GP when I talk to them." (P6, male, sub-acute)*

Theme 3: Perceived Impact of Using StrokeLine

[Sub-theme: Validation of Experience] Participants felt their experiences after having a stroke were validated and that there was value placed on the significance of their changed circumstances. In doing so, most participants felt they could allow themselves to better accept what had happened.

> *"She accepted what I said - she didn't sort of dismiss it as being trivial or not consequential. So for me, that was really good being confirmed in that way, that I had concerns that really needed to be looked at seriously, which was good." (P1, female, chronic)*

[Sub-theme: Empowerment] Participants felt empowered after contacting StrokeLine and felt better able to take charge of their care. They perceived their contact with StrokeLine equipped them with the skills they needed to be able to do things themselves.

> *"...and as a result... I listened to some podcasts, I downloaded books, and then I felt like I had more control about the experience that I was having." (P6, male, sub-acute)*

[Sub-theme: Hopefulness] Participants felt hopeful after their contact with StrokeLine, particularly in feeling like they could now get through the difficulties they experienced from stroke.

> *"I'm trying to regain as much independence as I can, and people keep telling me how well I'm doing. And I think, you know, yes I have come a long way." (P1, female, chronic)*

> *"So there was that little glimmer of hope that things might go a different way and I might be able to go back to getting the therapy that I felt I felt justified in asking for." (P6, male, sub-acute)*

[Sub-theme: Re-engaging with Ongoing Care] Participants felt motivated to take appropriate action in response to their needs, noting their contact with StrokeLine prompted them to better engage with their post-stroke recovery.

> *"But they gave me the confidence to actually move on and say, okay, this needs other attention." (P1, female, chronic)*

> *"I still felt overwhelmed about everything but I suppose there was that little bit of me that also was thinking that there is some light there and 'I' need to do something about it. So that was the thing. And I've learned that everybody has to fight for themselves. So nobody's going to knock on my door and say, " Hey, come and be part of the acquired brain injury unit." You've got to go out there and I suppose pipe yourself." (P6, male, sub-acute)*

Theme 4: Conceptualising StrokeLine Service Provision

[Sub-theme: Enhancing Existing Care] Participants noted that they did not know what to expect when first calling StrokeLine. After the call, however, participants understood the service to be valuable in enhancing their existing care and they would use it again.

> *"As I said I've engaged with the process on two occasions and I guess they've sort of like been little stable points in quite a confusing, disjointed process where I guess I needed that contact at those times and have been aware since the first time that if I needed that I could reach out again and obviously get a great response. Not with an expectation that all of my answers would be there but there would be someone to listen to what I had experienced and give me some advice even if it's advice that I was aware of - just like having someone else tell you that this is something that you should do is quite powerful on occasions, you might know where the resources are, you might know what the prudent thing might be to do - like going visit your GP - but until someone articulates that and says it out loud, it's like maybe you don't get around to doing it." (P6, male, sub-acute)*

> *"StrokeLine performed better than any other part of this system that I've stepped into." (P6, male, sub-acute)*

[Sub-theme: Scope of Practice] Participants understood that StrokeLine staff were unable to provide them with aspects of care that were 1) professionally outside the scope of practice of StrokeLine staff and 2) outside the scope of telehealth-based service provision offered by StrokeLine.

> *"The lass* [female] *I spoke to was very good at listening and asking me questions that I felt were really relevant. And although I didn't expect a diagnosis - obviously they're not in that sort of category. She did point me into a direction, like she did say to me, you probably need to make an appointment with a neurologist." (P1, female, chronic)*

> *"I think I have a better appreciation of what can be offered having contacted them twice. I know even though I would love someone to be able to sort out the hassles I've got with the bureaucracy around the medical system, I know that they are not able to do that..." (P6, male, sub-acute)*

[Sub-theme: Accessibility] Participants appreciated the value of StrokeLine existing as a telehealth-based service, particularly in regards to the immediate availability of support from the service and the ability to improve access to care for people living in areas with limited post-stroke services.

> *"You can just call the number and they're there." (P8, female, sub-acute)*

> *"Well, I think accessibility and particularly, as I said previously, for regional people - and rural people would have the same issue. And I think it's a huge issue because I was talking to someone this morning and things are still [capital city]-centric. Nothing happens beyond our [capital city]. And so I think being aware that there are people out there in remoter areas that really would find a service like this useful." (P1, female, chronic)*

[Sub-theme: Resource Limitations] All callers understood there to be potential resource limitations with the StrokeLine service, particularly around staffing that led to delays in response time. Feedback around effectiveness of service provision consequently centred around the preference for calls to be answered on the first try, suggesting the need for improvement in this area.

> *"I felt frustrated that I had to leave a voicemail at first. I understand though, that's because they can't answer everyone's calls and there's a lot of people that call. But I think the actual service is very good and effective. Yeah. The one thing I found tricky was the leaving the*

> *voicemail and then also having to wait. You know, sometimes you might call because you're feeling something right in that moment, and you might want support right then. And then they call back when they're free an hour later or whenever it is, and you might not want to talk about it anymore, I guess, even though it's still...the emotions are still there, you might just not want to speak about it then." (P8, female, sub-acute)*

> *"They need to revamp their answering machine because it leaves you with the feeling there's no one there. It's the way it's expressed. It needs to say something like "all our professional workers are busy at the moment" rather than saying "there's no one here" or sort of thing and you're left with the feeling of should "I ring back or not?" (P1, female, chronic)*

DISCUSSION

Stroke survivors were prompted to use the StrokeLine service after experiencing fragmented care provision in their post-stroke recovery and feeling abandoned by the healthcare system. Contact with StrokeLine was often initiated out of desperation and perceived as a last resort when other avenues of seeking advice and emotional support were exhausted. In contacting StrokeLine, all participants revealed individual agency in their active involvement in seeking continuity of care. Participants reported an overall positive experience while using StrokeLine and appreciated the professional response and expertise of StrokeLine staff during the call. Stroke survivors felt comfortable sharing their concerns with staff and valued being involved in the process of helping them find practical solutions.

