



**Consultation and communication  
with complementary medicine  
practitioners by those with chronic  
health conditions:  
An analysis of population- and  
practice-based datasets**

**by Hope Maree Foley**

Thesis submitted in fulfilment of the requirements for  
the degree of

**Doctor of Philosophy (Public Health)**

under the supervision of  
Distinguished Professor Jon Adams and Doctor Amie Steel

University of Technology Sydney  
Faculty of Health  
Australian Research Centre in Complementary and  
Integrative Medicine

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## **CERTIFICATE OF ORIGINAL AUTHORSHIP**

I, Hope Maree Foley, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Public Health), in the 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.

This research is supported by the Australian Government Research Training Program.

Signature:

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## FORMAT OF THIS THESIS

This thesis is structured in the format of Thesis by Compilation. It presents a single, cohesive body of work comprising a combination of traditional thesis chapters and published/publishable articles. In keeping with the format of Thesis by Compilation, content from articles resulting from the project which have been published or submitted for publication have been embedded within the relevant chapters of this thesis unabridged. Where this applies, a chapter preamble and relevant notes are included to indicate publication details. For published articles, journal-formatted copies of each work are included in the Appendices. A list of these articles and details on authorship contributions are provided below.

## PUBLISHED WORKS INCLUDED IN THIS THESIS

Of the five manuscripts incorporated into this thesis, four have been published or accepted for publication (in press) and one is under review. The manuscripts are as follows:

1. **Chapter 2.3.** Foley H, Steel A, Cramer, H, Wardle J & Adams J. Disclosure of complementary medicine use to medical providers: A systematic review and meta-analysis. *Scientific Reports*. 2019. 9:1
2. **Chapter 4.** Foley H, Steel A, McIntyre E, Harnett J, Sibbritt D, Wardle J & Adams J. Complementary medicine practitioner consultations amongst 1,314 individuals with chronic conditions: Characteristics of users, reasons for and predictors of use. *Complementary Therapies in Clinical Practice*. 2020. 40:101194
3. **Chapter 5.** Foley H, Steel A & Adams J. Consultation with complementary medicine practitioners by individuals with chronic conditions: Characteristics and reasons for consultation in Australian clinical settings. *Health and Social Care in the Community*. 2020. In press.
4. **Chapter 6.** Foley H, Steel A & Adams J. Perceptions of person-centred care amongst individuals with chronic conditions who consult complementary medicine practitioners. *Complementary Therapies in Medicine*. 2020. 52:102518
5. **Chapter 7.** Foley H, Steel A, McIntyre, E, Harnett, J, Sibbritt, D & Adams J. Disclosure of conventional and complementary medicine use to medical doctors and complementary medicine practitioners: A survey of rates and reasons amongst those with chronic conditions. *BMJ Open*. (Under review). *Submitted 18<sup>th</sup> May 2021*.

## STATEMENT OF CONTRIBUTIONS OF AUTHORS TO CO-AUTHORED WORKS INCLUDED IN THIS THESIS

As the author of this thesis and candidate for award, I have been the primary author of each article included within this thesis. For each of these articles, I have been principally responsible for determining the research question, performing analysis, drafting the full manuscript, overseeing the submission process and responding to peer-review. Support in all of these areas was provided by my supervisors, Distinguished Professor Jon Adams and Doctor Amie Steel.

During development of the published review article in Chapter 2.3, guidance in the conduct and interpretation of meta-analysis was provided by Associate Professor Holger Cramer, and additional support in interpretation of findings was provided by Professor Jon Wardle. All authors contributed to editing of the finalised manuscript.

Regarding articles published from this project's Phase One data (Chapters 4 and 7), additional support in the planning and interpretation of data analysis was provided by Doctor Erica McIntyre and Professor David Sibbritt. All co-authors for these two works contributed to the design and conduct of the broader project from which Phase One data was drawn, as well as final editing of the associated manuscripts.

### Signed:

#### Thesis author and PhD candidate

Hope Foley

Production Note:  
Signature removed prior to  
publication.

#### Supervisors

Prof Jon Adams

Production Note:  
Signature removed prior to  
publication.

Dr Amie Steel

Production Note:  
Signature removed prior to  
publication.

#### Co-authors

Adj. Assoc. Prof Holger Cramer

Production Note:  
Signature removed prior to  
publication.

Dr Joanna Harnett

Production Note:  
Signature removed prior to  
publication.

Prof Jon Wardle

Production Note:  
Signature removed prior to  
publication.

Prof David Sibbritt

Production Note:  
Signature removed prior  
to publication.

Dr Erica McIntyre

Production Note:  
Signature removed prior to  
publication.

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## ABSTRACT

**Background:** Chronic conditions contribute an increasing burden to health systems. The complexity and duration of chronic conditions create substantial challenges for patients and care providers, requiring ongoing, multi-disciplinary, person-centred care (PCC). While evidence suggests high utilisation of complementary medicine (CM) practitioner services by those with chronic conditions, research is limited regarding the role of CM consultations for these individuals. **Methods:** A cross-sectional survey design was employed across two phases at a national population level (Phase One, n=2,019), and a multi-profession CM clinical practice-based setting (Phase Two n=191). Analyses focussed on participants with chronic conditions (Phase One n=1,314, Phase Two n=153). Data were collected on socio-demographics, health status, CM and conventional medicine service utilisation behaviours, and patient communication regarding disclosure of treatment use to CM practitioners and medical doctors. Phase Two also examined patient perceptions of PCC during consultation with CM practitioners as compared with medical doctors. **Results:** Phase One found a substantial rate of CM practitioner consultation by those with chronic conditions (38%) and Phase Two found a high prevalence of chronic conditions amongst those consulting CM practitioners (80%). CM consultation by those with chronic conditions was motivated by a desire for improved wellbeing and supportive, compassionate care, alongside treatment of chronic conditions. Patient perceptions of PCC during CM consultation were consistently high, and were higher than perceptions of PCC during consultation with medical doctors. The Phase One and Phase Two datasets differed regarding rates of disclosure of treatment use to providers. However, the reasons reported for disclosing or not disclosing were similar across both datasets and for all professions; disclosure predominantly related to patient desires to have their health status fully understood, while non-disclosure related to a lack of provider inquiry. Disclosure was found to be associated with higher perceptions of PCC, regarding both CM ( $p=0.0118$ ) and conventional medicine ( $p=0.0033$ ) settings. **Conclusion:** This thesis maps a landscape of the role CM practitioners play for individuals with chronic conditions in Australia by exploring the characteristics, care-seeking and communication behaviours, and perceptions of care of these individuals regarding the CM consultation experience. This thesis describes the context of CM consultation for chronic condition management within the wider field of chronic illness care in Australia, highlighting a need for more pragmatic coordination of care. The results presented here call for further research that considers the potential utility of greater integration of CM in Australia for optimal, PCC for those with chronic conditions.

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# **1. INTRODUCTION**

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## **1.1 BACKGROUND**

As chronic conditions increasingly predominate the burden of disease and public health sphere globally (1) and in Australia (2), health systems and health care providers are challenged to respond to the changing health needs of patients and populations. The complexity and prolonged duration of chronic conditions can present obstacles to effective management, as well as producing substantial impacts on patients' wellbeing and quality of life (3). Multi-disciplinary, integrated and person-centred approaches to chronic illness care are recommended in order to manage the manifold effects of chronic conditions (4) and, correspondingly, patients often engage in multiple forms of treatment and care-seeking (5). Such care-seeking frequently involves the use of complementary medicine (CM), including the services of CM practitioners, who appear to be consulted at relatively high rates by those with chronic conditions in Australia (6). Reportedly, CM practitioner services are commonly sought for the nature of clinical care provided, which is perceived by patients to be holistic and person-centred in its approach (7). However, little is known regarding the nature of the care provided by CM practitioners to those with chronic conditions in Australia. There is a need to examine whether patient experiences of CM clinical care are aligned with the paradigm of person-centred care (PCC) recommended for chronic conditions (8), and to explore how CM practitioner services and associated treatment use are coordinated or communicated between patients and providers within the wider provision of chronic illness care. This thesis addresses the topic of CM clinical care for those with chronic conditions in Australia, employing a health services research framework to examine patient experiences of clinical care and communication through a lens of PCC.

## **1.2 SIGNIFICANCE AND SCOPE OF THESIS**

In consideration of the growing need to respond to the burden that chronic conditions place on contemporary health care systems and the high prevalence of CM use by individuals with chronic conditions, this project seeks to map the landscape of CM use, and experience of this use, by individuals with chronic conditions in Australia. This work will assist in revealing and understanding the potential role of CM within the wider scope of health care provision, particularly as person-centred and integrated care become progressively established as preferred paradigms within Australia's public

health domain. CM related health care-seeking behaviours by those with chronic conditions, patient experiences of care received, and patient-provider communication relating to coordination of care are explored in this thesis. Ultimately, insights generated by this project will be able to inform public health policy and practice guidelines to achieve improved patient care and chronic disease management.

### **1.2.1 Research aim**

To examine and describe the patient experience regarding person-centred care and communication behaviours of individuals with chronic conditions who consult with CM practitioners in Australia, in order to better understand the role of the CM consultation in health management for these individuals.

### **1.2.2 Research questions**

1. What are the characteristics of individuals who consult with CM practitioners in Australia for the management of chronic conditions?
2. Which CM professions are being utilised in Australia by individuals with chronic conditions?
3. What motivates individuals with chronic health conditions to utilise CM practitioner services in Australia?
4. Do individuals with chronic conditions experience person-centred care during clinical consultation with CM practitioners in Australia?
5. Does the experience of person-centred care differ during clinical consultation with CM practitioners compared to medical doctors in Australia?
6. What factors influence the care-related communication behaviours of individuals with chronic conditions during consultations with their care providers?

### **1.2.3 Research objectives**

1. Describe the characteristics of individuals with chronic conditions who consult with CM practitioners in Australia.
2. Describe the utilisation of CM practitioner services as distinct professions by individuals with chronic conditions in Australia.
3. Quantitatively assess the extent of person-centred care within the consultation experience for individuals with chronic conditions who consult with CM practitioners in the Australian community.
4. Describe differences in experiences of person-centred care between CM consultations and medical consultations for individuals with chronic conditions in Australia.

5. Describe the behaviours regarding communication of conventional medicine use to CM practitioners by individuals with chronic conditions.
6. Describe the behaviours regarding communication of CM use to conventional providers by individuals with chronic conditions.

#### **1.2.4 Thesis structure**

This body of work has been developed as a thesis by compilation. The project itself has been conducted as a cohesive, complete research process, resulting in a number of journal publications embedded within the relevant chapters of this thesis. The structure of this work is outlined below.

**Chapter 1** provides background information to contextualise the project and support the following chapters. An introduction is given to the contemporary circumstances surrounding chronic conditions and associated health care provision and policy. Complementary medicine is defined and described in relation to chronic illness care and person-centred clinical care.

**Chapter 2** reviews relevant literature in response to each core component of the research aim. Extant knowledge regarding the use of CM by those with chronic conditions is examined, as is current literature on patient experiences of person-centred chronic illness care. Patient-provider communication surrounding concomitant use of CM and conventional medicine is also explored. Section 2.3 of this chapter includes a systematic review and meta-analysis published in *Scientific Reports*.

**Chapter 3** describes the methodology of the project underlying this thesis, outlining the study design, phases of data collection, setting and sampling, instruments used, and data analysis.

**Chapter 4** presents the first body of results from the project. This chapter describes the characteristics of individuals with chronic conditions who consult with CM practitioners and their reasons for utilising CM practitioner services, drawing on data from a national population-based sample. This chapter draws comparisons between individuals who do and do not consult with CM practitioners amongst those with chronic conditions. The results from this chapter have been published in *Complementary Therapies in Clinical Practice*.

**Chapter 5** extends upon the results of Chapter 4, describing the characteristics and motivations of individuals with chronic conditions who consult with CM practitioners, discerning between those who consult with different CM professions. This chapter

draws on a clinical practice-based dataset. The results from this chapter have been published in *Health and Social Care in the Community*.

**Chapter 6** reports on patient perceptions of PCC during consultation with CM practitioners, comparing the patient experience of CM consultation with that of conventional medical settings. The results from this chapter have been published in *Complementary Therapies in Medicine*.

**Chapter 7** examines patient-provider communication behaviours regarding rates of and reasons for disclosure and non-disclosure of treatment use. Patient disclosure of conventional medicine use to CM practitioners is described alongside patient disclosure of CM use to medical doctors. This chapter draws on a national population-based dataset. A manuscript reporting the results of this chapter is currently under submission with *The International Journal of Clinical Practice*.

**Chapter 8** draws on a clinical practice-based dataset to further explore patient disclosure of treatment use to care providers and assesses the relationship between disclosure communication and PCC.

**Chapter 9** discusses the findings of this thesis, contextualising the results to previous research and current public health policy. This chapter identifies the implications of the project to chronic illness care and health policy, outlines the limitations of the research, and suggests potential pathways for future research to build upon the project findings.

**Chapter 10** concludes this thesis. This chapter summarises the central findings of this thesis and relates the results back to the research objectives and over-arching research aim.

## **1.3 CHRONIC CONDITIONS AND CONTEMPORARY HEALTH CARE PROVISION**

### **1.3.1 The nature and burden of chronic conditions**

Chronic conditions are diseases, illnesses and other health conditions which are ongoing rather than short-lived (acute) (9). While there is currently no universally accepted definition for chronic conditions, definitions consistently include themes of prolonged duration, limitation of functional capacity, complexity of aetiology or presentation, and need for ongoing medical care (9). The Australian Department of Health defines chronic conditions as those which “have complex and multiple causes; are generally long-term and persistent; and often lead to a gradual deterioration of health and loss of independence” (10).

Chronic conditions increasingly contribute to the burden of disease on a global (1) and Australian national level (2). While all societies, communities and demographics are impacted by the burden of chronic conditions, it is those from marginalised and vulnerable groups who are most affected and under-served, creating additional barriers to health equity (1, 11). A bi-directional relationship appears to exist between lower socioeconomic status and having a chronic condition, with each factor impacting on the other and drawing attention to social determinants of health in policy relating to chronic conditions (11). Chronic conditions account for approximately 63% of deaths globally, more than one-third of which are considered premature (4). In Australia, approximately two-thirds of the health system burden can be attributed to chronic conditions and more than 50% of individuals in Australia's general population have at least one chronic condition (2). Furthermore, many of these individuals experience multimorbidity, meaning they have been diagnosed with two or more concurrent chronic conditions (12), often with substantial impacts on quality of life (13). Estimates of multimorbidity in Australia range from one-quarter (14) to one-third (12) of the population, adding further complexity to the challenges of managing chronic conditions. This incurs a substantial economic, personal, social and community cost (2).

The burden of chronic conditions is due largely to improvements in prevention and treatment of infectious diseases, combined with an ageing population and post-industrial changes to lifestyle behaviours which are not necessarily conducive to health maintenance (1, 2). Sedentary behaviours related to contemporary social and environmental factors are associated with chronic conditions such as cardiovascular and metabolic diseases (15). Increasing consumption of highly processed foods can result in dietary nutrient profiles associated with cancer and other metabolic conditions (16). In addition, progress in medical science and general living conditions allow people to live longer, yet multimorbidity of chronic conditions increases with age, affecting quality of life for older members of society (17). Many of the leading risk factors contributing to the burden of chronic conditions are modifiable, such as tobacco use, poor diet, high body mass, alcohol use, physical inactivity and high blood pressure (18). In view of the high cost of chronic conditions and the modifiable nature of many associated risk factors, management and prevention of chronic conditions have become high priorities in public health policy (2, 4).

### **1.3.2 Contemporary provision of health services for management of chronic conditions**

Despite prioritisation of chronic conditions in public health, current health systems are not optimally designed for treatment, management or prevention of chronic conditions as they have historically developed to meet the burden of acute and infectious diseases (19). Since chronic conditions have begun to predominate within the landscape of health and disease, policymakers have committed a considerable amount of attention to addressing the necessary redesign of health systems, resulting in substantial improvements to chronic illness care (1, 3). At a global level, recognition of the importance of improving management of chronic conditions has led to implementation of associated targets within the United Nations Sustainable Development Goals (20). Likewise, the World Health Organization (WHO) has developed a global action plan for prevention and control of chronic conditions (4), informing policy for WHO member states. Australian health policy has been a beneficiary of the WHO global action plan, resulting in the National Strategic Framework for Chronic Conditions which has a strong focus on health equity, sustainability and accessibility (2). This Framework promotes a shift toward health systems which provide collaborative, evidence-based, person-centred approaches to chronic illness care and has resulted in efforts to improve integration of care such as development of practice nurse roles in chronic illness care and shared information systems (3).

Nonetheless, health systems and care providers continue to face challenges in the work of managing patients with chronic conditions. The Australian health system remains fragmented and poorly coordinated, accessibility barriers persist for individuals from low socioeconomic backgrounds and rural areas, and funding models often fail to account for the flexibility required in chronic illness care (3, 21). Further to this, clinical guidelines relied upon by care providers to ensure best practice in clinical care focus on single conditions and neglect to account for the complexities of multimorbidity (22). Limitations on the duration of consultation time in general practice also present providers with barriers to full exploration of complex conditions and patient circumstances (23), while referral processes to access specialist care can be convoluted and time-consuming for providers and patients (24).

Individuals with chronic conditions are also challenged in their own efforts to meet health needs directly and indirectly related to their conditions. The fragmentation of a siloed health system creates difficulties for patients in navigating to the services they need, while low health literacy presents an obstacle for patients to understanding their chronic conditions and identifying what services might be useful to them (3). The complexity of chronic conditions can involve clinical presentations which are



unresponsive to existing treatments (25, 26), as well as requiring the use of medications with undesirable side-effects that also need to be managed (27). Patients with chronic conditions may experience peripheral symptoms indirectly related to their condition, alongside quality of life needs which may be overlooked by providers focused on treating disease pathophysiology (28). Issues arising from poor patient-provider communication and conflicting information given from different providers can leave patients confused about their condition or appropriate self-management approaches (27). Additionally, functional disability associated with chronic conditions can impact on patients' social wellbeing and employment (29), while the financial cost of managing chronic conditions over time can impact patients' economic stability (30).

All aspects considered, chronic conditions present a demanding scenario for progressive change in health systems. The Australian health system's blend of public, private and not-for-profit contributors, and targeted disability support, under an overarching goal of universal health care provision creates a highly regarded, generally well-functioning system (31, 32). Regardless, like other health systems, it has developed over time primarily to be responsive to the historical dominance of acute and infectious diseases within the greater landscape of health and now faces a need to reform many aspects of care provision as that landscape evolves (31). As recognised in Australian government reports and policy, chronic conditions call for more complex, multidisciplinary approaches to care which account for the multiple contributing factors to chronic conditions, the increasing prevalence of multimorbidity, and condition-related non-medical factors which impact the wellbeing of patients (2, 33, 34). Greater attention must also be given to preventive measures – both at a population level to prevent initial development of chronic conditions, and at an individual patient level to prevent further deterioration of health or development of comorbidities (35). The empowerment of patients to take on greater agency in self-management through suitably tailored patient education may be instrumental to achieving these multifactorial approaches to complex care in chronic conditions (36). Improved coordination of the multiple forms of care patients access for chronic conditions would provide additional benefit, as such coordination is currently an extra burden on self-management capacity with patients often forced to coordinate some aspects of care themselves (5).

## **1.4 THE SIGNIFICANCE OF COMPLEMENTARY MEDICINE AS A HEALTH SERVICE RESOURCE**

### **1.4.1 Defining complementary medicine**

In seeking to meet the variety of needs associated with the complexity of chronic illness, many individuals with chronic conditions utilise multiple forms of health care, including complementary medicine (CM) (6). CM refers to a broad variety of health care practices, paradigms and products, defined as CM by their exclusion from dominant conventional medical practice and education (37). This definition of exclusion, which defines CM by what it is *not* (conventional medicine), creates ambiguity and leaves the vast array of independent CM practices and professions vulnerable to misunderstanding by the public, medical providers and policymakers (38). The breadth of the CM umbrella definition means the field of CM is often considered in terms of the intended functionality of its use, rather than in terms of the techniques or tools characteristic of any specific CM (38). Indeed, the defining nomenclature of “complementary medicine” itself denotes the trend in which CM is typically used as a complement to conventional medicine, rather than as an alternative or replacement (38). This is reflected in research which has identified that users of CM tend to have higher rates of conventional medicine utilisation than those who do not use CM (6, 39). CM may be self-prescribed by users in the form of products (e.g. herbs, supplements) or practices (e.g. yoga, meditation), as well as being prescribed by practitioners of CM professions, by integrative doctors who combine conventional medicine and CM therapies, and by some conventional medicine providers (40). When accessed via CM practitioners in clinical settings, CM treatments may be practitioner-enacted using techniques performed by the practitioner during consultation (e.g. massage, acupuncture), or patient-enacted using methods reliant upon the patient self-administering prescribed treatments or changing health behaviours (e.g. herbal medicine, dietary changes) (40). Efforts to categorise different forms of CM have seen distinctions drawn between those practices which exert their effect through different mechanisms, such as biologically-based CM (e.g. herbal medicine), manipulative and body-based CM (e.g. chiropractic), mind-body interventions (e.g. yoga), energy medicine (e.g. acupuncture), and whole medical systems of philosophy and practice (e.g. naturopathy) (41). The use and practice of CM around the world is often influenced by local culture, tradition and the prevailing socio-political climate (37).

#### **1.4.2 Complementary medicine in Australia**

Prevalence of CM use has notably increased around the world within the last two decades (42) and rates of use in Australia are estimated to be as high as 69% in the general population (43). Australian adult CM users are most commonly female, Caucasian, middle-aged, highly educated, middle to high income-earners, while

children are more likely to use CM if their parents are CM users (6). It has been identified that CM is often accessed for management of chronic conditions in Australia (6), although research on CM use specifically within the population of individuals with chronic conditions is limited. Those who access CM in Australia tend to use CM as preventive therapy and for direct treatment of disease and illness, including as an adjunct to conventional medicine in order to reduce side-effects of conventional treatments or to supplement treatment when conventional medicine yields unsatisfactory results (6). Psychosocial factors also appear to influence CM use in Australia, with reports of utilisation being driven by personal beliefs about health, a desire for more control by patients, or a patient desire for more support from care providers (6).

### **1.4.3 Complementary medicine clinical practice in Australia**

Australian individuals commonly seek CM practitioner services specifically due to perceptions that these practitioners offer holistic, supportive, empowering services (6). Australian CM users exhibit high rates of consultation with CM practitioners with an estimated two-thirds of users visiting a CM practitioner (43). Amongst the most commonly visited CM practitioners in Australia are chiropractors, massage therapists, naturopaths and acupuncturists (6).

The CM practitioner workforce in Australia represents a diverse array of professions including manual therapeutic and bodywork professions (e.g. massage therapy, myotherapy), mind-body and energy medicine professions (e.g. kinesiology, yoga), contemporary biologically-based professions (e.g. nutritional medicine), and traditional whole medical systems from China and India (e.g. traditional Chinese medicine, Ayurveda), as well as from Western traditions (e.g. naturopathy, Western herbal medicine) (44). CM practitioners in Australia typically hold vocational education qualifications at an advanced diploma or diploma level, although Bachelor degree and postgraduate qualifications are predominant in some professions such as chiropractic, osteopathy, acupuncture, Chinese herbal medicine and naturopathy (44). These professions require Bachelor qualifications as a minimum standard under national training and registration requirements, although such standards were only recently introduced for acupuncture, Chinese herbal medicine and naturopathy (45, 46).

Chiropractic, osteopathy and traditional Chinese medicine (including acupuncture) are registered CM professions in Australia through statutory regulation under the National Registration and Accreditation Scheme (NRAS), which holds the primary aim of maintaining safety of the public when accessing health care by ensuring health

professionals are adequately trained and qualified to practice their profession (47). The NRAS is applied to professions where risk of harm is considered sufficient enough that training and qualification must be regulated to protect consumers (47). Other CM professions in Australia have not yet been included in the NRAS due largely to perceived low risk of harm. However, ongoing calls for statutory regulation of professions such as naturopathy and herbal medicine highlight the increased utilisation of these professions, which are consulted in a primary care capacity by some patients, alongside both direct and indirect risks associated with their practice which may justify their inclusion in the NRAS (48, 49). Unregulated health professions in Australia – including CM professions – are bound by the National Code of Conduct for Health Care Workers, which provides mechanisms for enforcing standards of conduct to protect members of the public (50). Beyond this, the current circumstance for most CM professions in Australia is self-regulation, with the vast majority of CM practitioners maintaining membership with relevant professional associations which oversee profession-specific practice standards and complaint mechanisms (44).

Many CM practitioners in Australia share their clinical practice location with other health care practitioners from both CM and conventional medicine professions (44) and often cross-refer their patients to other providers (51). Likewise, general practitioners in Australia have reported making referrals for their patients to some CM practitioners – predominantly those registered under the NRAS (52, 53) – and demonstrate a variety of complex views on the inclusion of CM in patient care (54). However, CM practice remains substantially siloed within the wider field of health care provision in Australia with little formal integration (55).

#### **1.4.4 Complementary medicine in the chronic illness care landscape**

It has been reported that individuals with chronic conditions are over-represented amongst CM users (56), and this over-representation appears to extend to the Australian context (57). Patients with chronic conditions often report satisfaction with the care and outcomes they receive in CM treatment, particularly when consulting with CM practitioners, and value the inclusion of CM in their wider care provision (58-60). The value of including CM in the care provided to those with chronic conditions is recognised in the WHO Global Action Plan as a means of expanding quality service coverage to improve efficiency and equity of chronic illness care (4). While the WHO Global Action Plan informs the Australian National Strategic Framework for Chronic Conditions, the Framework does not explicitly mention CM as a potential resource for

managing chronic conditions (2). The Framework does, however, acknowledge the importance of coordinated, integrated approaches to chronic illness care (2).

Integrated models of care account for a continuum of individual needs via coordinated provision of access to a variety of services at different levels, relating not only to conventional medical diagnosis and treatment, but also ongoing health management, health promotion, preventive care, rehabilitative care and palliative care, as appropriate (2, 8). Some related models of care, such as integrative health care, extend beyond the integrated coordination of services to involve a collaborative, interdisciplinary approach between the various providers involved in the patient's care (61). It is this formal coordination and collaboration which distinguishes integrative health care and other integrated models of care from extant processes of care provision, whereby various services, including CM, are accessed independently by patients without coordinated support from providers (55). Integrated models of care should also be distinguished from integrative medicine, which typically involves a single provider (e.g. integrative doctor) who integrates different treatment approaches from a variety of conventional and complementary medicine disciplines into the care they provide within their own clinic (61).

There is growing acknowledgement amongst care providers of the potential utility of including CM services within integrated models of care globally (8, 37) and in Australia (62, 63). While integration of some CM services in Australia has increased since professions such as chiropractic, osteopathy, acupuncture and traditional Chinese medicine have achieved statutory regulation, CM is still predominantly accessed separately from conventional medical care in Australia (64). The integration of CM with conventional care for chronic conditions tends to be coordinated by patients themselves with little or no input from care providers (5). Yet, amongst those with chronic conditions in Australia who use CM, concomitant use of conventional pharmaceutical medicines and CM is common (57).

When concomitant use of CM and conventional medicine is well-coordinated and integrated for chronic illness management with appropriate provider support, it can offer potential benefits such as addressing gaps in treatment effectiveness and improving patients' sense of wellbeing (63, 65, 66). However, when concomitant use is not integrated with appropriate professional management, patients are vulnerable to potential risks of concomitant use, such as pharmacological/biochemical interactions (67) or assumptions about safety, efficacy and reliability of treatments (68). In order to reduce such risks and enhance potential benefits, there is a need to better understand

how concomitant use is managed by individuals with chronic conditions in Australia, and how these individuals communicate with their health care providers about concomitant use. This understanding may then assist in movement toward more collaborative, integrated approaches to concomitant use within the context of clinical care delivery and the broader field of public health. Such integrated approaches may be essential to ensuring chronic illness care adequately meets the needs and preferences of patients.

## **1.5 THE ROLE OF CONSULTATION AND COMMUNICATION IN CHRONIC ILLNESS CARE**

The management of chronic conditions is typically centred upon the provision of clinical care delivered through consultation with health care providers (69). The role of the consultation in clinical care is much greater than the provision of treatment through prescription of remedies. The relationship between the patient and practitioner – and the nature of how communication occurs between them during consultation – affects how patients experience their condition and how they engage with the care process, as well as impacting on health and quality of life outcomes (70, 71). Historically, many models of clinical care have been doctor-centred or illness/disease-centred (72), positioning the physician or other health care provider in control of the communication and treatment processes in a manner described as paternalistic or reductionist, whereby it is the *disease* being treated rather than the *patient* (73). In doctor-centred or paternalistic models of care, the health care provider is the agent and the patient yields their autonomy to the provider's decision-making processes around treatment (73). Movement away from these doctor-centred models to greater patient autonomy has occurred over the last several decades with approaches such as the biopsychosocial model, which recognises how the interplay of biological, psychological and social factors impact a patient's experience of health and healing (74). A deeper understanding of social determinants of health has also driven greater focus on patients' lived experiences and the need to address social factors which contribute to health inequity (75).

This increased focus on patient engagement may have benefits through more effective clinical communication, resulting in improved patient-provider rapport, patient knowledge and understanding about their health, patient self-efficacy, coordination of care, ethical practice, and alignment of care with evidence-based practice (71, 76). The increasing predominance of evidence-based practice – which seeks to promote clinical

decision-making based on the best available evidence – has evolved beyond a singular focus on scientific evidence to include both clinical expertise and patient preferences within its paradigm (77). The inclusion of patient preferences in the paradigm of evidence-based practice recognises that patient perspectives are essential to achieving favourable clinical outcomes and creates a coalescence of scientific evidence with patient-centredness (77). Treatment approaches that fail to account for patient perspectives may be inappropriate to the context of the individual’s life, resulting in ineffective treatments or patient non-adherence to treatments (77). In endeavours to produce evidence more readily applicable to practice and policy, and to improve the implementation of evidence-based practice, research methodologies have also evolved to better include patient perspectives in their design, which can be seen in fields such as implementation science (78). The translation of these evolving approaches to applied clinical practice and public health can be seen in the prominence of person-centred or patient-centred care in policy and clinical guidelines (8).

### **1.5.1 The paradigm of person-centred care**

Inspired by the work of psychologists and psychoanalysts, the paradigm of person-centred care (PCC) rests on the intention of *“understanding the patient as a unique human being”*, as described by psychoanalyst Enid Balint in 1969 (79). The paradigm has evolved substantially since, developing greater richness of definition and application, seeking to address the need of patients to be at the centre of their own care by being *“respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”* (80). While various definitions of PCC exist, the most comprehensive and well-established definition is encompassed by the eight principles developed by the Picker Institute, which were enshrined in the Institute of Medicine publication *Crossing the Quality Chasm* (80). The intent of the publication was to promote strategies for improving quality of health care, with person-centredness identified as a foundational domain of health care quality. The eight principles of PCC are as follows (80):

1. *Respect for patients’ values, preferences and expressed needs*  
PCC responds to the patient as an individual, accounting for their physical, emotional and cultural needs, and quality of life. PCC is tailored to the patient’s preferences regarding treatment options, decision-making and participation in care, responding to changes in these preferences over time.

2. *Emotional support – relieving fear and anxiety*  
PCC attends to the emotional aspects of illness and injury, such as fear, uncertainty, loneliness and other forms of distress.
3. *Physical needs and comfort*  
PCC is responsive to patients' needs regarding pain and other discomfort in a timely, expert manner tailored to the individual patient.
4. *Information, communication, and education*  
PCC ensures patients are informed and educated about their health and health care in accurate, trustworthy language they understand through effective patient-provider communication.
5. *Continuity and transition of care*  
PCC aims for care to be uninterrupted over time, provided through continuous caring relationships with providers, and for patients to be supported in navigating the transition to new services or settings.
6. *Coordination and integration of care*  
PCC ensures that the various services and procedures involved in a patient's care are coordinated for accurate and timely provision of care and information.
7. *Involvement of family and friends*  
PCC accommodates the role of family and friends, involving them in the patient's care as appropriate and recognising their contributions and needs.
8. *Access to care*  
PCC ensures patients have access to the care they need when it is needed.

While the terms “patient-centred care” and “person-centred care” are often used interchangeably, it has been noted that subtle differences exist between the two concepts with “patient-centred care” focussing more strongly on *functional* care while “person-centred care” extends beyond functionality to encompass *meaningful* care (81). For the purposes of this thesis, “person-centred care” has been chosen as the preferred terminology due to its greater conceptual reach. Nonetheless, substantial overlap exists between the two and literature using both terminologies have been treated as a cohesive collective throughout this project.

### **1.5.2 Person-centred care for individuals with chronic conditions**



PCC is considered a useful approach to address the need for health systems to meet the shifting landscape of disease regarding the reduced burden from acute conditions and increasing burden from chronic conditions in an efficient and sustainable manner (2, 8). The paradigm is increasingly recognised as a particularly valuable model of care in chronic illness management, due to its responsiveness to individual circumstances which can account for the complex impact of chronic conditions on health and quality of life (82). Extant literature examining PCC in family medicine for chronic conditions has identified that PCC acknowledges the individual patient's circumstances and expertise in their own health, while also legitimising the patient's experience of their condition, offering realistic hope and advocating for the patient within the wider health care system (83). This appears to occur through the development of continuous care and strong patient-provider partnership (83).

When PCC is delivered with an appropriate balance between psychosocial care and technical skill in disease treatment, it appears to improve outcomes in patient satisfaction and wellbeing, as well as potentially enhancing clinical treatment outcomes (84). Experimental studies using PCC interventions have highlighted this potential to improve clinical outcomes (85-87). Individuals with chronic conditions convey a desire for their care to be more person-centred in its delivery, seeking improved patient-provider communication and information provision, greater ease of accessibility of care, more support in self-management, improved continuity of care, more participation in clinical decision-making and a generally holistic approach from providers (82).

### **1.5.3 Person-centred care in complementary medicine clinical practice**

Practitioners of CM services have been seen to provide clinical care demonstrating a person-centred approach (7, 88), possibly due to the holistic philosophies underpinning CM practice which are closely aligned with the paradigm of PCC (89). A systematic review of literature pertaining to patient perceptions of PCC in CM was published in early 2017 (7) which speaks directly to this aspect of the current research project. The review identified thirty-six papers which had explored patient perceptions of clinical care relating to themes of PCC such as practitioner empathy and patient empowerment through naturalistic, observational research designs in clinical settings. The review found that individuals who consult with CM practitioners frequently report experiences of emotional support from their CM practitioner, as well as experiences of being empowered by the CM consultation, expressed as opportunities to take control over their health through enhanced self-efficacy. The review also found these individuals reported experiencing various aspects of PCC during consultation with CM

practitioners, such as a collaborative patient-practitioner relationship, a respectfully individualised approach to care, and strong communication surrounding information provision (7).

Additional research conducted since the publication of the review has explored PCC in a number of CM settings. Perceptions of PCC have been rated highly by those consulting with chiropractors in Canada (90) and Australia (91), particularly in aspects of care relating to respect for patient preferences, patient participation in care and provision of emotional support. An interview study with osteopathy patients in Australia found that these patients experienced osteopathic care as individualised or holistic, with appreciable provision of emotional support, alongside patient education about their health and self-management options (92). When naturopaths were interviewed in Australia regarding the care they provide for those with cardiovascular disease, it was identified that principles of PCC are integral to how naturopathic care is approached in this context (93). In addition, a pilot study of patient perceptions of PCC conducted in a multi-disciplinary CM teaching clinic in Australia identified not only consistently high perceptions of PCC, but also that these perceptions were increased amongst patients who had reported having a chronic condition (88). It has been suggested that the alignment between CM holistic philosophies and PCC leads CM to be particularly well-suited to chronic illness care (89).

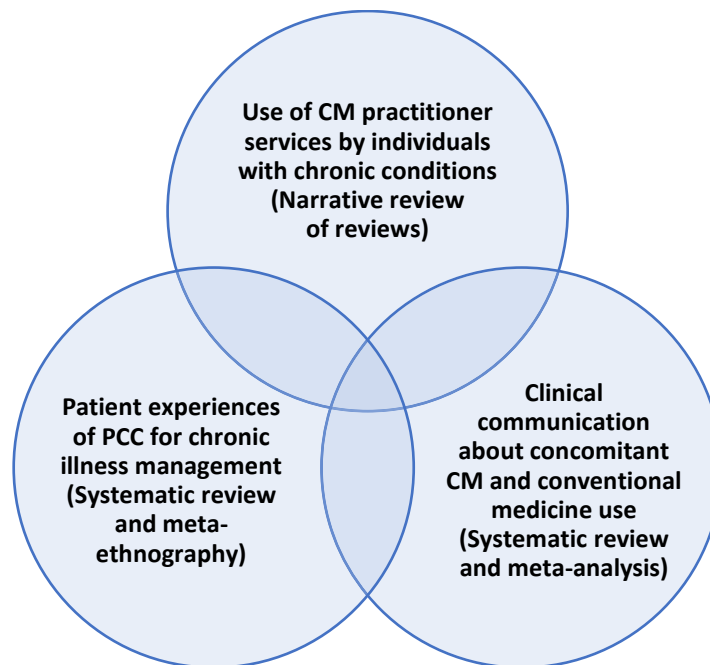
## **1.6 CHAPTER SUMMARY**

The nature of chronic conditions creates difficulties for patients in managing their health and impacts on patients' quality of life in a variety of ways, requiring care that responds to patients' individual circumstances. The challenge posed by chronic conditions to patients, health care providers and health systems necessitates a more patient-oriented approach to patient-provider communication, health care delivery and policy development. PCC has arisen as a proposed approach to more effectively manage the challenge of complexity in chronic conditions, providing tailored care with the potential to support and empower patients beyond treatment of disease pathology. In their own efforts to manage the personal burden of chronic conditions, patients often seek care from CM practitioners specifically due to patient perceptions that CM clinical care is holistic and person-centred in its approach. An examination of the use and experience of CM practitioner services and patient-provider communication during clinical consultation for those with chronic conditions is necessary to better understand the role of these services in chronic illness care.

## 2. LITERATURE REVIEW

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The overall aim and objectives of this thesis are underpinned by three substantive topic areas: the *use of CM practitioner services by individuals with chronic conditions*, *patient experiences of PCC for chronic illness management* and *clinical communication about concomitant CM and conventional medicine use*. As such, this project must be informed by existing evidence in these topic areas while addressing important gaps in the available literature. To ensure this is achieved, this chapter presents a discrete literature review for each substantive topic area (see Figure 2.1).



**Figure 2.1** Intersecting topic areas for literature review

The first review focuses consultation with CM practitioners for chronic illness care. A substantial body of literature has examined the broader use of CM by those with chronic conditions, inclusive of CM products, practices and practitioner services. Due to the high volume of research on this topic, a narrative review is presented within this chapter which examines a collection of recent review articles, alongside selected original research of importance. This narrative review overviews CM use by those with chronic conditions and what is currently known within this literature regarding CM consultation. A meta-ethnography is then presented which reviews the depth of qualitative literature regarding patient experiences of clinical care for chronic

conditions, examined through a lens of PCC. This meta-ethnography is intended to provide context for the project's examination of PCC in CM consultation by mapping the landscape of care received by those with chronic conditions more generally in a broad scope of health care settings. Finally, clinical communication about concomitant CM and conventional medicine use is then explored through a systematic review and meta-analysis of disclosure of CM use to medical providers. This systematic review also highlights the paucity of research on disclosure of conventional medicine use to CM practitioners.

## **2.1 CM USE AND UTILISATION OF CM PRACTITIONER SERVICES BY INDIVIDUALS WITH CHRONIC CONDITIONS**

The use of CM services, products and practices by individuals with chronic conditions has been examined throughout a broad array of studies within the last fifteen years, outlining descriptive factors such as prevalence of use and type of CM used, typically within populations of those with specific diagnoses. A number of reviews have been published from this cumulative research, providing overviews of CM use amongst those with chronic conditions such as arthritis (94, 95), gastrointestinal conditions (96), depressive disorders (97), HIV (98), cardiovascular disease (99), multiple sclerosis (100), fibromyalgia syndrome (101), asthma (102) and diabetes (103). In addition, CM use for chronic conditions has been examined in Australia (57) and internationally (104), as has the association between CM use and having a chronic condition in the general population (6, 105). The following review explores key empirical literature regarding the use of CM and consultation with CM practitioners by those with chronic conditions.

### **2.1.1 Prevalence of CM use amongst those with chronic conditions**

Reviews of CM use amongst those with chronic conditions typically report a wide range for estimated prevalence regardless of the condition being examined. For example, a review examining use by those with depressive disorders reported a range of 0.7%-86% (97), while a review of use in HIV reported a range of 15%-100% (98). A survey study of individuals with common chronic conditions (asthma, diabetes, arthritis, osteoporosis, heart and circulatory conditions) conducted in Australia (n=7,805) reported a prevalence rate of 24% for regular CM use overall, with differences depending on the diagnosis ranging from 2% (asthma) to 40% (osteoporosis) (57). When prevalence of CM use by those with chronic conditions is compared with CM use

within the general population, rates are often higher amongst those with chronic conditions, and tend to increase further for those with multimorbidities (56, 106).

A review of CM use in HIV covering studies conducted in North America, Europe and Australia reported separate prevalence rates for having consulted a CM practitioner (15-16%) (98). Another international survey (104) of individuals with a range of chronic conditions focused solely on use of CM provided by CM practitioners, reporting a range of 32%-46%, depending on the condition, with a six-month average prevalence of 38% (104). A Canadian survey of CM use compared the use of CM practitioner services between the general population and those with a range of chronic conditions, noting higher odds of having consulted CM practitioners for those with some chronic conditions (asthma, migraine) and lower odds for others (diabetes) (106). Altogether, there is little focus in the literature, beyond simple descriptive factors, reporting on the CM provided to those with chronic conditions via consultation with a CM practitioner.

The estimated prevalence of CM use amongst those with chronic conditions is impacted by how CM use is defined, which varies considerably across studies. The category of CM is sometimes defined broadly, inclusive of activities such as prayer and physical exercise (95), while other studies focus on specific types of CM such as acupuncture or herbal medicines (97). Similarly, the use of CM is defined with differing time parameters between studies, recorded as use within the previous six months, twelve months, or use ever across the lifetime (98). In addition, distinctions are rarely made between CM use that is self-prescribed or that which is provided by a CM practitioner and while this distinction can be assumed for CM that is, by necessity, provided by a practitioner (e.g. chiropractic), it is not possible to deduce whether other types of CM are being used based on practitioner advice or by through patients' self-prescription (e.g. herbal medicine).