After using StrokeLine, participants perceived a positive impact on their stroke journey. They felt their experiences were validated, motivating and empowering them to take charge of their recovery. Participants felt a renewed sense of hopefulness and noted they would use StrokeLine again if needed, as they now knew what they could expect from the service. Stroke survivors were also able to form a better conceptualise StrokeLine service provision after the call. They understood the value of the service to enhance existing care. Further, they understood the service was limited by both the scope of practice of StrokeLine staff and the telehealth-based model of care under which the service functions. Participants, however, also understood the potential strength of the service in providing timely access to support in geographical areas with limited post-stroke services. Finally, when suggesting recommendations for improving the StrokeLine service, all participants perceived structural limitations around resource allocation and staffing. Consequently, most recommendations for improvement were believed unlikely to be actioned if these perceived limitations to resource allocation were not first resolved. Recommendations for service improvement included; (i) increasing the awareness and promotion of the service (ii) increasing the likelihood of answering calls in the first instance and (iii) providing a more personable voicemail message if this could not be achieved. Furthermore, another recommendation is increasing awareness of StrokeLine for stroke survivors.

Although participants noted receiving very limited care provision post hospital-discharge and even later in their stroke recovery, most participants in this study noted receiving an information pack when discharged from hospital in which they later found the StrokeLine number. Numerous studies have highlighted the importance of providing information 'just in time' to facilitate the self-management of care in stroke (5, 20). If information is provided at a time when a person is not ready to take ownership of their condition, most often people are left feeling overwhelmed and abandoned by their healthcare providers (21). As such, self-management of care is contingent on people revealing individual agency and seeking to take active control in the continuity of their care (22). Helpline interactions, therefore, are able to reinforce self-management by providing timely support, relevant information and empowering callers when the caller choose to engage (23).

In the current study, concerns discussed during the call were often multi-layered and there was never a singular, or definitive, reason for calling StrokeLine. Information, advice and support were often all sought during the same call and callers were unable to distinctly differentiate between what was offered to them. Interactions of a similar nature in helpline-based care provision are discussed extensively in the research. Arvidsson et al. (2019) identified that understanding the precise description of a caller's problem when they called a rheumatology telephone helpline was difficult (10). Initially characterising the caller's experience by building a feeling of mutual trust and solidarity, however, later aided in clarifying the explicit reason for the call (10). As such, the strength of telephone-based service provision lies in the call-takers ability to combine emotional support with practical information (24).

Strengths and Limitations

The interview process allowed participants to express their stroke experiences in a continuum before, during and after their contact with StrokeLine. Understanding the wider context of factors prompting stroke survivors to call StrokeLine highlights the gaps in current provision of care in stroke and could provide insight into understanding the longer term needs of stroke survivors. This study was also guided by partnership with the Stroke Foundation in Australia, allowing findings from the study to support timely feedback for service improvement and relevant reporting to policy-makers.

The level of post-stroke impairment of each participant was also not explicitly captured during the interview process and the experiences and perceived impact of using StrokeLine in severe stroke versus mild stroke may differ. Users of the stroke line service who self-reported as having had a stroke were included in this study, future studies could include participants who have clinician or medical record confirmed stroke to further validate findings. Although not an exclusion criterion, no stroke survivors with communication difficulties expressed an interest in participating in the study. All participants were also from European backgrounds and findings may not be inclusive of the views of other cultural backgrounds. Future studies could incorporate Strokeline service users from more diverse backgrounds to identify if changes could be made to improve service delivery to broader populations.

Recommendations

Future research should seek to explore the definition of information, support and advice in stroke care to understand how and when to best provide each across the continuum of stroke recovery and to better match the expectations of stroke survivors. Further research should also seek to understand how best to integrate services (such as StrokeLine) within existing health systems at an appropriate time within the stroke illness trajectory. Better understanding factors prompting stroke survivors to reveal individual agency to take control of their care continuity may provide insight into when to best have services available to support their self-management. There is also a need to better understand factors of non-participation and low engagement with StrokeLine. In response to the COVID-19 pandemic, the relevance of telehealth-based care provision and a focus on value-centred healthcare redesign warrants an economic evaluation of StrokeLine service provision. As such, this study highlights implications for policy makers in supporting the future sustainability of services such as StrokeLine.

CONCLUSION

Stroke survivors used a stroke helpline in response to fragmented care provision in other settings and after using the service, most perceived a positive impact on their stroke recovery. Participants felt empowered and motivated to take re-engage with their ongoing care. Stroke survivors also understood StrokeLine to be able to enhance their existing care. Stroke survivor awareness of the StrokeLine service could be improved. Structural limitations were perceived as the main driver for the delayed response time in answering calls in the first instance.

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Supplementary:

Interview Guide

Topic	Narrative-Inducing Question
Experience using StrokeLine	1. Can you please tell me about how you came to make the call to StrokeLine?
Impact of using StrokeLine	2. Can you please tell me about any changes in your life that have occurred as a result of contacting StrokeLine?
Evaluation of StrokeLine	3. Could you please tell me about your thoughts of the service you received by StrokeLine?