The variation in parameters used to define CM use makes it difficult to determine the prevalence of CM use amongst those with chronic conditions, both broadly and with regards to clinical consultation. Accurate estimates of prevalence are further impeded by influential factors specific to location, culture, health system structures and condition type. Regardless, it is reasonable to conclude from the substantial amount of literature that CM use is common amongst those with chronic conditions and that such use often includes consultation with CM practitioners. There is also consistency in reports that CM use and consultation are generally higher amongst those with chronic conditions than amongst the general population - warranting investigation of patient experiences

of CM consultation for those with chronic conditions to ensure optimal patient care and risk management are performed during treatment of this clinical population.

### **2.1.2 Characteristics of CM users with chronic conditions**

The socio-demographic differences between individuals with chronic conditions who do and do not use CM are similar to those seen in the general population. This similarity may relate to the observation that those with chronic conditions are over-represented amongst CM users at the outset (6, 56). Regardless of chronic condition status, CM use is typically associated with being female sexed/gendered and having a higher education (94, 96, 98, 104, 106), while middle to older age is often correlated with CM use (6, 57, 97, 103, 105). Some reviews also found an association of CM use with higher economic status (6, 98, 106), although this varies by location and is possibly influenced by the financial accessibility of both CM and conventional medicine within different health systems. The socio-demographic associations identified in the literature are also influenced by how CM use is defined – for example, whether or not prayer is included in the definition of CM appears to alter associations with educational status (95).

Characteristics relating to an individual's health status appear to influence CM use amongst those with chronic conditions. In studies which examine health status variables, CM use for chronic conditions is seen to be associated with increased severity and number of symptoms, having comorbidities, longer disease duration, and number of prescribed medications (56, 97, 98, 104). CM use is also frequently found to be associated with poorer perceived physical and mental health (6, 97, 98, 104, 105), while an international survey study noted a correlation between consulting with CM practitioners and having a greater sense of control over one's health (104). It is also noted that individuals who use CM have higher rates of conventional medical use than other members of the general population (6). CM is typically used alongside conventional medicine rather than as an alternative to it (56, 57, 95, 97-100) and does not appear to affect patient adherence to pharmaceutical medications (97, 99). This concomitant use of CM and conventional medicine by individuals with chronic conditions, alongside associations between CM use and number of prescribed medications, highlights a need to ensure that care provided to those with chronic conditions accounts for appropriate management across all areas of health care use in order to avoid adverse outcomes from treatment interactions.

The relevance of examining and understanding socio-demographic and health status associations with CM use in chronic illness is underscored by the importance of social

determinants of health in the context of promoting health equity. This is particularly relevant to health systems in countries like Australia, where health policy is intended to align with WHO guidelines and goals, including the goal of providing universal health care (11). Australian health policy explicitly outlines a commitment to reducing the burden of chronic conditions in accordance with the WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases (2). The objectives of the Global Action Plan include a focus on the necessity of addressing the social determinants of health which can perpetuate the increasing burden of chronic conditions, as well as creating obstacles to reducing that burden (4). An understanding of how social determinants of health relate to CM use amongst those with chronic conditions can help shape practice and policy to ensure the value of CM practitioners in improving chronic illness care is best utilised to target those with the greatest need for such care.

### **2.1.3 Type of CM used for Chronic Conditions**

When prayer and spiritual healing were excluded by review authors, reviews which examined the type of CM used by those with chronic conditions found that vitamins, herbs and other supplements are the most frequently used (94-99, 103), with specialised diets and nutritional counselling also attracting high use amongst those with multiple sclerosis (100). While self-prescribed CM use was generally more prevalent, consultation with CM practitioners was still commonly reported. Massage, acupuncture, homeopathy, chiropractic and herbal medicine are commonly accessed through CM practitioners by those with chronic conditions, and associations are often noted between the type of CM profession consulted and the diagnosis reported by participants (94-98, 100-103, 106). These reported associations are outlined in Table 2.1.

While some studies have examined the use of CM practitioner services by those with chronic conditions, including exploring associations between condition and CM profession types, these studies are predominantly descriptive and provide little insight into the role played by CM practitioners in chronic illness care. It is not known which factors contribute to the associations identified, whether patients seek specific CM professions for specific condition-related reasons, or how the CM consultation experience is perceived by patients with chronic conditions.

**Table 2.1 Associations between chronic condition diagnosis and CM professions most commonly consulted**

<b>Diagnosis</b>	<b>CM professions most commonly consulted</b>	<b>Reference</b>
<b>Arthritis</b>	Massage therapists Chiropractors Acupuncturists	(94, 95)
<b>Asthma</b>	Acupuncturists	(102)
<b>Depressive disorders</b>	Mind-body therapists Acupuncturists Homeopaths Massage therapists Naturopaths Traditional Chinese medicine practitioners	(97)
<b>Diabetes</b>	Chiropractors Massage therapists Practitioners providing nutritional advice	(103)
<b>Fibromyalgia</b>	Acupuncturists Chiropractors Massage therapists	(101)
<b>Gastrointestinal disorders</b>	Manipulative therapists Mind-body therapists Acupuncturists	(96)
<b>HIV</b>	Massage therapists Acupuncturists	(98)
<b>Multiple sclerosis</b>	Acupuncturists Chiropractors Massage therapists	(100)

#### **2.1.4 Motivations for using CM**

A number of reviews have examined the factors that motivate those with specific chronic conditions to use CM. For those with arthritis, CM use was largely intended to reduce pain and to manage other symptoms where conventional medicine has been unsuccessful (94, 95). Managing symptoms as an unmet need was also a common motivating factor amongst those with depressive disorders (97), HIV (98), and



fibromyalgia syndrome (101). Other commonly reported reasons for using CM were a desire for greater control or autonomy over health (94, 97, 98, 100, 101), a willingness to try anything that might help (94), to promote wellbeing or quality of life (97-99), a belief that CM is safe (94, 97, 99) or has fewer side effects than pharmaceuticals (97, 99), a belief that CM can cure (94), recommendations from or general cultural inclusion of CM by family and friends (94, 95, 97, 100), previously experienced benefits (99), and philosophical reasons relating to personal values and beliefs, such as a desire for more holistic care (97, 99, 101). In the Australian general population, use of CM appears to be motivated by a desire for holistic and preventive care, symptom reduction, a belief that CM is safe, philosophical personal beliefs, a desire for hope or greater patient control over health, and a perception of CM practitioners as supportive, while for those with chronic conditions in Australia there is a particular influence on CM use from dissatisfaction with conventional medicine or unmet needs regarding disease management (6). It also appears that many Australians are using CM specifically to treat chronic conditions which have been recognised by the Australian Government as National Health Priority Areas, including cancer, asthma, arthritis and other musculoskeletal diseases, cardiovascular diseases, mental health and diabetes (6).

The reasons people report for using CM provide potential insights into the perceived and experienced benefits of CM, as well as which health needs may not be adequately met through conventional medical services. While motivations such as a desire to improve wellbeing appear to be universal amongst users of CM, other motivations may be related more specifically to having a chronic condition, having a particular chronic condition, or consulting with a particular type of CM practitioner (107). The use of CM is generally seen to be motivated more strongly by “pull” factors, whereby CM is sought because the user finds it attractive and congruent with their philosophical beliefs about health (6, 107). However, CM users with chronic conditions may be more likely than others to also report “push” motivations arising from dissatisfaction with conventional care and unmet needs (6). Whether motivations for use differ between occasions when CM is used for self-care and when CM is accessed via consultation with a CM practitioner is unclear, as few studies have focused specifically on practitioner-provided CM. An examination of the motivations to consult CM practitioners by those with chronic conditions would assist in understanding the role CM practitioners play for these individuals.

### **2.1.5 Missing pieces: gaps in the literature**

Existing literature on the use of CM by those with chronic conditions provides useful information about the characteristics of these individuals, as well as indications of the prevalence and types of CM used. These studies offer a broad foundation from which to pursue more definitive lines of inquiry into the role of CM in chronic illness management. However, the breadth of this literature offers little insight into the role of CM practitioners in providing clinical consultation, with sparse data on patient behaviours or experiences of seeking CM clinical care for chronic conditions. Moreover, of the few studies which have examined practitioner-provided CM for those with chronic conditions, very little data is currently specific to the Australian context, and patient motivations for CM clinical care-seeking remain unexamined, as do patient perceptions of the consultation experience.

### **2.1.6 Conclusion**

In order to determine the role played by CM practitioners for those with chronic conditions in Australia, research within the Australian population and within CM clinical environments that sufficiently centres upon patient perspectives must be undertaken. Australian public health policy relating to management of chronic conditions acknowledges the value of person-centred and integrated health care, in alignment with WHO guidelines (2). One of the obstacles to achieving this alignment, as noted in government reports, is the fragmentation of Australia's health system with care being largely uncoordinated and difficult for patients to navigate (34). As CM use appears to be prevalent and valued by those with chronic conditions, it is essential that appropriate research be undertaken to facilitate alignment of health care practice with these policies. This requires comprehensive investigation of the use of CM practitioner services by those with chronic conditions from a person-centred perspective and with a focus on factors which could improve coordination and integration of care for better patient outcomes.

## **2.2 PATIENT EXPERIENCES OF PERSON-CENTRED CARE DURING CONSULTATION FOR INDIVIDUALS WITH CHRONIC HEALTH CONDITIONS: A META-ETHNOGRAPHY**

The ultimate aim of this thesis is to better understand the role of the CM consultation in health management for individuals with chronic conditions, and objectives for reaching this aim include examination of experiences of PCC for these individuals. The focus on the paradigm of PCC in this project is driven by the recommendation of PCC as an ideal model of clinical care in chronic illness management in international (4) and national (2) health policy and supporting research (82, 83), as discussed in section 1.5.2. As those with chronic conditions often access multiple forms of care to meet their complex and varied health needs, a full understanding of patient experiences of PCC in CM consultation can only be developed by first understanding how patients experience PCC during consultation within a broader scope of health care settings, including both conventional medicine and CM consultations. An examination of the general perceptions of PCC by those with chronic conditions provides background context with which to compare and contrast the degree and nature of PCC perceived by patients with chronic conditions during CM consultation, as well as identifying gaps in the literature pertaining to CM clinical care for chronic illness.

In response to the need for this examination of patient experiences of PCC for chronic illness management, a systematic review and meta-ethnographic analysis of relevant literature was undertaken to synthesise a conceptual understanding of the topic. The review examines literature reporting on patient perceptions of care for those with chronic conditions and appraises the nature of this care against the eight principles of PCC to determine how PCC is or is not experienced by these patients. Thus, this meta-ethnography discerns the degree to which prevailing patient perceptions of chronic illness care align with PCC, rather than assessing only explicitly person-centred research. The eight principles of PCC, as detailed in section 1.5.1, are as follows (108):

1. Respect for patients' preferences, values and needs
2. Emotional support
3. Physical needs and comfort of the patient
4. Information and education
5. Continuity of care and transition of care
6. Coordination and integration of care
7. Involvement of family and friends
8. Accessibility of care

### 2.2.1 Meta-ethnographic approach

Meta-ethnography is an approach to synthesising qualitative literature that employs more systematic methods and produces a greater depth of conceptual interpretation than conventional narrative reviews (109). The approach was developed by researchers Noblit and Hare in the 1980s and consists of seven iterative, over-lapping steps, summarised in

Figure 2.2 (110). Meta-ethnographic approaches develop novel insights, concepts and theories through interpretive translation of findings from the studies under review, rather than aggregating the findings as a collective (111). This iterative, interpretive approach is considered especially useful when reviewing literature regarding experiences and behaviours as it is rooted in social theory, and retains the explanatory context underlying each study while generating new insight beyond the “sum of the parts” of the collective studies (112, 113).

This review was initially intended to be conducted as a systematic review. However, a meta-ethnographic synthesis was chosen after conducting the literature search, due to the richness of qualitative data elucidated in our search, alongside the utility of meta-ethnography as a means of translating descriptions of patient experiences to the paradigm of PCC. Meta-ethnography is thus aligned with the aim of this review, which is to use the lens of PCC to describe the experiences of individuals with chronic conditions during clinical consultation with health care providers.

<b>Noblit &amp; Hare’s (1998) seven step process of meta-ethnography</b>	
1.	Getting started – identifying the area of interest (research aims and rationale)
2.	Deciding what is relevant to the initial interest (literature search and selection)
3.	Reading the studies (critical reading and data extraction)
4.	Determining how the studies are related (within-study translation)
5.	Translating the studies into one another (across-study translation)
6.	Synthesising the translations (synthesis of findings)
7.	Expressing the synthesis (communication the findings)

**Figure 2.2 The process for conducting meta-ethnography**

## **2.2.2 Methods of search and synthesis**

Before commencement of this review, a protocol was developed in accordance with the PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) checklist (114) and registered with the PROSPERO database for prospectively registered systematic reviews in health and related disciplines (record no. CRD42018087151) (115).

A literature search was conducted on 25 January 2018 across four databases: AMED, CINAHL, PsycINFO and PubMed. The search strategy was constructed using three search strings developed from different aspects of the review aim: PCC (S1), patient experience (S2) and chronic conditions (S3). S1 included the terms “patient-centred” and “person-centred” alongside terms relating to clinical care, clinical communication and patient-provider relationships in order to capture all studies which explored clinical care regardless of whether the research topic was explicitly focused on PCC. S2 encompassed terms relating to patient experiences, while S3 included terms to identify studies on either chronic conditions generally or a selection of chronic conditions identified as contributing strongly to the burden of disease in Australia (116) and internationally (1, 35).

Boolean operators and truncation were used to include spelling variations and similar terms as appropriate. In order to capture recent studies reflective of contemporary health care settings, a date range was set covering literature published between January 2008 and January 2018. The full search strategy is presented in Table 2.2. Manual searching was also conducted within the reference lists of included articles during study selection and of review articles discovered during the screening process.

**Table 2.2 Search strategy for literature review of meta-ethnography**

<b>Protocol Title:</b> Experiences and perceptions of person-centred care by individuals with chronic conditions				
<b>Search Strategy:</b> S1 AND S2 AND S3				
Database	String 1 (S1)	String 2 (S2)	String 3 (S3)	Date range
<b>AMED (EBSCOhost)</b>	patient-cent* OR person-cent* OR "whole person" OR "individuali*ed * care" OR "patient-* relationship" OR "patient-* communication" OR "therapeutic alliance" OR "therapeutic relationship" OR biopsychosocial	patient AND (experience OR perspective OR perception)	"chronic * disease" OR "chronic * condition" OR "chronic * illness" OR non-communicable OR obesity OR diabetes OR cancer OR "cardiovascular disease" OR asthma OR "mental health" OR anxiety OR depression OR arthritis OR "musculoskeletal condition"	January 2008 to January 2018
<b>CINAHL (EBSCOhost)</b>				
<b>PsycINFO (EBSCOhost)</b>				
<b>PubMed (NLM)</b>				

**2.2.2.1 Selection criteria and screening process**

Citations collected from the literature search were downloaded to EndNote X8 (Clarivate Analytics 2017) reference management software. Duplicates were removed before screening the citations against selection criteria. The selection criteria were defined with the purpose of including literature reflective of the experiences and perspectives of individuals with chronic conditions consulting with providers in a range of contemporary health care settings. With consideration to the nature of PCC, it was deemed imperative that data be reported from patient perspectives, while length of time since diagnosis of a chronic condition was given attention to ensure the context of chronicity was accounted for. Accordingly, studies were deemed to be eligible for inclusion if they met the following criteria:

1. Constituted original, peer-reviewed research;

2. Employed naturalistic observational study designs;
3. Presented patient-reported data;
4. Described experiences of PCC (or an absence of PCC) in clinical consultation with health care practitioners of conventional or CM professions. Experiences of PCC were defined as patient reports regarding aspects of care that aligned with any of the eight principles of PCC (108);
5. Participants had been diagnosed with a chronic condition at least 12 months prior to the study;
6. Participants were adults, capable of communicating, without cognitive impairment.

Studies were excluded from the review if they involved an experimental study design as they could not be considered reflective of contemporary health care practice. No literature was excluded on the basis of language.

Citations were initially screened by HF in accordance with selection criteria by title, then by abstract content. Remaining citations were read in full-text by HF and retained when all selection criteria were met. Due to the large number of studies retained at this stage, full-text reading began with the methods section of articles to more efficiently screen against selection criteria. These retained citations were sorted into quantitative and qualitative designs during a second full-text reading, during which it was observed that quantitative data was sparse and narrowly focused on specific aspects of clinical care (e.g. information provision to patients), while qualitative data was abundant and reported richly on a broad scope of clinical care experiences. The retained papers were shared with AS in full-text for a second perspective. Discussion within the whole research team (HF, JA, AS) regarding the sparse quantitative data and the rich qualitative data led to a revision of the review methodology, whereby it was decided by consensus that a meta-ethnographic analysis was most suited to the available literature, as outlined in section 2.2.1. This revision of methodology led to the inclusion of an additional selection criterion:

7. Reported qualitative data including thick description (qualitative data is reported in detail and interpreted within context) (117).

The eMERGe meta-ethnography reporting guidelines (111) were employed throughout the proceeding review process. Full text articles were assessed once more against the additional criterion by HF. Where the inclusion of a study was in question, the research team (HF, AS, JA) discussed the study and compared it against those already included until a consensus decision was made regarding its suitability for synthesis.

### *2.2.2.2 Critical reading and data extraction*

Selected studies were collected in PDF formats, arranged chronologically in ascending year of publication, and subjected to repeated critical reading by HF with each article read at least three times for familiarisation. The initial round of critical reading was conducted alongside data extraction of the study characteristics, which were extracted into a pre-prepared table covering year of publication, study design, location by country, study setting, type of health care provider involved, participant population, participant conditions/diagnoses, sample size and funding source. The data extraction table also included a column for each of the eight principles of PCC, which were used as a template to identify which principles were reported in each paper.

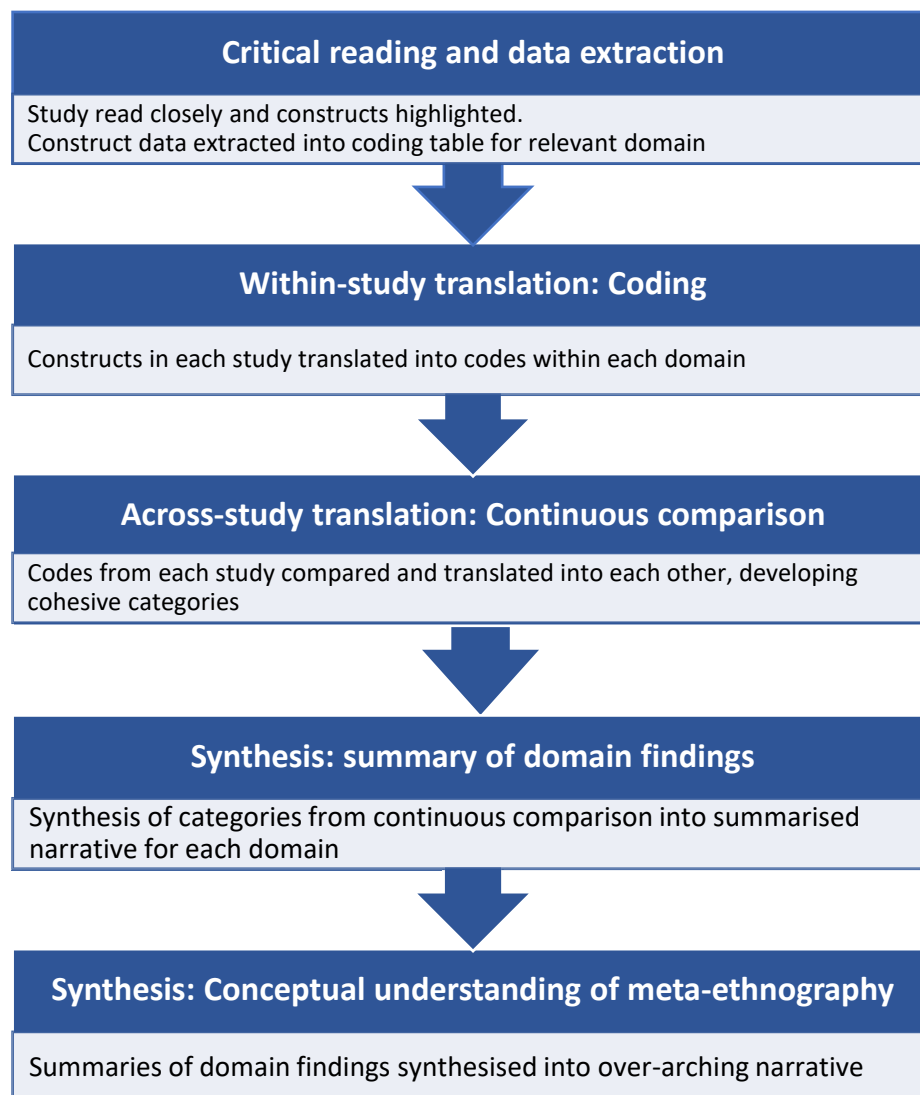
An additional round of critical reading was conducted on the findings sections of selected studies for each of the eight principles. These subsequent rounds included colour-coded highlighting of PDFs corresponding to each principle of PCC, which was marked in the data extraction table to indicate whether that principle was reported in a positive manner or a negative manner in each study. A positive mark was made if the study participants had reported experiencing that principle of PCC (e.g. participants felt their preferences were respected), while a negative mark was made if the study participants had actively reported an absence of the principle (e.g. participants felt their preferences were disrespected or dismissed). This provided a visual means of overviewing general trends reported across the literature regarding which aspects of PCC were reported and the typical nature of associated reports, as well as a cross-reference guide to use when comparing studies during synthesis.

Coding tables for each principle were also pre-prepared into which the highlighted data were extracted during critical reading, with additional columns to be utilised for coding during within-study and across-study translation. Data extracted into the coding tables included the relevant constructs (themes from each study and explanatory content) relating to each principle of PCC, as well as each study's aim to retain context during coding. Construct data were extracted in the order they appeared in each article, so as to maintain the narrative of the study. As data were extracted, italics were applied to represent first-order constructs (quotes made by participants) and bold text was used to represent second-order constructs (interpretations made by researchers) to ensure appropriate context was considered during coding and synthesis. Critical reading and data extraction were performed by HF, with key papers and associated data extraction tables reviewed by JA.



### 2.2.2.3 Translation and synthesis

Translation and synthesis occurred across four steps: 1) within-study translation (coding); 2) across-study translation (continuous comparison); 3) summary of principles (synthesis of findings for each principle of PCC); and 4) synthesis of the conceptual understanding of the meta-ethnography. A flowchart of the process from critical reading to synthesis is presented in Figure 2.3.



**Figure 2.3 The translation and synthesis process**

Within-study translation aims to determine how the selected studies are related by creating a list of coded themes from each paper and juxtaposing them (109). Our

approach to within-study translation involved creation of a list of codes from the extracted construct data in the coding tables. Construct data were translated into codes representing how findings of each article related to each principle of PCC. The same codes were applied to each study as appropriate, with amendments and additional codes generated through an iterative process of comparing the original constructs of each study with the developing list of codes. This iterative process allowed integration of common and recurring concepts into each code, as well as identification of concepts unique to any particular study. Colour-coded highlighting was employed to visually track which parts of the construct data each code was drawn from. While within-study translation was conducted using primarily second-order constructs, as is the manner of meta-ethnographic process (110), first-order constructs were referred to throughout the translation process to avoid reification by ensuring coding was appropriately contextualised to the patient perspective.

The function of across-study translation is to translate studies into one another. This translation is conducted by examining the *meaning* of concepts, then searching for similarities and differences of that meaning between studies (118). We conducted across-study translation through continuous comparison in chronological order of study publication date relating to each principle of PCC. Chronological order is often recommended in meta-ethnography to account for potential contextual or environmental changes occurring over time (113). The first two studies were translated into one another, collapsing or separating codes into synthesised categories of meaning, into which the codes of the third study were translated, and so on. To ensure the categories were reflective of each study's meaning, continual reference was also made to the original extracted construct data and each study's reported aim. Meaning was translated by considering the vocabulary used, the context of the study and the definitions of each PCC principle (80). This iterative process of coding and categorisation functions as scaffolding to develop the conceptual interpretation which represents the findings of meta-ethnography, in contrast to traditional methods of qualitative synthesis which use coding to develop findings in the form of descriptive or explanatory themes.

The categories produced in across-study translation were then used to synthesise each principle into a narrative summary. Translation and synthesis were conducted by HF and checked by JA and AS. At the conclusion of across-study translation for each principle, the two papers which had contributed the most data to translation for that principle were selected for feedback, with one highlighted PDF and corresponding coding table each sent to JA and AS for assessment and feedback. Upon conclusion of

summarisation for all eight principles, the resulting summaries were reviewed and edited by all members of the research team.

The final synthesis of an over-arching 'conceptual understanding' of the meta-analysis was conducted by comparing the summaries for each principle to identify patterns, recurring themes, and relationships between the principles. These patterns, themes and relationships were then examined to draw new meaning from the findings by integrating the context and relationships of each principle into a cohesive, holistic overview (see section 2.2.3.5).

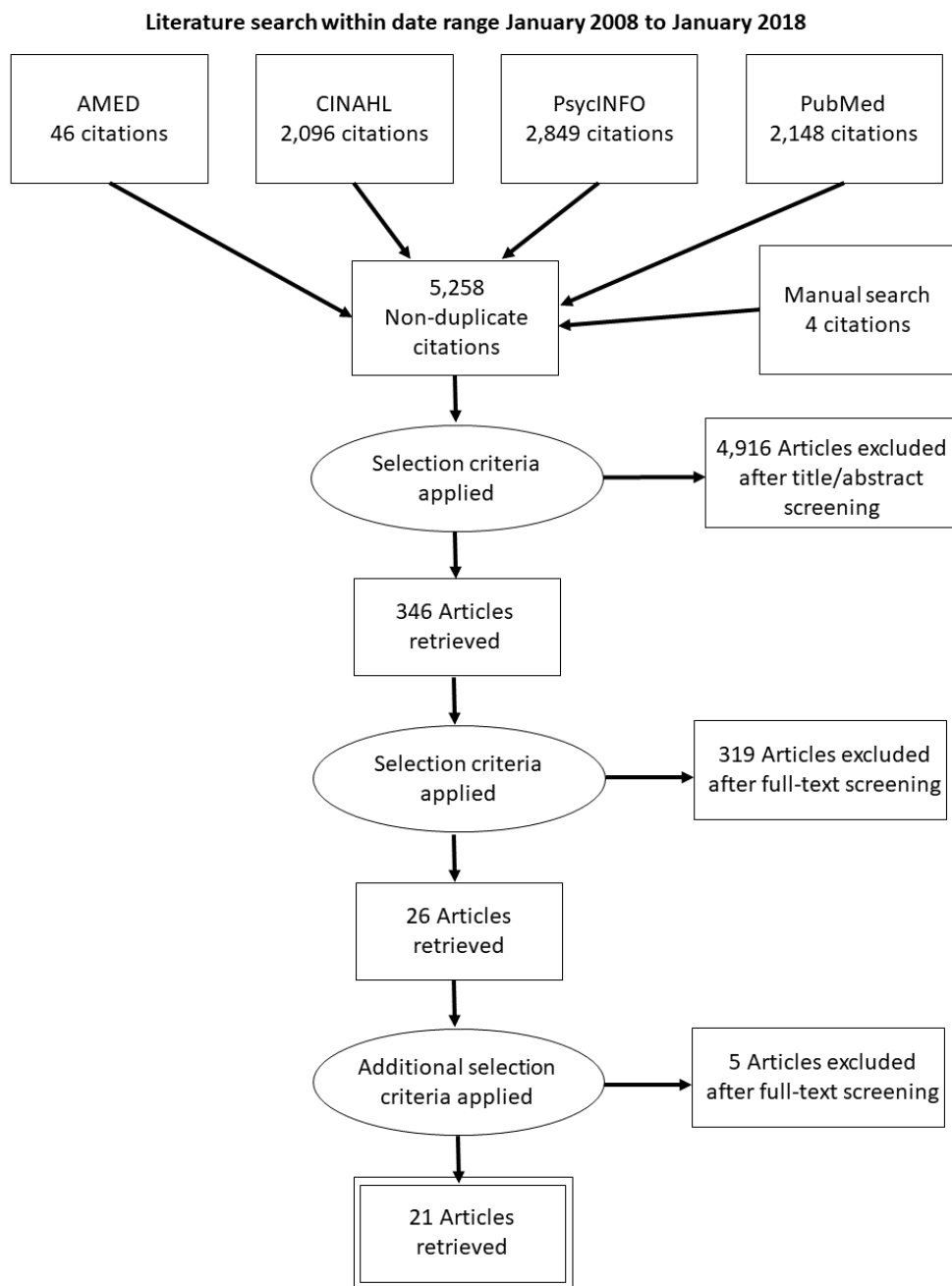
#### *2.2.2.4 Critical appraisal*

The critical appraisal method employed to assess the quality of studies in this meta-ethnography was Toye et al.'s model (119). Toye et al.'s approach is based on an examination of the facets of research methodology considered to contribute most importantly to the goals of a meta-ethnography, namely to produce a new conceptual understanding through interpretive analysis (109). The model considers whether a study meets the criteria of 1) Conceptual clarity and 2) Interpretive rigour. Conceptual clarity refers to whether the paper presents concepts in a manner that enables theoretical insight, while interpretive rigour refers to the trustworthiness of the research, examining three sub-criteria of a) context, b) inductive interpretation and c) interpretation being challenged (119).

Due to concerns in qualitative meta-syntheses that richness of data is sacrificed when inclusion of studies rests on critical appraisal, we conducted critical appraisal following completion of the synthesis process as a measure of the contributions of each paper to the synthesis (119). In accordance with Toye et al.'s approach, papers were assessed as meeting each criterion in a manner that was satisfactory or unsatisfactory/not reported, and defined as a key paper (KP), satisfactory paper (SAT) or fatally flawed paper (FF). The identification of key papers rested primarily on having strong conceptual clarity and having provided a substantial richness of data to the final synthesis. Studies were considered fatally flawed if any aspect of their methodology actively undermined conceptual clarity or interpretive rigour, with the intention that the trustworthiness of the contributions of these studies to the synthesis would be examined.

### **2.2.3 Findings**

The literature search culminated in a total of 5,258 non-duplicate citations, of which twenty-one were found to meet all eligibility criteria and were selected for review and synthesis. Two articles were drawn from the same study and were both included in the selection as they reported on different aspects of care (120, 121). The most common reason for studies being screened out at the full-text stage was that the length of time since diagnosis was either less than twelve months or not reported. Other reasons were data not being directly related to principles of PCC, samples not being limited to those with chronic conditions, experimental and quasi-experimental study designs, data sources not being clearly reported, data not being patient-reported, or findings discussing what patients value hypothetically rather than in relation to actual experiences of care. After the introduction of the additional selection criterion, five studies were also screened out for an insufficiency of qualitative data. A flow-chart of the study selection process is shown in Figure 2.4.



**Figure 2.4 The study selection process**

### *2.2.3.1 Study characteristics*

Selected studies were published between 2008 to 2017 and used primarily interview study designs (23, 120-130). Other study designs included focus groups (131-134), combined interviews and focus groups (135, 136), ethnography with interviews (24), patient narrative case study (137), and exploratory open-ended cross-sectional survey (138). Broad geographical coverage was seen with studies conducted in the United

States (23, 134, 135, 137), Sweden (122-124, 133), the United Kingdom (120, 121, 126), Australia (130, 131), Canada (129, 136), Spain (127), Finland (125), Germany (132), Mexico (24), and Tanzania (128), including one study that collected data from participants in Canada, the United States and the United Kingdom (138).

Settings for recruitment and data collection were most commonly health care clinics or hospitals (23, 24, 120-124, 126, 128, 132-137). Other settings included community service centres and associated support groups (120, 121, 131, 136), general community settings at participant convenience (23, 127, 129), online support groups (138), public health organisation networks (125) and condition-specific support organisations (130). The type of professionals providing the care which participants reported on typically included a variety of health care providers who were often specialised in the chronic conditions the participants were diagnosed with (23, 120, 121, 123, 126-128, 131-134, 136, 137). Some studies focussed on care provided by primary care practitioners (physicians, specialists) (24, 129, 135, 138) or nursing professionals (nurses, nurse specialists, nurse practitioners (122, 124, 125), while one study reported on experiences of care with traditional Chinese medicine practitioners, representing the only CM profession amongst selected studies (130).

Populations under study were typically comprised of adult patients with chronic conditions relating to the research aim of the study, however three studies specifically recruited women (23, 130, 135), one study examined care for participants from specific language groups (English, Turkish, Arabic) (131), and one study explored the experiences of young adults who had transitioned from paediatric to adult care (126). One study involved participants with a variety of chronic conditions (diabetes, breast cancer, asthma, stroke, hepatitis C, nephropathy) (23), another study involved participants with either HIV or diabetes (128), while others focussed on participants with diabetes (122, 125, 131, 134, 135), cancer (127, 129, 130, 136, 137), fibromyalgia (24, 138), multiple sclerosis (120, 121), cystic fibrosis (126), irritable bowel syndrome (123), rheumatoid arthritis (124), mental illness (132), and epilepsy (133). Sample sizes ranged from one (137) to 115 (134), with a total of 508 individual participants across the selected studies and an average sample size of twenty-five. Full details of study characteristics are presented in Table 2.3.

**Table 2.3 Characteristics of studies included in synthesis**

<b>Paper</b>	<b>Year</b>	<b>Study Design</b>	<b>Country</b>	<b>Study setting</b>	<b>Care providers</b>	<b>Population</b>	<b>Condition</b>	<b>Sample</b>	<b>Funding*</b>
Egeli et al. (138)	2008	Exploratory open-ended cross-sectional survey	Canada, USA, UK	Online fibromyalgia support groups and email	Physicians	Patients with fibromyalgia	Fibromyalgia	42 39 F 3 M	Not reported
Fox & Chesla (23)	2008	Interpretive phenomenological interview	USA	Local health centre, hospital, private offices and participant homes	Health care providers	Women aged 35-55 with chronic disease	Diabetes, breast cancer, asthma stroke, hepatitis C, nephropathy	25 25 F	Not reported
Edwall et al. (122)	2008	Narrative interviews	Sweden	Diabetes nurse-led primary care clinics	Diabetes nurse specialists	Patients receiving diabetes nurse-led care	Type 2 diabetes mellitus	20 10 F 10 M	Skaraborg Institute for Research and Development, Skaraborg Research and Development Council, Norrmalm Primary Care Centre
Furler et al. (131)	2008	Focus groups	Australia	Community health service and ethnic support groups	GPs, dieticians, diabetes nurse educators, podiatrists, nurses	English, Turkish and Arabic speaking patients	Type 2 diabetes	52 24 F 26 M	NHMRC
Arora (137)	2009	Patient narrative case study	USA	Not defined	Primary care doctor, specialists, nurses, physiotherapists	Cancer survivor	Lymphoma with associated cardiomyopathy and heart failure	1 1 M	Not reported
Matthews et al. (135)	2009	In-depth interviews and focus group	USA	Three primary care practices	Physician	Older women with type 2 diabetes	Type 2 diabetes	5 5 F	Not reported
Hakanson et al. (123)	2010	Qualitative interviews	Sweden	Gastroenterology outpatient clinic in hospital	Primary, specialist and emergency care providers	Outpatients receiving treatment for IBS	Irritable bowel syndrome (IBS)	9 7 F 2 M	Ersta Hospital, The Swedish Association of People with

Paper	Year	Study Design	Country	Study setting	Care providers	Population	Condition	Sample	Funding*
									Stomach and Bowel Diseases
Bala et al. (124)	2012	Exploratory interview	Sweden	Nurse-led rheumatology outpatient clinics in three hospitals	Nurses with training in rheumatology	Rheumatoid arthritis patients with ≥3 contacts	Rheumatoid arthritis	18 17 F 1 M	Stig & Ragna Gorthon Foundation
Urquhart et al. (136)	2012	Focus groups and interviews	Canada	Tertiary care cancer centres and community survivor support groups	Health care providers in follow-up care	Cancer survivors receiving follow-up care	Breast cancer and colorectal cancer	23 17 F 6 M	Nova Scotia Health Research Foundation
Loos et al. (132)	2013	Focus group	Germany	District hospital and social psychiatry centre	Mental health care practitioners		Severe mental illness	23 F 15 M 8	7 <sup>th</sup> Framework Program of the European Union
Wedlund et al. (133)	2013	Focus groups	Sweden	Hospital neurological rehabilitation clinic	Rehabilitation team (neurologist, neuropsychologist, physiotherapist, social worker, registered nurse)	Patients receiving rehabilitative care for epilepsy symptoms	Epilepsy	17 14 F 3 M	AFA Insurance
Halkoaho et al. (125)	2014	Semi-structured interviews	Finland	Two public health organisations	Nurses	Patients receiving diabetes counselling	Type II diabetes	15 6 F 9 M	Not reported
MacDonald et al. (126)	2015	Semi-structured interviews	UK	Outpatient cystic fibrosis clinic	Health care practitioners in the clinic	Young “expert patients” transitioned to adult care	Cystic fibrosis	8 2 F 6 M	No funding received
Abt Sacks et al. (127)	2016	Phenomenological grounded theory interview	Spain	Various sites in 15 communities, locations chosen by participants	Hospital nurses, surgeons, doctors, liaison services	Breast cancer patients	Breast cancer	41 40 F 1 M	Not reported



Paper	Year	Study Design	Country	Study setting	Care providers	Population	Condition	Sample	Funding*
Colmenares-Roa et al. (24)	2016	Hospital ethnography, in-depth interviews	Mexico	Private clinic and public hospital offering specialised services	Rheumatologists	Patients with fibromyalgia	Fibromyalgia	8 5 F 3 M	No funding received
Mwangome et al. (128)	2016	In-depth interviews	Tanzania	Referral hospital, district hospital, health centre and dispensary	Various HIV health care providers	Individuals receiving care at recruiting clinics	Diabetes and HIV	19 10 F 9 M	NICHE and Ifakara Health Institute
Young et al. (134)	2016	Focus groups	USA	Family medicine and hospital out-patient clinics	Diabetes care providers	Patients receiving diabetes care	Type 2 diabetes mellitus	115 82 F 23 M	Medical College of Wisconsin
Howard et al. (129)	2017	In-depth interviews	Canada	In-person or telephone by participant convenience	General practitioners and oncology specialists	Survivors of childhood cancer receiving long-term follow-up	Leukaemia, lymphoma, brain and other solid tumour, sarcoma	30 18 F 12 M	Canadian Institutes of Health Research
Porter et al. (130)	2017	Semi-structured interviews	Australia	Email via Breast Cancer Network Australia	Traditional Chinese medicine (TCM) practitioners	Women with breast cancer using TCM	Breast cancer	13 F	Not reported
Methley et al. (120)	2017a	Semi-structured interviews	UK	Community groups and primary care practices	General practitioners, specialist and practice nurses	People with multiple sclerosis	Multiple sclerosis	24 18 F 6 M	National Institute of Health Research
Methley et al. (121)	2017b								

\*Primary funding source

### 2.2.3.2 Reported principles of PCC

The PCC principle most commonly reported on was *Information and education of the patient (P4)*, which was discussed by patients in a positive manner in twelve papers (24, 122, 124, 125, 127-129, 131, 133, 136-138), while its absence or inappropriate delivery was also discussed in twelve papers (23, 24, 123-125, 127-129, 132, 135, 136, 138). The principle of *Emotional support (P2)* was also common, with positive experiences reported in nine papers (23, 122, 124, 127, 128, 130, 131, 134, 137) and negative experiences or absence of emotional support reported in twelve papers (23, 120, 121, 123, 124, 127, 128, 131, 134, 135, 137, 138). *Physical needs and comfort of the patient (P3)* (24, 121, 123, 124, 128-130, 133, 135-138) as well as *Accessibility of care (P8)* (24, 120, 121, 123, 124, 126, 128-131, 136, 138) were also frequently discussed, arising in twelve articles each.

The principle which was reported on the least in patient experiences of care was *Involvement of family and friends (P7)*, which was discussed in only three papers, with positive reports in all three (125, 128, 133) and an absence or negative reports arising from two (128, 133). *Coordination and integration of care (P6)* was also somewhat sparse throughout the literature, reported on in eight papers (120, 124, 126, 127, 129-131, 137). Full details of the frequency of reporting of PCC principles are presented in Table 2.4.

**Table 2.4 Principles of person-centred care reported on in selected studies**

Study	Principles of person-centred care								Key for principles of person-centred care
	P1	P2	P3	P4	P5	P6	P7	P8	
Egeli et al. 2008 (138)	+	-	-	+	/	/	/	-	P1 = Respect for patients' needs, preferences and values (whole-person care)
Fox & Chesla 2008 (23)	+	+	/	-	-	/	/	/	
Edwall et al. 2008 (122)	/	+	/	+	+	/	/	/	P2 = Emotional support
Furler et al. 2008 (131)	/	+	/	+	/	+	/	+	
Arora 2009 (137)	+	+	+	+	/	+	/	/	P3 = Physical needs and comfort of patient
Matthews et al. 2009 (135)	/	-	-	-	/	/	/	/	
Hakanson et al. 2010 (123)	+	-	+	-	/	/	/	-	P4 = Information and education of patient
Bala et al. 2012 (124)	/	+	+	+	+	+	/	+	
Urquhart et al. 2012 (136)	/	/	+	+	-	/	/	-	P5 = Continuity of care and transition of care
Loos et al. 2013 (132)	+	/	/	-	/	/	/	/	
Wedlund et al. 2013 (133)	+	/	+	+	-	/	+	/	P6 = Coordination and integration of care
Halkoaho et al. 2014 (125)	+	/	/	+	/	/	+	/	
MacDonald et al. 2015 (126)	+	/	/	/	/	-	/	-	P7 = Involvement of family and friends
Abt Sacks et al. 2016 (127)	+	+	/	+	+	+	/	/	
Colmenares-Roa et al. 2016 (24)	/	/	+	+	-	/	/	+	P8 = Accessibility of care
Mwangome et al. 2016 (128)	/	+	-	+	/	/	+	+	
Young et al. 2016 (134)	/	+	/	/	+	/	/	/	
Howard et al. 2017 (129)	/	/	-	-	-	-	/	-	
Porter et al. 2017 (130)	/	+	+	/	/	-	/	+	
Methley et al. 2017 (120, 121)	+	-	+	/	+	+	/	+	

+ Presence of principle (positive report), - Absence of principle (negative report), / Principle not reported (no data)

### *2.2.3.3 Relationships between reviewed studies*

Meta-ethnographic analyses categorise the translation of studies as reciprocal (reporting similar or confirmatory findings), refutational (reporting contradictory findings) or complementary (reporting on different aspects of the same topic) (109). The arrangement of studies into the eight principles provides a concise overview of the complementary relationships between our reviewed studies, which report on different aspects of patient experiences of PCC. Consideration of whether patient reports denoted positive experiences of each principle, or whether they denoted an absence or negative experience demonstrate that some studies related to each other in a reciprocal way (reporting similar findings). Other studies reported findings dissimilar to each other, however, during translation they were not considered refutational as these findings were not truly contradictory; rather they indicated that within the context of chronic illness, patient care is complex and experiences of PCC are likely influenced by many factors. These dissimilar findings were thus more representative of an additional level of complementary translation. The combination of reciprocity and complementarity led to substantial retention of within-study translation codes as across-study translation categories, with categories encompassing a greater richness of meaning rather than collapsing of meanings together. The following findings from translation and synthesis explore the details of the observed complexity in patient experiences of PCC.

### *2.2.3.4 Synthesis of principles*

This section outlines the synthesis summary for each principle of PCC. Indicative quotes from key papers are provided for each principle to offer examples of construct data extracted. These indicative quotes present the second-order constructs from synthesised papers with associated first-order constructs (in italics) for supporting context.

#### *2.2.3.4.1 PRINCIPLE 1: RESPECT FOR PATIENTS' NEEDS, VALUES AND PREFERENCES*

Patients with chronic conditions report a variety of perceptions regarding whether their needs, preferences and values are respected during clinical care. Understanding the patient's subjective experience may be the foundation of this principle – patients desire to be listened to and believed about how they experience their condition and how it affects their daily life (23, 123, 126, 138). Care can then be tailored to individuals' needs (126, 127, 133), resulting in patient participation in and adherence to treatment (23, 120, 125, 138), as demonstrated by Fox & Chesla (2008) (23) in Indicative Quote

1 below. When patients are not heard and understood, treatment is less individualised, often resulting in patient disengagement (23, 123, 126, 132, 138).

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**Indicative Quote 1.**

*‘He would say, “I really would like you to be on the insulin pump.” And say the reasons why. “What about this?” And I said, “No I don’t want to.” And he finally said, “I’m really confused about you. Why are you resisting this?” And I said, “You know that I faint when you give me a blood test. Don’t like needles.” He said, okay, “I understand that.”’*

There was between them a commitment to understand the concerns of the other and to negotiate the progress of treatment in a manner that was mindful of these concerns. Out of respect for Tillie’s reluctance, the physician paced recommendations to her readiness. His willingness to wait and to puzzle with her about her reluctance to try the pump enabled her self-exploration. ... Tillie felt respected.

From the narrative, it seems that the physician accepted Tillie’s position on her diabetic management, and even though she did not want to do as he recommended, he continued to actively work with her to improve her health. His flexibility was key to how they worked together and, we might surmise, was key to her eventual willingness to take the leap.

**(From Fox & Chesla 2008 (23))**

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While patients differ in their desire to participate actively in their care, the *opportunity* to participate is key (23, 120, 123, 127, 132, 137). Being included in decision-making makes patients feel respected and empowers them to engage with the care process to the extent they prefer, resulting in a sense of autonomy and self-efficacy (23, 120, 123, 127, 132, 137). Being given the opportunity to participate also increases trust in the provider’s advice, enhancing treatment adherence (23, 120). Patients who are not given such opportunities can perceive a loss of control, causing disengagement and non-adherence (23). Within clinical decision-making, patients value the coalescence of technical skill and interpersonal care, preferring care to be both evidence-based and aligned to their individual circumstances (127, 138).

#### 2.2.3.4.2 PRINCIPLE 2: EMOTIONAL SUPPORT

Emotional support is important and highly valued by patients with chronic conditions (120, 127, 130, 134), illustrated by their reports that when lacking emotional support, they seek it from other providers (134). Emotional support requires the provider to listen and empathise (123, 134, 138), which empowers patients through a sense of

participation in care (23, 122, 137). The importance of listening is demonstrated by Egeli et al. (2008) (138) in Indicative Quote 2. The provision of emotional support with honesty also builds trust, which in turn facilitates treatment adherence, prevents patient disengagement, inspires hope and relieves the stress, anxiety and feelings of isolation that can accompany chronic conditions (23, 122-124, 127, 128, 137).

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**Indicative Quote 2.**

The word 'listen' appeared frequently in the written responses. Participants requesting that physicians listen reported feeling ignored, rushed, belittled, and that care was inadequate. As one participant wrote:

*'Listening is the big thing that makes a difference. There are limited treatments for fibromyalgia, so giving the patient a voice helps emotionally.'*

**(From Egeli et al. 2008 (138))**

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When bad news or constructive criticism is delivered, emotional support from the provider can alleviate patient fear and shame while providing a sense of security in the treatment process (122, 127, 128). Lack of emotional support in such circumstances provokes distress (131, 135). Facing the ongoing psychosocial challenges of chronic conditions without emotional support from providers may lead to feelings of uncertainty (135, 137), while dismissal of emotional needs can evoke a sense of distress or humiliation for patients (23, 121, 123, 124, 127, 134, 138).

#### 2.2.3.4.3 PRINCIPLE 3: PHYSICAL NEEDS AND COMFORT OF PATIENT

Experiences of care regarding physical needs and comfort vary for those with chronic conditions. Patients with 'invisible' conditions (where the pathology is difficult to define) (24, 123, 129, 138) and patients in public health settings sometimes report challenges with having these needs met, while those visiting specialist or private clinics often report favourable experiences (24, 123, 129, 133, 136). In cases of 'invisible' conditions, patients feel their physical needs are unaddressed due to poor understanding of the condition or provider dismissal of symptoms (particularly pain) as psychological rather than physical (24, 123, 129, 138). This leads to a sense of abandonment, which may be relieved in specialist settings where a deeper understanding of the condition offers patients validation and more adequate treatment (24, 123, 129). Physical needs and comfort for those with chronic conditions are best addressed when technical and psychosocial care are combined (24, 124, 137), as described by Bala et al. (2012) (124) in Indicative Quote 3 below. Inadequate attention

by providers to patients' physical needs can lead to symptoms being missed, patient disengagement, and reduced quality of life for patients (121, 133, 135).

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**Indicative Quote 3.**

The care during infusion treatments was described as skilful when the nurses' approach imbued feelings of security and calm in connection with the insertion of peripheral venous catheters and infusion reactions:

*' . . . there is no uncertainty when it comes to her. She is calm and confident, and absolutely stable, which makes me feel that way too.'*

**(From Bala et al. 2012 (124))**

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In settings designed primarily for acute care, those with chronic conditions can feel guilty for seeking care to address physical needs indirectly associated with their condition (136), or frustrated with the difficulty of having their needs met (129). These feelings inhibit care-seeking, risking inadequate treatment (129, 136). Conversely, in specialist settings where care is tailored to the condition, patients describe receiving comprehensive care extending beyond their immediate pathology, improving their quality of life and self-management (24, 123, 129, 133). This comprehensive care was also experienced in CM clinics (130). The physical environment of clinics can also be especially important for those with chronic conditions whose mobility or physical comfort can be inhibited by pain and disability (24, 124), or who may require attention to privacy due to stigma surrounding their condition (e.g. HIV) (128). Physical comfort and privacy are described as more well-tailored to these patients in private and specialist settings (24, 124, 128).

*2.2.3.4.4 PRINCIPLE 4: INFORMATION AND EDUCATION OF THE PATIENT*

When patients are well-informed about their condition and treatment, they are motivated to follow treatment advice, confident in self-management and satisfied with participation in care (24, 122, 124, 128, 131, 137, 138), especially when information is individualised to their needs (127). This confidence arising from such patient education is demonstrated in Indicative Quote 4 below, from Edwall et al. (2008) (122).

Insufficient information from providers can leave patients distressed or uncertain about their health and lacking in self-management skills (23, 24, 123, 127, 129, 135, 136). With inadequate knowledge about their condition, patients are also challenged to inform providers of relevant symptoms, resulting in missed opportunities for treatment and preventive care (23, 129, 135).

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**Indicative Quote 4.**

This means becoming confident and independent with help to understand diabetes and disease management; a reflected competent process of learning, doing and knowing what is best for oneself. It means internalizing the daily mastery of diabetes and gives a feeling of safety in your own body. It comprises reliance on the diabetes nurse specialist (DNS) and oneself in a feeling of disease management independence and confidence in everyday life:

*'I started to think about how I felt when I had been working hard in the garden and realised...again with the DNS's help...that my blood sugar was too low...I needed something sweet.'*

When patients were guided within the disease process, they also developed the ability to use and transform this energy and take care of their own disease control.

**(From Edwall et al. 2008 (122))**

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Trust in the provider is integral to patient acceptance of information and education (23, 24, 122, 127). When a provider's knowledge is perceived as untrustworthy or inadequate, patients seek information elsewhere, which can be either empowering or confusing for the patient (125, 127, 132, 135, 136). Specialised services play an important role for those with chronic conditions, often providing quality information and detailed patient education (124, 125, 127, 131, 133, 135). Patients with 'invisible' or poorly understood conditions (e.g. fibromyalgia) can find themselves educating their provider about the condition and express a desire for providers to be better informed (138). For those with such conditions, receiving comprehensive information about their condition from trusted providers can offer emotional validation and relief (123, 133).

Information provision and education are most effective when delivered in accordance with respect for patients' needs, preferences and values (P1), and emotional support (P2) (23, 24, 127, 129, 132, 136). Patients with chronic conditions require information tailored in quality and quantity to their level of health literacy (24, 124, 127, 135-137), timed in an appropriate manner (127, 129, 136), with sensitivity to their emotional and cognitive state (24, 127, 132, 133, 136). Information delivered in a disrespectful way damages the trust patients have in their providers and, subsequently, adherence to treatment.

Patients with chronic conditions frequently report the amount of time given to standard general practice consultations to be insufficient for discussing their varied and complex



needs (123, 127, 135). For some patients, this problem can be somewhat ameliorated through the provision of additional educational resources such as written materials, phone calls, and appropriate referrals to secondary, allied, complementary and specialist services, though consultation time with their primary care provider is still highly valued (124, 127, 131, 133, 136).

#### 2.2.3.4.5 PRINCIPLE 5: CONTINUITY OF CARE AND TRANSITION

Patient experiences of continuity and transition vary in chronic illness care, with positive reports relating largely to relational continuity (continuous care from the same trusted provider), and unfavourable reports relating to an absence of relational continuity or disruptions when transitioning between different care settings (121, 122, 124, 127, 129, 133, 134, 136). For patients with chronic conditions, relational continuity enables long-term, uninterrupted care and familiarity, which avoids the frustration of patients repeating long and complex histories (121, 127, 129, 133, 134). Relational continuity also fosters trust, supports patients to communicate openly about sensitive issues and enhances patient education, leading to greater self-efficacy and independence (121, 122, 127, 129, 133, 134, 136). A lack of relational continuity results in interruptions to treatment, patient uncertainty and, in some cases, clinical mismanagement (23, 24, 121). Patient appreciation of relational continuity is illustrated below in Indicative Quote 5, from Methley et al. (2017b) (121).

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#### **Indicative Quote 5.**

Relational continuity ... was reported to be highly valued by all participant groups. In primary and secondary care, long-term relational continuity allowed professionals to learn patients' medical histories and psychosocial context, allowing them to holistically appraise new or progressed symptoms:

*'I would say that I feel quite safe with him [GP]. I think it makes me feel safe that I don't actually have to remember to say what year this happened, can you remember when, so I don't have to have the explanations because he's got it all there and he knows.'*

It was thought to allow easier discussion of potentially sensitive topics.

**(From Methley et al. 2017b (121))**

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Transitioning between care types (e.g. intensive to general settings, paediatric to adult settings) is often difficult for patients with chronic conditions, involving insufficient support in navigating such a shift and leading to feelings of abandonment and distress

(129, 133, 136). Relational continuity eases these challenges and is so valued by some patients they will travel long distances to maintain a relationship with their trusted provider (121).

#### 2.2.3.4.6 PRINCIPLE 6: COORDINATION AND INTEGRATION OF CARE

Patient experiences relating to coordination and integration of chronic illness care largely rely on a primary care provider as the gatekeeper to other services (124, 127, 131, 137). Effective coordination and integration of the various services required by patients with chronic conditions enhances patient-perceived quality of care through reduced suffering, improved healing and quality of life (127, 137). When not supported to navigate services, patients may experience difficulty accessing some services, and opportunities for adjunctive care may be missed (127, 129). This is improved through communication between different service providers (120, 127, 129, 137), as illustrated by Howard et al. (2017) (129) in Indicative Quote 6.

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#### **Indicative Quote 6.**

When a specialist successfully communicated the survivors' risks and recommendations for risk-based care to the family doctor, their knowledge and willingness to be involved improved.

*Dr. [specialist] was talking and sharing test results and reports back with my GP and I think she [general practitioner] finally understood what my needs were. So now she's a little bit more on the ball with, okay, well we'll have to get you in for a mammogram, we'll have to go test you for your bone scans. Now we've got to get this now and I think she's a little bit more aware that it may be different than say any other patient.*

**(From Howard et al. 2017 (129))**

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Effectively coordinated and integrated approaches to chronic illness care offer patients security, while a lack of coordination between different sources of care leaves patients feeling insecure, untrusting and confused (124, 127). Poor coordination may manifest as patients receiving contradictory information from their various providers, or shortfalls in care when responsibilities are not clearly divided between the providers (124, 127, 129).

Integration of various allied health and CM services appears to play an important role for some patients with chronic conditions (120, 130). Some patients take great value from CM use, expressing a preference for an integrated approach to the inclusion of

CM in their care, and for more support from their conventional care providers in managing concomitant use (130). The integration of psychological services can also be valued by some patients in response to the psychosocial impact of living with chronic conditions and can help to clarify when pharmaceutical treatment for psychological symptoms is required (120).

#### 2.2.3.4.7 PRINCIPLE 7: INVOLVEMENT OF FAMILY AND FRIENDS

Patients with chronic conditions commonly report utilising family and social networks as resources to manage their conditions or quality of life. However, this typically happens as part of patients' self-management, rather than being facilitated by health care providers (125, 128). Some patients enlist the assistance of friends, family and neighbours with health care qualifications, outside of formal care settings (128). Others express a desire for more support services and information about their chronic condition tailored to their family members (133). Others still face challenges whereby the burden of being a caregiver for family members can interfere with their ability to manage their own chronic condition (125).

As part of their health care provision, many patients find group care/education sessions with others (sharing insights and experiences of their condition) a valuable source of social support and validation to reduce feelings of isolation (128, 133). The value of group care is described by Wedlund et al. (2013) (133) in Indicative Quote 7, below.

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#### **Indicative Quote 7.**

Group sessions gave the opportunity to listen to how others dealt with their everyday problems and, in that way, get ideas on how to solve their own issues. Participants pointed out, both from positive and negative experiences of being in a group, the importance that the participants in such groups have similar levels of function. A couple of groups talked about the value of meeting patients with other neurological diseases treated in the same rehabilitation unit.

*"I believe the support from the other members of the group was extremely important—sharing our experience, supporting each other. That was extremely helpful, in my opinion. One became stronger as a person, too."*

**(From Wedlund et al. 2013 (133))**

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Formally and informally, some patients with the same condition actively learn from each other to improve their self-management skills (128). In some communities,

however, certain conditions (e.g. HIV) carry social stigma which act as a barrier to receiving the support of family and friends, reducing the patient's capacity to fully engage in community (128). Conversely, within these same communities, leaders can sometimes use their social status to protect patients from stigma and ensure their needs are catered to as community members (128).

#### 2.2.3.4.8 PRINCIPLE 8: ACCESSIBILITY OF CARE

Patients with chronic conditions predominantly report general practice as the most accessible service, presenting a central gateway for access to and navigation of other services (121, 130). While specialist services are less accessible logistically, they provide care more well-tailored to chronic conditions (24, 123, 124, 126, 136). Allied services are reported as more difficult to access due to lengthy delays but are highly valued by patients in helping meet their needs (120, 121, 136). CM is also valued highly by some patients and was often readily accessible, however, financial obstacles prevent ease of access when not covered by health insurance (130).

Patients with 'invisible' conditions report difficulties accessing care and other resources related to their condition, such as disability benefits, due to providers either dismissing symptoms or disbelieving their condition as a genuine pathology (24, 123, 138). This is ameliorated in specialist services where patients' conditions are well-understood (24, 123), as described in Indicative Quote 8 below, from Hakanson et al. 2010 (123).

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#### **Indicative Quote 8.**

Annie, a 41-year-old woman, had multiple experiences from emergency care settings because of her recurrent episodes of severe abdominal pain. For a long time, she kept being redirected to health care providers who were unable to help her. She talked about the contrast between her previous experiences of encounters with health care providers and what it was like when she was finally referred to a specialist clinic:

*"There was a huge difference in how you were received. Even when I have been relatively free of symptoms she [the doctor] performed a real checkup."*

Being acknowledged also meant being provided legitimacy through diagnosis after a long illness trajectory, involving the struggle to get help from what the participants experienced as an insufficient health care delivery system.

**(From Hakanson et al. 2010 (123))**

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These specialist services are strongly preferred, providing patients with security (123, 124, 126, 136). However, specialist services often involve long waiting times and complex processes of referral through general practice (24, 136).

Insufficient time during consultation is reported as an obstacle to accessing adequate or quality care (24, 129, 138). This is perceived as a problem with health systems rather than with providers, and is more commonly reported regarding general practice than specialist services (24, 129). Time required to travel to or wait for services is also an obstacle to accessibility of care, particularly when multiple decentralised services are required (128, 129). This problem is compounded for patients whose condition results in reduced mobility or who reside in rural areas (120, 128). Patients appreciate when communication technologies such as telephone consultations provide additional, time-sensitive points of access (124).

The accessibility of private sector services is well-tailored to the needs of patients with chronic conditions (24, 128-130). However, financial inequity is reported to inhibit such access (24, 128-130). Patients who are financially unable to access the care they need resort to less effective options for treatment or go without care entirely (24, 128). This is exacerbated by the economic burden of chronic health management, which can reduce a patient's ability to undertake paid work due to disability and redirect substantial financial resources to health care over time (128, 129). This problem is avoided by patients who have access to well-structured public health initiatives specific to their condition or needs (124, 128, 129, 136).

#### *2.2.3.5 Conceptual understanding*

Patients with chronic conditions perceive positive experiences of PCC when trusted providers demonstrate empathy, understanding and respect for patients' lived experiences, and tailor care to both condition-related needs and patients' individual circumstances. Collaborative patient-provider relationships characterised by relational continuity enable effective clinical communication between patients and providers, building patient trust and security. The trust and security that patients develop when they receive and participate in PCC encourage patients with chronic conditions to practice treatment adherence and develop self-efficacy.

Patients perceive obstacles to aspects of PCC when health systems or providers are not attuned to the needs specific to chronic conditions, or do not account for the effects of determinants of health such as socioeconomic status and disability. Absence or insufficiency of PCC is perceived by patients with chronic conditions as distressing,

causing disengagement from care, non-adherence to treatment, and poor self-management skills. The extent to which the scope of PCC principles are experienced by patients with chronic conditions varies, with an expressed need for more coordinated, integrated care that encompasses social and familial resources.

#### *2.2.3.6 Critical appraisal*

Nine of the twenty-one studies were identified as key papers, providing substantial rich data in a complementary fashion, collectively covering the scope of PCC principles (23, 120, 121, 123, 124, 127, 129, 133, 135, 138). None of the papers were considered fatally flawed, with the remaining twelve studies categorised as satisfactory. All twenty-one papers were satisfactory in the criterion of conceptual clarity, likely as a result of selection criteria requiring a substantive amount of thick description. All studies provided satisfactory context, while six papers either poorly performed or poorly reported on means of challenging interpretation and four did not explore contradictory data adequately to meet the inductive criterion. Results of the critical appraisal process are presented in Table 2.5.

**Table 2.5 Results of critical appraisal**

Study	Conceptual clarity	Interpretive rigour			Outcome
		Context	Inductive	Interpretation challenged	
Egeli et al. 2008 (138)	S	S	S	S	KP
Fox & Chesla 2008 (23)	S	S	S	S	KP
Edwall et al. 2008 (122)	S	S	U	S	SAT
Furler et al. 2008 (131)	S	S	S	S	SAT
Arora 2009 (137)	S	S	S	U	SAT
Matthews et al. 2009 (135)	S	S	U	S	KP
Hakanson et al. 2010 (123)	S	S	S	S	KP
Bala et al. 2012 (124)	S	S	S	S	KP
Urquhart et al. 2012 (136)	S	S	S	S	SAT
Loos et al. 2013 (132)	S	S	S	S	SAT
Wedlund et al. 2013 (133)	S	S	S	U	KP
Halkoaho et al. 2014 (125)	S	S	U	S	SAT
MacDonald et al. 2015 (126)	S	S	S	U	SAT
Abt Sacks et al. 2016 (127)	S	S	S	S	KP
Colmenares-Roa et al. 2016 (24)	S	S	S	S	SAT
Mwangome et al. 2016 (128)	S	S	S	U	SAT
Young et al. 2016 (134)	S	S	S	U	SAT
Howard et al. 2017 (129)	S	S	S	S	KP
Porter et al. 2017 (130)	S	S	U	U	SAT
Methley et al. 2017 (120, 121)	S	S	S	S	KP

S = Satisfactory in meeting criteria, U = Unsatisfactory in meeting criteria, or criteria inadequately reported

KP = Key paper, SAT = Satisfactory paper, FF = Fatally flawed paper

## 2.2.4 Discussion

This meta-ethnography maps a comprehensive and detailed overview of the experience patients with chronic conditions have regarding PCC in clinical consultation with health care providers. The importance, value and utility of PCC for chronic conditions is highlighted by the nature of patients' positive reports, which relate PCC to patient-perceived quality of care, physical and emotional wellbeing, adherence to treatment, and patient self-management. The integral role of PCC in the chronic

condition context is further reinforced by patients' negative reports, whereby the absence of PCC is related to unfavourable outcomes such as patient-perceived inadequacy of care, emotional distress, non-adherence to treatment, alongside missed opportunities for treatment, preventive care and development of patient self-management skills.

Our findings suggest that experiences of PCC vary for those with chronic conditions and appear to be influenced by factors related to the nature of chronic conditions, as well as structural aspects of health systems. For example, the receipt by patients of comprehensive care is challenged by the impacts of chronic conditions on patients' lived experience in varied ways not easily addressed within the limits of general practice. These challenges may be exacerbated for patients with conditions that are 'invisible' or poorly understood, yet may be overcome when health systems enable well-coordinated access to specialist, allied and complementary care. These findings regarding additional obstacles for those with certain conditions are consistent with other literature identifying unmet needs amongst those with conditions that are complex or difficult to treat, such as fibromyalgia (139) or endometriosis (140), and a need for providers to better understand and legitimise patient experiences of chronic illness (83). The challenges to providing optimal PCC for chronic conditions in general practice and public health settings considered in this meta-ethnography are also consistent with the perspectives of providers and policymakers expressed elsewhere. Such perspectives identify structural issues within health systems leading to a lack of integrative multi-disciplinary approaches to chronic illness care, inadequate promotion of patient education and self-management, inflexible funding structures, and accessibility barriers for some demographics (e.g. low income earners, rural residents) (3, 34, 141). While it is the intention of PCC to address such challenges and barriers (80), it appears there is a bidirectional relationship whereby issues relating to chronic conditions and health system structures also present barriers to implementation of some principles of PCC.

Descriptions of patient experiences across different principles of PCC suggest that some principles are given more attention than others in clinical care – or some principles may play more integral roles than others – yet there is a general inter-relatedness of the eight principles. Some principles of PCC appear to facilitate or rely on others to deliver positive patient experiences, such as information and education being supported by respect for patient preferences and emotional support. Cohesive themes connect the different principles, with each part of the PCC paradigm contributing toward patient experiences, and potentially also treatment outcomes. For



example, positive experiences of various principles encourage patient adherence to treatment and development of self-efficacy skills, while negative experiences can discourage adherence. These outcomes appear to be related to patient descriptions of relational factors occurring between patients and providers during care, such as building (or failing to build) trust, respect and a sense of security for patients. These relational factors could be the catalyst for the favourable outcomes associated with PCC in observational (142) and experimental studies (143), as well as for the general impact of patient-provider relationships on treatment outcomes reported in other literature (70). The importance of relational continuity in chronic illness care reported within our meta-ethnography suggests the role of patient-provider relationships may be especially important in chronic conditions, where ongoing care is required over lengthy periods of time.

Our findings support the utility of PCC as a paradigm of clinical care well-suited to chronic conditions, accounting for the need for individualised approaches to patient management. Indeed, the syntheses of multiple PCC principles referred to patients' appreciation of care tailored to their unique circumstances, suggesting an holistic dynamic in PCC that responds to the complexity of chronic conditions. This particular responsiveness of PCC to chronic illness needs has been recognised in related research (82) and policy (2, 4). While there may be limitations to implementing the various facets of an individualised approach in any single primary care setting (144, 145), PCC recognises that coordination and integration with other services and resources can provide a more complete individualised approach (80), which is also consistent with our findings. Current international and Australian national health policy recommend improved coordination and integration of services to better address the burden of chronic conditions on health systems, individuals and communities (2, 4).

Inclusion of specialist and allied services in care, when accessibility permitted such inclusion, was perceived by patients in a particularly positive light throughout our meta-ethnography. However, some patients reported their preferences for including non-conventional care such as CM services in their treatment were not respected by conventional medical providers. Respect for patient preferences surrounding the type of care they access should be considered integral to PCC as it relates to multiple PCC principles, including *Coordination and integration of care*. Appropriate coordination and integration of care is not only intended to enhance patient access to the types of care they need, prefer and value; it may also be important for patient safety and risk management when patients engage in concomitant use of different types of care, such as pharmaceutical medicines and CM treatments (146). This meta-ethnography

discussed the value patients with chronic conditions place on the role of relational continuity with trusted primary care providers, who are also seen by patients to act as gatekeepers to other forms of care. It may be that simple communication between patients and providers about coordination and integration of different types of care could enhance this aspect of PCC for chronic conditions. Australian government reports identify the fragmentation and poor coordination of services in the public health system as obstacles to achieving optimal chronic illness care (34), and research indicates that those with chronic conditions in Australia are typically coordinating their own concomitant use of conventional medicine and CM without support from suitable health care professionals (5). Thus, approaches to structural change in health care delivery through both policy and organisational frameworks that enable more effective coordination and integration of care for those with chronic conditions could be foundational to enhancing PCC in chronic illness management (34).

#### *2.2.4.1 Limitations*

The findings of this meta-ethnography must be interpreted within the context of certain limitations. Primarily, it must be considered that the reviewed studies were not focussed specifically on the paradigm of PCC; rather, the studies reported on patient experiences of care which were translated through a lens of PCC. The implication of this is additional risk regarding loss of context during analysis, although attempts to mitigate loss of context were made via careful attention during translation and synthesis to each study's aims and first-order constructs, and the definitions of PCC principles.

Another limitation of this meta-ethnography is that it encompasses patient experiences with a variety of different health care providers whose varying professions may contribute differently to how PCC is delivered. The methods used in many of the reviewed studies prevented separate analyses regarding different types of providers and it was not within the scope of this analysis to report on that level of specificity. However, the strength of this approach is that the findings will more authentically reflect the broader experiences of those with chronic conditions, who typically consult providers from multiple professions throughout the course of seeking care (104).

#### *2.2.4.2 Gaps in the literature*

While the search strategy used for this meta-ethnography was designed to capture studies examining both PCC as an explicit focus and more general patient experiences of clinical care for chronic conditions, none of the selected studies were purposely

specific to the paradigm of PCC. This was true of the selected studies both before and after the introduction of additional selection criteria to narrow the focus of the review to qualitative literature within a meta-ethnographic design. The lack of direct focus on PCC is contrary to the importance given to PCC in policy regarding management of chronic conditions (2, 4) and indicates a need for research which examines, by design, patient perceptions of PCC for those with chronic conditions.

There was also a lack of studies examining clinical care for individuals with chronic conditions in CM settings, with only one study included in the meta-ethnography, which was within the specific scope of TCM care for women with breast cancer (130). Additionally, all six of the quantitative studies which were screened out after the methodology was narrowed to qualitative literature were conducted in conventional medicine settings (147-151), suggesting a paucity of both qualitative and quantitative data regarding PCC for chronic illness management in CM. Considering the prevalence of CM use amongst those with chronic conditions is estimated to be relatively high and increasing (56), it is important for research to explore how the interface between PCC, chronic conditions and CM plays out from patient perspectives. Such research would enable better understanding of the role CM practitioners play within the wider scope of chronic illness care.

### **2.2.5 Conclusion**

Patients with chronic conditions report a range of experiences regarding the person-centredness of clinical care in general health care settings, with both positive and negative experiences highlighting the role of PCC for this population. While the value of PCC as a tool for chronic illness management is recognised in health care practice and policy, it appears there are still barriers to achieving its full implementation in conventional medical settings. In addition, the practice of PCC in CM settings for those with chronic conditions remains relatively unexamined. Some findings from this meta-ethnography imply that patients have a desire for improved coordination and integration of various health care services, including of CM services with conventional care. With primary care providers often serving as a central gateway for coordination of patients' care, examination of patient-provider communication in conventional medical settings could provide insight into methods for enhancing coordination and integration of care.

## **2.3 DISCLOSURE OF COMPLEMENTARY MEDICINE USE TO MEDICAL PROVIDERS: A SYSTEMATIC REVIEW AND META-ANALYSIS**

This third section of the literature review chapter for this thesis examines patient-provider communication regarding patient use of both CM and conventional medicine. This review provides a foundation from which to address research objectives 5 and 6, as outlined in section 1.2. These objectives focus on patient communication behaviours during consultation with providers in both CM and conventional medical settings with regards to concomitant use of CM and conventional medicines. Delving into the nature of these communication behaviours is crucial to understanding how wider coordination and integration of CM and conventional medicine occurs – or does not occur – in clinical consultation for those with chronic conditions who consult CM practitioners. Previous research suggests that patients themselves currently carry the burden of such coordination in Australia, with little involvement from health care providers (5). This previous research indicates a need to identify how this may be improved to optimise patient care and ensure adequate risk management in cases of concomitant use of multiple forms of treatment. Considering that CM is typically used as a complement to conventional medical care (38), this examination of how concomitant use is communicated between patients and providers is an essential element in the broader research aim of this thesis regarding the role of the CM consultation in health management for individuals with chronic conditions.

Very little research has examined patient communication of conventional medicine use during consultation with CM practitioners. A few studies have included brief reports on rates of disclosure of conventional/pharmaceutical medicine use to CM practitioners, which were included to compare with rates of disclosure of CM use to medical doctors (152, 153). However, the topic has not been thoroughly explored. Consequently, this literature review focuses on assessment of patient disclosure of CM use to conventional medical providers, reporting on rates of disclosure and reasons for disclosing or not disclosing, through a systematic review and meta-analysis of contemporary literature.

### **2.3.1 Publication of review**

The review presented within this chapter has been published as follows:

Foley H, Steel A, Cramer, H, Wardle J & Adams J. Disclosure of complementary medicine use to medical providers: A systematic review and meta-analysis. *Sci Rep*. 2019. 9:1

A copy of the full published article is included below. The journal-formatted version can be viewed in Appendix 2.1

### **2.3.2 Introduction**

Health care seeking invariably involves choices regarding the use of what can often be many competing health care services, treatments and providers from both within and beyond the public health care system. This level of individual choice in health seeking is increasingly recognised with person-centred care being given predilection as a favourable model of care provision in public health (8, 154), situating individuals as active participants at the centre of their health management. Patient autonomy and preference are important features of person-centred care (8) to be considered by medical providers alongside safety and treatment outcomes in their patient management.

Amidst this context, complementary medicine (CM) - a broad, varied field of health care practices and products customarily excluded from conventional medical practice and dominant health care systems (155) – is often the focus of relatively hidden patient health seeking yet is making its presence felt in primary care, chronic disease management and other areas (156). Despite appreciable gaps in evidence of effectiveness (157), CM use remains prevalent amongst the general population (42). While there is controversy amongst medical providers around the role and value of CM (158), the vast majority of CM use is concurrent to conventional medicine (159) with CM users visiting a GP more frequently than non-CM users (6).

Serious adverse effects and harm from CM appear relatively rare but substantial associated direct and indirect risks remain (68, 160), particularly regarding ingestive biologically-based CM (such as herbal medicines or supplements) (67, 161, 162), which may be obtained from unreliable sources, self-prescribed or consumed without professional supervision (55, 68). Exacerbating such risks is an absence of both awareness of concurrent CM and conventional medicine use, and of procedures ensuring appropriate oversight of concurrent use (68). Furthermore, patients often approach CM as inherently safe and may not perceive a need to communicate their CM use to medical providers (163, 164). Addressing the risks associated with concurrent use is the responsibility of both patients and their medical providers (165), and arguably essential for general practitioners in their capacity as primary care gatekeepers (166).

A previous review of the literature pertaining to CM use disclosure to medical providers published in 2004 identified twelve papers published between 1997-2002 reporting a CM disclosure rate of 23-90% alongside key factors - patient concern about possible negative response from their medical provider, patient perception that the medical provider was not sufficiently knowledgeable in CM and therefore unable to contribute useful information, and the absence of medical provider inquiry about the patient's CM use – fuelling non-disclosure (146). Disclosure has been increasingly identified as a central challenge facing patient management amidst concurrent use over the last 13 years (167, 168) but no systematic review or meta-analysis has been conducted on this topic over this recent period.

In direct response, this paper provides an update to the previous review, assessing research findings regarding CM use disclosure to medical providers since 2003. Our review employs a qualitative synthesis to explore disclosure rates, patient attitudes to disclosure, reasons for disclosing and not disclosing, and the role of patient-provider communication in disclosure. In addition, to gain further insight into the extent of this important health services issue across settings, we undertook a meta-analysis of disclosure rates among patients using ingestive biologically-based CM.

### **2.3.3 Methods**

A review protocol was developed in accordance with the PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist (114) and MOOSE (Meta-analysis of Observational Studies in Epidemiology) guidelines (see Supplementary Methods S1 online) (169). We developed the protocol for the systematic review before initiating the literature search. The protocol was not registered on a systematic review protocol database. The strategy for the meta-analysis was developed after all articles had been selected for the systematic review based upon the trend we observed in the rates of disclosure among individuals using biologically-based CM products. Prior to initiating the meta-analysis the protocol was modified to define the statistical methods we would employ for the quantitative synthesis. The final manuscript was prepared in accordance with AMSTAR guidelines (170) where appropriate with respect to the observational nature of the review aim.

#### **2.3.3.1 Review aim**

This review aims to describe the prevalence and characteristics of disclosure of CM use to medical providers.

### 2.3.3.2 Search strategy

The search strategy was informed by the review published by Robinson & McGrail (146). A search was conducted on 13-14 February 2017 on the EBSCOhost platform of the following databases: AMED, CINAHL, MEDLINE, and PsycINFO. Three search strings were combined to identify studies which assessed the use of CM, patient-provider communication, and conventional medicine clinical settings. CM search terms were chosen on the basis of CM modalities identified as common in use among the general population in recent literature (171). Truncation symbols were applied where appropriate to capture related terms. The full search string was as follows: S1 (*complementary medicine OR complementary therap\* OR alternative medicine OR alternative therap\* OR natural medicine OR natural therap\* OR acupunctur\* OR aromatherap\* OR ayurved\* OR chiropract\* OR herbal\* OR phytotherap\* OR homeopath\* OR hypnosis OR hypnotherap\* OR massage OR naturopath\* OR nutrition\* OR diet therap\* OR vitamin therap\* OR supplement OR osteopath\* OR reflexology\* OR traditional Chinese medicine OR yoga*) AND S2 (*disclos\* OR communicat\* OR patient use OR reasons for use OR discuss\**) AND S3 (*medical practi\* OR general practi\* OR health care provider OR primary care provider OR physician*). The full search strategy is outlined in Table 2.6.

In order to provide an update on the review by Robinson & McGrail (146), a date range of January 2003 to December 2016 was set. The reference and bibliographic lists of all studies included in the review were searched to minimise the likelihood of missed citations. In addition, any systematic reviews identified during the literature search which presented data on topics related to the primary research aim were also searched manually. The authors contributed their own content expertise in clinical practice, health services research and primary care to ensure important known articles were not overlooked.

**Table 2.6 Search strategy for systematic review**

Protocol title	Disclosure of complementary medicine use to medical providers: An update and systematic review		
Date	Jan 2003 – Dec 2016		
Database Platform	Search String	Expanders	
<b>AMED</b> <i>EBSCOhost</i>	<b>S1</b> (complementary medicine OR complementary therap* OR alternative medicine OR alternative therap* OR natural medicine OR natural therap* OR acupunctur* OR aromatherap* OR ayurved* OR chiropract* OR herbal* OR phytotherap* OR homeopath* OR hypnosis OR	Apply related words,  Apply equivalent subjects.	
<b>CINAHL</b> <i>EBSCOhost</i>	hypnotherap* OR massage OR naturopath* OR nutrition* OR diet therap* OR vitamin therapy OR supplement OR osteopath* OR reflexolog* OR traditional Chinese medicine		
<b>MEDLINE with full text</b> <i>EBSCOhost</i>	OR yoga) <b>AND S2</b> (disclos* OR communicat* OR patient use OR reasons for use OR discuss*)		
<b>PsycINFO</b> <i>EBSCOhost</i>	<b>AND S3</b> (medical practi* OR general practi* OR health care provider OR primary care provider OR physician)		

### 2.3.3.3 Selection criteria

Our review included cross-sectional data from observational studies as this research design was deemed the most appropriate for determining prevalence of health behaviours, determinants and outcomes (172). All observational study designs constituting original, peer-reviewed research were considered for the qualitative synthesis if they reported on rates of, or reasons for, disclosure/non-disclosure of CM use to conventional medicine providers by a broad range of members from the general population. CM use was defined as the use of any practice or product falling outside of those considered part of conventional medicine (40), whether administered as self-treatment or by a CM practitioner. We excluded experimental study designs, which may have impacted on natural communication patterns between patients and providers, alongside studies assessing specific populations which could not reasonably be considered to represent a broad range of individuals (e.g. disease-specific populations). Studies were not excluded on the basis of language.



During selection of studies for meta-analysis, additional criteria were applied with respect to homogeneity, in order to ensure the central estimate of disclosure frequency would provide external validity. This additional criteria required that participants were adults, the study reported a true and well-defined rate of disclosure occurring within the previous twelve months, and involved participants who used biologically-based CM (herbs/plant-based medicines, vitamins, minerals and other oral supplements). Of those papers reporting studies sharing a common data source (e.g. if multiple papers reported on data from the same survey study), we included only one of those publications in order not to artificially inflate our sample size. In such cases, the risk of bias was evaluated for all such publications and only included that publication deemed to have the lowest risk of bias.

#### *2.3.3.4 Study selection*

Citations were exported into EndNote X8 (Clarivate Analytics 2017) reference management software for assessment. Following removal of duplicates, the initial citations were screened against inclusion/exclusion criteria by title and abstract. Review and commentary articles were set aside for a manual search of their included studies. Remaining citations were screened by full-text perusal and those found to adhere to all selection criteria were selected for review. The reference lists of the selected studies were manually searched for additional articles. Full review of all eligible citations was conducted by the lead author (HF). A selected sample of eligible studies (10%) were reviewed at each stage of screening by a second reviewer (AS), as were any studies under question, and discrepancies were addressed through discussion until consensus was reached. The justification for excluding articles following screening the full text was recorded.

#### *2.3.3.5 Data extraction and risk of bias assessment*

Papers selected for review were re-read thoroughly with data extracted into pre-prepared tables outlining study characteristics, outcomes of interest (disclosure/non-disclosure rates and reasons) and parameters of those outcomes (CM type disclosed, how disclosure was defined). Further to this, papers were read in full-text once more to identify other notable findings relating to disclosure, which were categorised and tabulated heuristically. The template for data extraction was drafted during the pre-review protocol development phase with agreement from all authors. Data extraction was conducted by one reviewer (HF) with a selected sample (10% alongside any data

under question) checked by another reviewer (AS). Any discrepancies were addressed through discussion until consensus was reached.

The resulting tables were examined to identify studies meeting the criteria for meta-analysis. These identified studies were subjected to risk of bias assessment using Hoy et al.'s tool for prevalence studies, which assesses ten items across four domains (sample selection, non-response bias, measurement bias, analysis bias) alongside a summary score (173). Studies identified as high risk of bias were excluded from the final selection for meta-analysis. Risk of bias was considered high if four or more items were not adequately addressed, if the first three items indicated an unacceptable level of sampling bias, or if item ten was not adequately addressed as this item affected calculation of disclosure rates.

#### *2.3.3.6 Data synthesis and statistical analysis*

Due to the expected heterogeneity of each study's parameters of disclosure, no average disclosure rate was calculated for the full review; instead a meta-analysis was conducted on those studies demonstrating sufficient homogeneity in study design and a low risk of bias. The principal summary measure used for meta-analysis was disclosure rate of CM use to medical providers. Meta-analysis was conducted using events (number of disclosers) and subset of sample size (number of CM users) to determine event rates of disclosure. Where studies reported disclosure rates only as percentages, events were calculated using figures for the number of participants who responded to the disclosure question. Where these figures were unavailable, the study was considered to fail to address item 10 on the risk of bias assessment tool and was excluded from meta-analysis.

Statistical heterogeneity between studies was explored using  $I^2$  and chi-square statistics.  $I^2$  values greater than 25%, greater than 50%, and greater than 75% indicate moderate, substantial, and considerable heterogeneity, respectively (174). Due to the relatively low power of this test, a P value of 0.10 or less from the chi-square test was regarded to indicate significant heterogeneity (174). Analysis was completed using Comprehensive Meta-Analysis V3 software (Biostat Inc. 2017).

### **2.3.4 Results**

From an initial 5,071 non-duplicate citations, eighty-six studies were selected for review. The reasons for exclusion at full-text screening are provided in Table 2.7.

**Table 2.7 Studies excluded at full text appraisal with reasons for exclusion**

First Author	Year	Title	Reason for Exclusion
Anbari (175)	2015	Evaluation of Trends in the Use of Complementary and Alternative Medicine in Health Centers in Khorramabad (West of Iran)	Did not report on disclosure of CM use
Avogo (176)	2008	The effects of health status on the utilization of complementary and alternative medicine	Did not report on disclosure of CM use
Ben-Arye (177)	2014	Asking patients the right questions about herbal and dietary supplements: Cross cultural perspectives	Experimental study, used intervention to deliberately increase disclosure rates
Desai (178)	2015	Health care use amongst online buyers of medications and vitamins	Did not report on disclosure of CM use
Emmerton (179)	2012	Consumers' experiences and values in conventional and alternative medicine paradigms: a problem detection study (PDS)	Did not report on disclosure of CM use
Featherstone (180)	2003	Characteristics associated with reported CAM use in patients attending six GP practices in the Tayside and Grampian regions of Scotland: a survey	Did not report on disclosure of CM use
Harnack (181)	2003	Results of a population-based survey of adults' attitudes and beliefs about herbal products	Did not report on disclosure of CM use
Hunt (182)	2010	Complementary and alternative medicine use in England: results from a national survey	Did not report on disclosure of CM use
Zhang (183)	2008	Complementary and alternative medicine use among primary care patients in west Texas	Did not report on disclosure of CM use

### 2.3.4.1 Risk of bias assessment

Twenty studies met the initial inclusion criteria for meta-analysis and were subjected to assessment of reporting quality and risk of bias using Hoy et al.'s tool for prevalence studies (173). Collectively, studies performed poorly across most domains relating to external validity, either due to poor methodological conduct or inadequate reporting on methods relating to target population (item 1), random selection (item 3) and response bias (item 4). However, sampling frame representation was well conducted and reported (item 2). Domains relating to internal validity were addressed well, with the exception of instrument validity (item 7).

Of the twenty studies, four were found to exhibit a high risk of bias due to poorly defined parameters for disclosure rate definition or analysis (184-187) and were consequently excluded from meta-analysis. The remaining sixty-six studies which did not meet the initial inclusion criteria for meta-analysis represented a heterogeneous range of study designs in which disclosure was not reported as a primary outcome, but

as a secondary outcome or qualitative finding, and thus the resulting data underwent narrative synthesis without risk of bias appraisal. Table 2.8 displays full details of risk of bias assessment.

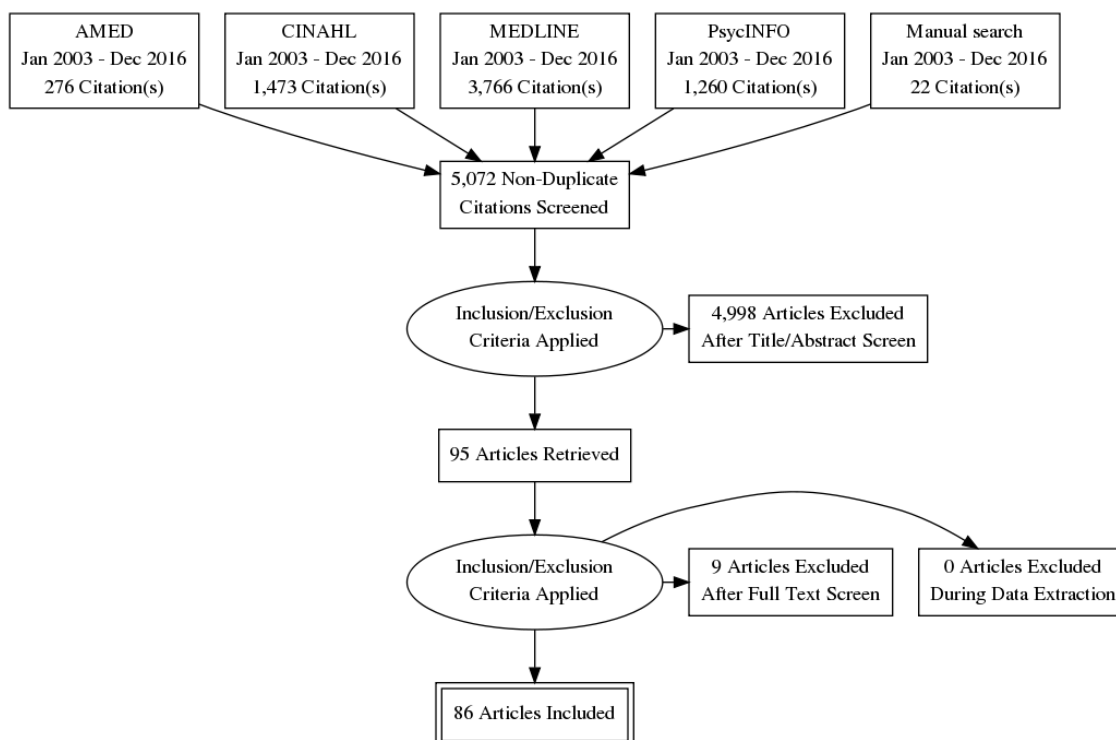
#### *2.3.4.2 Study characteristics*

Of the eighty-six studies reviewed, seventy-nine provided quantitative data (43, 152, 153, 184-186, 188-260), three qualitative data (261-263), and four mixed-method data (187, 264-266) relevant to CM disclosure rates and/or reasons for disclosure/non-disclosure (selection process summarised in Figure 2.5). Nine studies were excluded following review of the full text. A vast majority of the selected studies (n=83) used a cross-sectional survey design (43, 152, 153, 184, 185, 187-260, 264-266), two employed a multistage qualitative approach (261, 262), and one an ethnographic interview design (263). While the final selection of research spanned twenty countries, just under half of the studies (n=40) were conducted in the United States (US) (184-188, 190, 193-206, 208, 209, 211, 226, 229, 230, 237-241, 244, 250, 251, 255, 257, 258, 262-264). Settings were diverse with data collection occurring primarily in general practice or hospital clinics (187-191, 194, 195, 207, 210, 212-216, 218, 219, 224, 226-229, 231, 232, 236, 237, 242, 247, 248, 251, 253, 256, 257, 259, 261, 262, 264-266), face-to-face in participants' households (186, 192, 198-202, 204-206, 217, 220, 222, 234, 235, 238-241, 243, 244, 250, 252, 254), or by telephone and/or mail (43, 152, 184, 193, 197, 203, 208, 209, 223, 225, 245, 246, 258, 260). Less common settings included CM clinics (153, 187, 218), retail outlets (211, 221, 249, 255), community meal sites (196, 263), seminars (228, 230), and online platforms (185, 233).

**Table 2.8 Risk of bias assessment for meta-analysis selection (selected papers in bold)**

Paper	External Validity			Internal Validity						Summary	
	Item 1 Population	Item 2 Sampling frame	Item 3 Sample selection	Item 4 Non- response bias	Item 5 Method of data collection	Item 6 Case definition	Item 7 Instrument validity	Item 8 Mode of data collection	Item 9 Prevalence period	Item 10 Parameter of interest	Item 11 Overall risk
<b>Djuv 2013</b> (227)	N	Y	N	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
Faith 2015 (184)	Y	Y	Y	Y	Y	Y	Y	N	Y	N	High
<b>Gyasi 2015</b> (234)	N	Y	Y	N	Y	Y	Y	Y	Y	Y	<b>Low</b>
<b>Herron 2003</b> (188)	N	Y	N	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
<b>Hori 2008</b> (213)	N	Y	N	Y	Y	Y	N	Y	Y	Y	<b>Low</b>
<b>Hsu 2016</b> (237)	N	Y	N	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
<b>Jou 2016</b> (206)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	<b>Low</b>
Kennedy 2005 (198)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Low
Wu 2011 (204)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Low
McCrea 2011 (185)	N	N	N	N	Y	N	N	Y	Y	Y	High
<b>Mileva-Pecheva 2011</b> (219)	N	Y	Y	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
<b>Naja 2015</b> (235)	Y	Y	Y	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
<b>Nur 2010</b> (217)	N	Y	Y	Y	Y	Y	N	Y	Y	Y	<b>Low</b>
Rivera 2007 (186)	N	Y	Y	N	Y	Y	N	Y	Y	N	High
<b>Shumer 2014</b> (231)	N	Y	N	Y	Y	N	Y	Y	Y	Y	<b>Moderate</b>
<b>Tan 2004</b> (191)	N	N	Y	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>
Tarn 2015 (187)	N	Y	N	N	Y	Y	N	Y	Y	N	High
<b>Thomas 2004</b> (192)	Y	Y	Y	N	Y	Y	N	Y	Y	Y	<b>Low</b>
<b>Torres-Zeno 2016</b> (238)	N	Y	Y	N	Y	Y	Y	Y	Y	Y	<b>Low</b>
<b>Vitale 2014</b> (232)	N	Y	N	N	Y	Y	N	Y	Y	Y	<b>Moderate</b>

N = criterion not adequately met; Y = criterion adequately met



**Figure 2.5 Literature search and study selection flow chart: Prisma flowchart outlining process of literature search and selection of articles for review.**

While some samples consisted entirely of CM users (197, 202, 203, 206, 233, 239, 248), most involved a subset of CM users within a larger sample. Full samples ranged from 35 to 34,525 with an average of 4,144. Amongst those studies reporting figures for the subset of CM users, samples ranged from 28 to 16,784 with an average of 1,268 and a total of 101,417. Participants were predominantly adults with a small number of studies focussed on older adults (152, 196, 209, 244, 245, 255, 260, 263, 264), children (197, 210, 214, 218, 223, 247, 253, 256, 265, 266), adolescents (194, 247), or all age groups (212, 249, 262). More than half of the studies included users of various types of CM (n=45) (43, 152, 153, 184, 188, 189, 191, 194, 195, 202, 203, 206, 209, 210, 212-214, 216, 218, 222, 223, 225, 226, 230-232, 235, 238, 239, 246, 247, 252-263, 265, 266), while others were limited to users of specific types of CM such as herbs and/or supplements (185-187, 190, 196-199, 204, 205, 207, 208, 211, 215, 217, 219-221, 224, 227-229, 233, 236, 237, 242-245, 248-251, 259, 264), yoga (200, 241), tai chi (201, 240), mind-body medicine (193), practitioner-provided CM (192), or local traditional medicine (234).

Almost half of the selected studies (n=40) used a convenience sampling method (153, 185, 187-190, 194-196, 207, 210-216, 218, 219, 224, 226-232, 236, 237, 242, 247, 251, 253, 256, 257, 259, 261, 264-266). However, twenty-two studies used a nationally representative sample (43, 184, 192, 193, 198-206, 223, 235, 239-241, 244, 246, 250, 68

260), while others applied some method of probability randomisation (152, 191, 208, 225, 234, 238, 249), stratification (186, 197, 209, 217, 220, 222, 243, 258), weighting (221, 254, 263), or purposiveness (245, 248, 252, 255, 262) during sampling. Table 2.9 provides full details of the study characteristics identified from the reviewed literature.

Following risk of bias assessment, sixteen studies were considered suitable for meta-analysis of CM disclosure rates. Two were excluded from analysis (198, 204) on the basis that they used data from an earlier version of the same national survey as reported in another included manuscript (206). Studies selected for meta-analysis represented a wide geographical spread including North America (188, 206, 237), Central America (238), Continental Europe (219, 227, 232), the United Kingdom (192), the Middle East (191, 217, 235), West Africa (234), and Asia (213, 231). Sample sizes included in the meta-analysis ranged from 35 to 7,493 with an average of 840 and a total of 11,754 CM users. Papers excluded due to a high risk of reporting bias represented an additional 3,222 CM users.

#### *2.3.4.3 Prevalence and parameters of disclosure*

Rates of disclosure varied substantially across studies, ranging from 7% (264) to 80% (193). Studies including biologically-based CM fell within a range of 7% (264) to 77% (196), while the highest rate of disclosure (80%) was reported by researchers assessing the use of mind-body medicine exclusively (193). Parameters used for defining and measuring disclosure also varied, with the most common parameters outlined as participant disclosure of their use of CM within the last twelve months to a medical provider (n=30) (152, 184-186, 189, 191, 193, 197-202, 204, 206, 209, 213, 217, 218, 220, 221, 223, 231, 232, 234, 235, 237, 238, 245, 250, 265, 266). Others studies examined participants' disclosure to a medical provider of their current CM use (188, 224, 227-229, 233, 248, 259, 261), use within the last month (187, 205, 219, 236), use within the last 24 months (202, 203), had always/usually/sometimes/never disclosed (43, 192, 211, 216, 222, 260), had ever discussed their CM use with a conventional provider (190, 195, 215, 225, 226), had partially or fully disclosed their CM use (208, 264), had disclosed when asked (194), had discussed before use (242), reported rates of disclosure per episode of use (239), or how the patient felt about disclosing (230, 262). A number of papers did not explicitly define their parameters for measuring disclosure (153, 196, 207, 210, 212, 214, 240, 241, 243, 244, 246, 247, 249, 251-258, 263).

**Table 2.9 Study characteristics and details of disclosure**

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Herron (188)	2003	Cross-sectional survey	5 teaching physician offices	United States	Adult patients of rural physician clinics	176 (110)	49%	Various CM	Not reported.
Najm (255)	2003	Cross-sectional survey	Senior centres and shopping malls	United States	Community-dwelling older adults in ethnically diverse neighbourhoods, age ≥65	525 (251)	38%	Various CM	Archstone Foundation and Irvine Health Foundation.
Stevenson (261)	2003	Semi-structured interview	20 general practice clinics and homes of clinic patients	England	Patients of participating clinics, age ≥16	35 (28)	NR	Various CM	UK Department of Health. Sir Siegmund Warburg's voluntary settlement.
Canter (245)	2004	Cross-sectional survey	Self-administered, recruited by magazine and website	Britain	British adults aged ≥50	271 (NR)	33%	Herbs and nutrients	No funding received.
Giveon (189)	2004	Cross-sectional survey	25 primary care clinics	Israel	Patients of HMO clinics	723 (261)	55%	Various CM	Not reported.
Kuo (190)	2004	Cross-sectional survey	6 Primary care clinics, via SPUR-Net PBRN	United States	Adult patients visiting clinics for routine, non-acute care, age ≥18	322 (116)	31-67%	Herbs	Agency for Healthcare Research and Quality. Bureau of Health Professions.
Rolniak (257)	2004	Cross-sectional survey	Emergency department of teaching hospital	United States	Adult patients who were medically stable, age ≥18	174 (82)	69%	Various CM	Mercy Foundation
Tan (191)	2004	Cross-sectional survey	2 University hospitals, internal & surgery polyclinics	Turkey	Adult patients age ≥18, residents of Eastern Turkey	714 (499)	15%	Various CM	Not reported.
Thomas (192)	2004	Cross-sectional survey	Omnibus survey, conducted in households	England, Scotland, Wales	Adults living in UK, age ≥16	1,794 (179)	37%	Practitioner-provided CM	UK Department of Health.
Wolsko (193)	2004	Cross-sectional survey	Telephone, random digit dialling	United States	English-speaking adult residents	2,055 (397)	80% <sup>d</sup>	Mind-body therapies	National Institutes of Health.
Braun (194)	2005	Cross-sectional survey	Urban adolescent ambulatory clinic	United States	Adolescents attending ambulatory clinic, age 12-18	401 (273)	14%	Various CM	National Institutes of Health. Maternal and Child Health Bureau.
Busse (153)	2005	Cross-sectional survey	Naturopathic college clinic	Canada	Patients of clinic, age ≥18	174 (161)	59%	Natural products	Canadian Institutes of Health.
Kim (195)	2005	Cross-sectional survey	4 Emergency departments, 2 teaching, 2 community	United States	Emergency department patients age ≥18, not in acute/emotional distress.	539 (199)	36%	Various CM	Not reported.
Lim (252)	2005	Cross-sectional survey	Homes of participants	Singapore	Adult citizens and permanent residents, age ≥18	468 (356)	26%	Various CM	Not reported.
Shahrokh (196)	2005	Cross-sectional survey	Congregate meal sites in 4 counties	United States	Community-dwelling older adults	69 (35)	77%	Herbs and nutrients	Not reported.
Wheaton (197)	2005	Cross-sectional survey	Computer Assisted Telephone Interview	United States	American adults and their children who used herbs in past 12 months	2,982 (2,982)	34%	Medicinal herbs	Not reported.
Bruno <sup>a</sup> (244)	2005	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	General population older adults, ≥65	5,860 (NR)	43%	Herbs	Not reported.



First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source	
Kennedy <sup>a</sup> (198)	2005	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	30,412 (5,787)	33%	Herbs & supplements	No funding received.	
Kennedy <sup>a</sup> (199)	2008	Secondary analysis of data from Kennedy 2005 (above), describes characteristics of disclosers by ethnic sub-group						18%-37%		
Birdee <sup>a</sup> (200)	2008	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	Civilian adults, sub-population: yoga users	31,044 (1,593)	25%	Yoga	National Institutes of Health.	
Birdee <sup>a</sup> (201)	2009	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	Civilian adults, sub-population: t'ai chi, qigong users	31,044 (429)	25%	T'ai chi & Qigong	National Institutes of Health.	
Chao <sup>a,b</sup> (202)	2008	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	10,759 (10,759)	39%	Various CM	National Institutes of Health	
		Cross-sectional survey	2001 HCQS data set			2,003 (2,003)	66%			
Faith <sup>b</sup> (203)	2013	Cross-sectional survey	2001 HCQS data set	United States	General population adults, age ≥18	1,995 (1,995)	71%	Various CM	Not reported.	
Wu <sup>a,c</sup> (204)	2011	Cross-sectional survey	2002 NHIS Alt Med Suppl. 2007 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	30,427 (5,787) 22,657 (3,982)	33% 46%	Herbs & supplements	Not reported.	
Gardiner <sup>a</sup> (250)	2007	Cross-sectional survey	2002 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	31,044 (5,787)	34%	Herbs	National Institutes of Health	
Laditka <sup>c</sup> (205)	2012	Cross-sectional survey	2007 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	22,783 (16,784)	62%	Cognitive health supplements	No funding received.	
Shim <sup>c</sup> (239)	2014	Cross-sectional survey	2007 NHIS Alt Med Suppl.	United States	General population adults, age ≥18	7,347 (7,347)	46%	Various CM	Not reported.	
Jou (206)	2016	Cross-sectional survey	2012 NHIS Alt Med Suppl.	United States	General population adults ≥18 using both CM & primary care physician	7,493 (7,493)	59%	Various CM	University of Minnesota.	
Cincotta (247)	2006	Cross-sectional survey	University Hospital of Wales Royal Children's Hospital	Wales Australia	Infants, children and adolescents (or their parent/carer) of any age attending hospital as inpatient or outpatient	500 (206) 503 (258)	34% 37%	Various CM	Not reported.	
MacLennan (254)	2006	Cross-sectional survey	Health Omnibus Survey of South Australian households	Australia	South Australian residents, age ≥15	3,015 (1,574)	47%	Various CM	Not reported.	
Saw (207)	2006	Cross-sectional survey	Penang Hospital	Malaysia	Adult patients from cardiology, neurology, infectious and nephrology wards, age ≥18	250 (106)	9%	Herbal medicine	Not reported.	
Shah (208)	2006	Cross-sectional survey	Mail via market research co.	United States	Adult Ohio residents age ≥18	210 (100)	11%-44%	Herbal	Not reported.	
Shive (258)	2006	Cross-sectional survey	Telephone interview-administered questionnaire	United States	General population adults with over-representation of minorities, age ≥18	6,305 (NR)	55-72%	Various CM	National Institutes of Health, National Cancer Institute	
Cheung (209)	2007	Cross-sectional survey	By mail, random selection by driver's licence date of birth	United States	Community-dwelling older adults, age ≥65	445 (278)	53%	Various CM	Center for Gerontological Nursing, University of California.	

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
									University of Minnesota. College of St. Catherine. Minnesota Gerontological Society.
Clement (248)	2007	Cross-sectional survey	16 randomly selected primary health care facilities	Trinidad	Patients aged ≥16 who used herbal remedies	265 (265)	23%	Herbal remedies	Not reported.
Jean (210)	2007	Cross-sectional survey	University-affiliated hospital	French Canada	Children (parents of) attending the hospital as outpatients	114 (61)	47%	Various CM	No funding received.
Rivera (186)	2007	Cross-sectional survey	Households in border cities of El Paso & Ciudad Juarez	United States & Mexico	Residents of border cities, adults.	1,001 (661)	33% (USA) 14% (Mexico)	Herbal products	Paso del Norte Health Foundation.
Xue (43)	2007	Cross-sectional survey	Computer Assisted Telephone Interview, random digit dialling	Australia	Australian adults, age ≥18	1,067 (735)	45% <sup>e</sup>	Various CM	RMIT University. Sydney Institute of Traditional Chinese Medicine. Chiropractor Association of Australia. Australian Acupuncture and Chinese Medicine Association. Australian Research Centre for Complementary and Alternative Medicine.
Zhang (260)	2007	Cross-sectional survey	Computer-assisted telephone interview	Australia	Australian general population adults age ≥18, sub-population: older adults age ≥65	178 (NR)	60%	Various CM	Not reported.
AlBraik (242)	2008	Cross-sectional survey	Primary health care clinic in Abu Dhabi	United Arab Emirates	United Arab Emirates nationals (citizens) attending clinic for general health care	330 (250)	32%	Herbal medicine	Not reported.
Archer (211)	2008	Cross-sectional survey, pilot study	Urban herb store	United States	Store customers, age ≥18	35 (32)	37%	Herbs & supplements	Not reported.
Aydin (243)	2008	Cross-sectional survey, pilot study	Participant households and offices	Turkey	General population adults ≥18, representative of local population	873 (484)	26%	Herbal medicine	Not reported.
Cizmesija (212)	2008	Cross-sectional survey	14 primary care practices	Croatia	Patients in primary healthcare, all ages	941 (301)	60%	Various CM	Not reported.
Hori (213)	2008	Cross-sectional survey	General outpatient clinics of Shiseikai Daini Hospital	Japan	Adult outpatients of non-specialist clinics, age ≥18	496 (246)	42%	Various CM	Not reported.
Low (253)	2008	Cross-sectional survey	Paediatric clinics and hospitals	Ireland	Children (parents of) attending as outpatients and inpatients	185 (105)	40%	Various CM	Not reported.
Ozturk (214)	2008	Cross-sectional survey	Paediatric outpatient clinics of 3 hospitals	Turkey	Children (parents of) attending paediatric outpatient clinics	600 (339)	51%	Various CM	Not reported.

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Robinson (256)	2008	Cross-sectional survey	North West London multi-ethnic hospital	England	Children (parents of) children attending general and sub-specialist outpatient clinics	243 (69)	46%	Various CM	No funding received.
Shakeel (215)	2008	Cross-sectional survey	Aberdeen Royal Infirmary	Scotland	Patients admitted to general, cardiothoracic and vascular surgery wards, age ≥16	430 (196)	40%	Herbal and non-herbal	Not reported.
Levine (152)	2009	Cross-sectional survey	Telephone, randomly selected	Canada	Community dwelling older adult Ontarians, age ≥60	1,206 (616)	75% <sup>e</sup>	Natural health products	Samuel McLaughlin Foundation, Toronto.
Shelley (262)	2009	Multistage qualitative	Low-income serving primary care clinics and community, via RIOS Net PBRN	United States	Patients of participating clinics and members of predominantly Hispanic and Native American communities, all ages	93 (NR)	NR	Various CM	National Center for Complementary and Alternative Medicine.
Delgoda (249)	2010	Cross-sectional survey	18 pharmacies	Jamaica	Adults and parents/carers or children who were using prescription medicines	365 (288)	18% <sup>e</sup>	Herbs	International Foundation for Science, University of the West Indies, SuperPlus Food Stores
Mc Kenna (216)	2010	Cross-sectional survey	Urban general practice	Ireland	Adult patients attending urban GP ≥18	328 (89)	34%	Various CM	RCSI
Nur (217)	2010	Cross-sectional survey	Households and workplaces	Turkey	Adult Sivas residents, age ≥18	3,876 (1,518)	38%	Herbs	Not reported.
Shorofi (259)	2010	Cross-sectional survey	4 metropolitan hospitals in Adelaide	Australia	Hospitalised adults, age ≥18	353 (319)	38%-48%	Herbs and other CM	Not reported
Araz (266)	2011	Cross-sectional survey	Outpatient university clinic	Turkey	Children (parents of) and parents, age ≥17	268 (193)	32%	Various CM	Not reported.
Ben-Arye (218)	2011	Cross-sectional survey	Conventional & CM clinics	Israel	Children (parents of) and parents, insured	599 (NR)	19%, 61% <sup>f</sup>	Various CM	No funding received.
McCrea (185)	2011	Cross-sectional survey	State university, online	United States	College students of introductory psychology course	305 (89)	25%	Herbs	Not reported.
Mileva-Pecheva (219)	2011	Cross-sectional survey	General practice clinics	Macedonia	Adult outpatients of GP clinics, age ≥18	256 (105)	57%	Vitamin & mineral food supplements	Not reported.
Picking (220)	2011	Cross-sectional survey	Households in 3 districts	Jamaica	Adults from urban and rural districts	372 (270)	19%	Herbal medicine	Commonwealth Scholarship Commission. University of the West Indies. Environmental Foundation of Jamaica. Forest Conservation Fund. International Foundation for Science (Sweden).

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Alaaeddine (221)	2012	Cross-sectional survey	Shopping malls	Lebanon	Adults, age 18-65	480 (293)	55% <sup>e</sup>	Herbal medicine	Faculty of Medicine, Saint-Joseph University.
Elolemy (222)	2012	Cross-sectional survey	Households within Riyadh region (city and surrounds)	Saudi Arabia	Residents of Riyadh region, age ≥18	518 (438)	51%	Various CM	No funding received.
Kim (223)	2012	Cross-sectional survey	Telephone, list-assisted random-digit dialling.	Korea	Children (parents or caregivers of), non-institutionalised, age ≥18	2,077 (1,365)	29%	Various CM	Ministry for Health, Welfare & Family Affairs, Korea.
Samuels (224)	2012	Cross-sectional survey	Department of internal medicine	Israel	Hospitalised internal medicine patients, not under sedation	280 (43)	74%	Non-vitamin, non-mineral supplements	Mirsky Foundation
Thomson (225)	2012	Cross-sectional survey	2010 QSS (Queensland social survey) data, telephone	Australia	Adults living in Queensland, Australia	1,261 (778)	60%	Various CM	School of Nursing, Midwifery & Health, University of Stirling
Zhang (226)	2012	Cross-sectional survey	Ambulatory family medicine clinics in 2 cities	United States	Adult patients of participating clinics, age ≥18	468 (452)	55%	Various CM	Texas Tech University Health Sciences Center.
Arcury (263)	2013	Ethnographic interview	Senior meal & housing sites	United States	Community-dwelling older adults, age ≥65	62 (39)	59%	Various CM	National Center for CAM
Djuv (227)	2013	Cross-sectional survey	General practice office	Norway	Patients visiting the GP office, age ≥18	381 (164)	18%	Herbs	Liaison Committee between Central Norway RHA and NTNU.
Lorenc (265)	2013	Cross-sectional survey	4 Primary Care Research Network GP practices	England	Children (carers of) attending GP, age ≥16	394 (179)	25%	Various CM	King's Fund.
Chang (246)	2014	Cross-sectional survey	2007 telephone survey	Taiwan	General population adults, age ≥18	1,260 (NR)	45%	Various CM	Department of Health, Executive Yan, ROC
		Cross-sectional survey	2011 telephone survey			2,266 (NR)	52%		
Chiba (228)	2014	Cross-sectional survey	Healthfood seminars, pharmacies, hospitals.	Japan	In-patients, ambulatory patients & healthy subjects, age <20 to >80	2,732 (874)	28-30%	Dietary supplements or food	Health and Labour Sciences Research Grants.
Chin-Lee (229)	2014	Cross-sectional survey	Community medical practice and community pharmacy	United States	Patients seeking primary health care services, age 18-89	164 (49)	41%	Probiotics	Not reported.
Jang (264)	2014	Cross-sectional survey and audio analysis	Academically-affiliated physician offices	United States	Older adult primary care patients, ≥50, with new, worsening or uncontrolled problem	256 (142)	7%-42%	Dietary supplements	University of California at LA. National Institute on Aging.
Nguyen (230)	2014	Cross-sectional survey	Remote area medical events in 2 counties	United States	Patients seeking free medical care at remote area medical events, age ≥18	192 (94)	44%	Various CM	Not reported.
Shumer (231)	2014	Cross-sectional survey	3 Rural family medicine clinics	Japan	Adults who visit rural Japanese family medicine clinics, age ≥20	519 (415)	23%	Various CM	Shizuoka Prefectural Government.
Vitale (232)	2014	Cross-sectional survey	Primary health centre	Croatia	Adult patients visiting primary health centre for any reason, age ≥18	228 (187)	34%	Various CM	Not reported.

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Chiba (233)	2015	Cross-sectional survey	Online via market research company	Japan	In-patients, ambulatory patients, non-patients, using both CM & medication, age <20 to >60	2,109 (2,109)	26%	Dietary supplements	Health and Labour Sciences Research Grants.
Faith (184)	2015	Cross-sectional survey	National Cancer Institute's HINTS 3 (telephone, mail)	United States	General population adults, age ≥18	7,674 (1,729)	52%	Various CM	Not reported.
Gardiner (251)	2015	Cross-sectional survey	Boston Medical Centre	United States	Adults age ≥18	558 (333)	18% <sup>e</sup>	Supplements and herbs	National Center for CAMs
Gyasi (234)	2015	Cross-sectional survey	Households within two settlements of Ashanti	Ghana	Adult community members, age ≥18	324 (279)	12%	Traditional CM of Ghana	Council for the Development of Social Science Research in Africa. Institute for Research in Africa and French Embassy in Ghana Grant Programme.
Naja (235)	2015	Cross-sectional survey	Face to face in households	Lebanon	Lebanese adults	1,500 (448)	28%	Biologically-based CM	Lebanese National Council for Scientific Research.
Tarn (187)	2015	Cross-sectional survey and audio analysis	Primary care, integrative and CM clinics	United States	Adult outpatients of participating clinics, age ≥18	603 (477)	34-49%	Dietary supplements	National Center for CAM. Office of Dietary Supplements.
Ben-Arye (236)	2016	Cross-sectional survey	In-patients, academic clinic	Israel	Adult inpatients, age ≥18	927 (458)	70%	Herbs & supplements	No funding received.
Cramer (241)	2016	Cross-sectional survey	2012 NHIS Alt Med Suppl.	United States	Civilian adult sub-population: yoga users	34,525 (4,422)	34%	Yoga	German Assn of Yoga Teachers.
Hsu (237)	2016	Cross-sectional survey	Public health centre	United States	Adult patients of Chinatown public health centre, age ≥18	50 (35)	31%	Chinese herbal	Not reported.
Lauche (240)	2016	Cross-sectional survey	2012 NHIS Alt Med Suppl.	United States	Civilian adult sub-population: t'ai chi, qigong users	34,525 (NR)	42%	T'ai chi & Qigong	Not reported.
Torres-Zeno (238)	2016	Cross-sectional survey	Household interviews	Puerto Rico	Adults in Bayamon municipality, age ≥18	203 (187)	36%	Various CM	Not reported.

CM = complementary medicine; NR = Not reported; Disclosure rate = % of CM users

<sup>a</sup> Studies conducted different analyses on sub-populations from the same 2002 NHIS data source

<sup>b</sup> Studies use same 2001 HCQS data, with slightly different sample size and results due to how data was handled

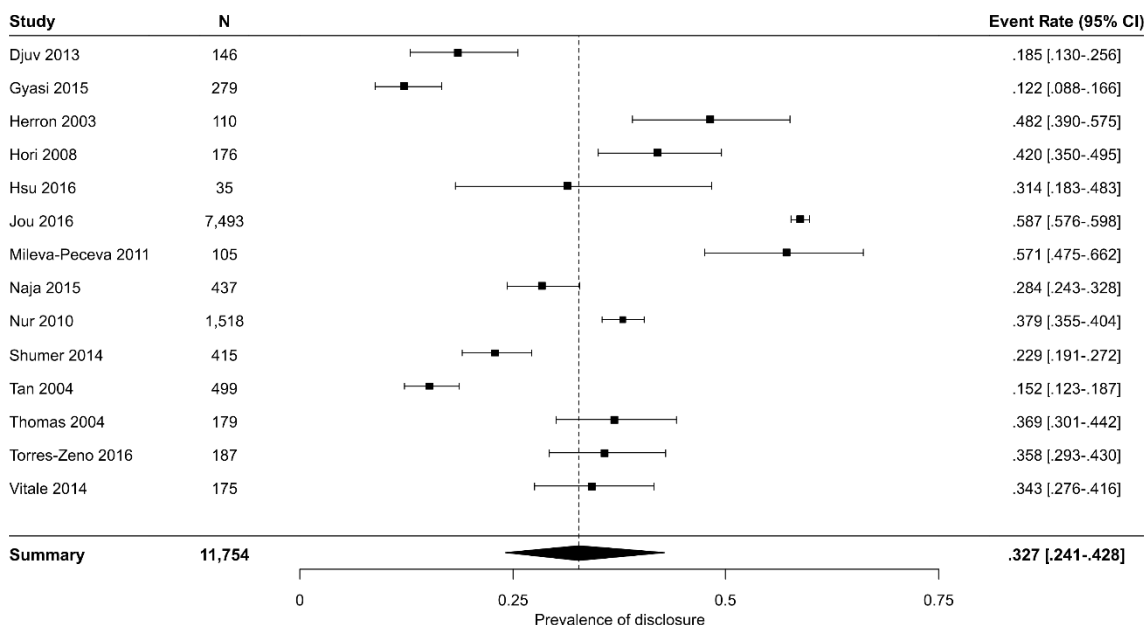
<sup>c</sup> Studies use same 2007 NHIS data, with slightly different sample size and results due to how data was handled

<sup>d</sup> Rate is % of CM users who also saw a physician

<sup>e</sup> Rate is % of CM users who were also taking conventional medications

<sup>f</sup> Disclosure of CM to physician by patients from conventional clinics (19.4%) vs CM (61.2%) clinics

The outcomes of the meta-analysis of the rate of disclosure of CM use by individuals using biologically-based CM is presented in Figure 2.6. The measure of central tendency provided an overall disclosure rate of 33% (95% CI 24.1% to 42.8%,  $I^2 = 98.6\%$ ). Between the fourteen included studies, the lowest reported disclosure rate was 12% and the highest was 59%. Heterogeneity was assessed across the fourteen samples (Q-value 904.955,  $p < 0.001$ ,  $I^2 = 98.563$ ). Although homogeneity was affected by the substantially larger sample size in Jou et al.'s 2016 study (206), the paper was not excluded as it used a strong, internationally recognised dataset with very low risk of bias. The employment of a random effects model accounted for the impact of this study on homogeneity and its inclusion was not found to impact significantly on the measure of consistency within this model.



**Figure 2.6 Meta-analysis results: disclosure rates for biologically-based complementary medicine. Results of meta-analysis assessing rates of disclosure of biologically-based complementary medicine use to medical providers.**

#### 2.3.4.4 Reasons for non-disclosure and disclosure

Twenty-five studies reported participant reasons for non-disclosure (43, 153, 189, 190, 206-209, 217, 226-229, 233-235, 240, 242, 248, 255, 257, 260-263), and four reported reasons for disclosure of CM use to medical providers (208, 261-263). The most commonly cited reasons patients gave for non-disclosure were fear of the provider's disapproval (153, 189, 206-208, 217, 226-228, 233-235, 240, 242, 255, 257, 260-263),

followed by the provider not asking (43, 153, 190, 206-209, 217, 226-228, 233, 234, 240, 248, 260-263), the patient perceiving disclosure as unimportant (43, 153, 206-209, 217, 226, 228, 229, 234, 235, 240, 242, 248, 255, 257, 260), belief the physician would not have relevant knowledge of CM (153, 189, 206, 208, 217, 226-228, 257, 263), lack of time during consultation or forgetting (153, 189, 206, 208, 209, 226, 228, 242, 255), belief that CM was safe and would not interfere with conventional treatment (153, 228, 233, 235, 261), the patient not using CM regularly or at the time of consulting with the conventional provider (206, 228, 233, 235), and previous experiences of a negative response from conventional providers (206, 234, 240, 262). The most commonly cited reason for disclosure was that the provider asked about CM use (208, 261, 262), followed by the patient expecting the provider to be supportive of their CM use (262, 263), believing disclosure was important for safety (208, 263), belief the provider would have relevant knowledge or advice about CM (208), and belief that disclosing CM use may help other patients with the same condition (208). Full details of reasons are shown in Table 2.10.

When participants were asked whether they thought disclosure was important, more than 67% agreed it was (189, 214, 218, 230, 260). This percentage was highest (93%) among participants who were surveyed in CM clinics (218), which was consistent with other studies reporting higher disclosure rates among users of practitioner-provided CM compared with self-administered CM (202, 203, 231, 239). Conversely, one study found lower disclosure rates among those using practitioner-provided CM, specifically where participants were consulting a CM practitioner and a medical provider for the same condition (152).

**Table 2.10 Reasons for non-disclosure and disclosure**

	No. of studies	Studies reporting reason	Studies reporting as main reason <sup>a</sup>
<b>Reasons for non-disclosure</b>			
Patient was afraid of physician's response or thought physician will disapprove	20	(153, 189, 206-208, 217, 226-228, 233-235, 240, 242, 255, 257, 260-263)	
Physician didn't ask or wasn't interested	19	(43, 153, 190, 206-209, 217, 226-228, 233, 234, 240, 248, 260-263)	(206-209, 227, 234)
Patient didn't think it was important or necessary	18	(43, 153, 206-209, 217, 226, 228, 229, 234, 235, 240, 242, 248, 255, 257, 260)	(43, 217, 226, 228, 229)
Didn't think physician had relevant knowledge/wasn't their business to know	10	(153, 189, 206, 208, 217, 226-228, 257, 263)	(189)
No time/physician too busy/didn't think about it/forgot	9	(153, 189, 206, 208, 209, 226, 228, 242, 255)	(153)
Thought CM was safe/wouldn't interfere with treatment	4	(228, 233, 235, 261)	(233)
Was not using CM at the time/not using CM regularly/not attending a physician at the time	4	(206, 228, 233, 235)	(235)
Previous negative response or bad experience with disclosing	4	(206, 234, 240, 262)	
Patient had enough knowledge about CM	1	(153)	
Wanted to compare advice between conventional and CM practitioners	1	(263)	
Desire to protect cultural knowledge about CM	1	(263)	
Concerns physician will see patient's CM use as detracting from their income	1	(263)	
<b>Reasons for disclosure</b>			
Physician asked	3	(208, 261, 262)	
Patient believed physician would be supportive	2	(262, 263)	
Patient believed it was important for safety reasons	2	(208, 263)	(208)
Patient believed physician would have relevant knowledge or advice about CM	1	(208)	
To help someone else with the same condition	1	(208)	

<sup>a</sup>Studies in which the corresponding reason was the reason most commonly reported by participants.



#### *2.3.4.5 Impact of provider response on decisions to disclose*

In a qualitative analysis, Shelley et al. found patients' perceptions of how their medical provider might respond to their CM use was an important factor in the decision of whether or not to disclose (262). A perception of the medical provider as accepting and non-judgemental encouraged disclosure while fear of a negative response from their medical provider led to non-disclosure (262). One paper reported 59% of participants wanted to discuss CM with their medical provider (despite only 49% having done so), and 37% of non-disclosers wished it were easier to have such discussions (188). In another study, the percentage of participants who wanted to discuss CM with their provider represented a substantial majority at 82% (despite only 60% having done so) (212).

When the actual response of the provider to disclosure of CM use was explored by researchers, negative or discouraging responses were reported by a minority of respondents representing less than 20% of disclosers (152, 221, 227, 235, 255), or were not reported at all (261). However, in five papers positive or encouraging responses to disclosure of CM use by a medical doctor were reported by a substantial proportion of respondents representing 32-91% of disclosers (152, 214, 227, 229, 235, 255). Neutral responses from medical providers were also common, reported by 8-32% of disclosers in three studies (227, 235, 261).

#### **2.3.5 Discussion**

This review and meta-analysis provides a detailed overview and update of CM use disclosure to medical providers. Regarding the update to the 2004 paper (146) afforded by this review, a substantially larger volume of literature reporting on CM disclosure was identified in our search, suggesting an increase in researcher interest in this aspect of patient-provider communication. Our analysis reveals little discernible improvement to disclosure rates over the last thirteen years. Consistent with the findings of the previous review, we found reports of disclosure vary widely. However, our additional meta-analysis on selected papers shows approximately two in three CM users do not disclose their CM use to medical providers. In view of the potential risks associated with unmanaged concomitant use of conventional and complementary medicine (68, 162), the value of increasing this rate of disclosure is accentuated.

Furthermore, our narrative review identified three distinct yet interrelated findings relating to patient-practitioner communication. Firstly, disclosure of CM use to medical providers is influenced by the nature of providers' communication style; secondly, perceived provider knowledge of CM use is a barrier to discussions of CM use in

clinical consultation; and thirdly, such discussions and subsequent disclosure of CM use may be facilitated by direct inquiry about CM use by providers. We consider this in the context of contemporary person-centred health care models.

Communication style was a repeated factor affecting disclosure rates in this review; disclosure of CM use was found to be encouraged by patient perceptions of acceptance and non-judgement from medical providers (262), and inhibited by patient fears or previous experiences of discouraging responses from providers (153, 189, 206-208, 217, 226-228, 233-235, 240, 242, 255, 257, 260-263). In practice, negative responses from medical providers appear to represent a deviation from the more commonly positive or neutral responses noted by participants of the reviewed studies as well as others (267, 268). However, such fears and subsequent non-disclosure of CM use could potentially be addressed by medical providers through communication with patients about CM in a direct, supportive, non-judgemental manner to build trust and communicative success (269).

The reviewed literature shows patient perceptions of medical providers as lacking relevant knowledge about CM is a notable reason for non-disclosure. While examination of provider attitudes was not within the scope of this review, three reviewed papers included an assessment of medical providers' attitudes toward discussing CM and identified lack of CM knowledge as a cause of providers' reluctance to initiate such discussions (226, 261, 262). Providers' own perceived lack of CM knowledge as an obstacle to patient-provider CM communication also reflects other research examining provider perspectives on CM (270, 271). While the inclusion of CM in medical school curricula does occur in some countries (e.g. the US (272), Canada (273), UK (274), Germany (275), and Switzerland (276)), and is of interest to medical students (277, 278), this level of CM learning appears insufficient to equip medical providers with the confidence to address patient CM queries (270, 271). Furthermore, the depth and scope of CM knowledge to be realistically encouraged amongst medical providers has been contested (274, 275) and may be best facilitated on a case by case basis taking into account the circumstances of both provider and patient involved. Ideally, regardless of the level of CM knowledge held, the medical provider should strive to facilitate overall coordination and continuity of care for patients covering all treatments and providers, including those of CM.

Our analyses suggest there may be a vital role for medical providers in facilitating patient preference by enquiring with patients about CM in order to help improve disclosure rates. Other studies show discussions in conventional medical settings

about CM use are more commonly patient rather than provider initiated (268, 279), a pattern reflected in the findings of some papers in this review (188, 218, 226). This pattern suggests provider initiation of such discussions may be an avenue for improving disclosure rates, which may be achieved by means such as standard inclusion of CM use inquiry in case-taking education for medical students, as is currently the case in Switzerland (280). Indeed, examination of the impact on disclosure rates of specific questions related to dietary supplements found medical providers' questioning more than doubled the rate of supplement use disclosure (177). This communicative success may be facilitated through employment of person-centred approaches to clinical care, which encompass patient involvement in shared decision-making, provider empathy and recognition of patients' values (269), encouraging a shared responsibility for communication and subsequent discussion of CM use.

While this review provides insight which could be integral to improving patient care during concomitant use of CM and conventional medicine, it also reveals the complexities of patient-practitioner communication in contemporary clinical settings. Further research into the nature of prevailing communication patterns, including differences in disclosure behaviours between populations of different demographics, is needed. As research into disclosure becomes more nuanced and data collection more consistent (e.g. through development and use of standardised instruments), future research could examine changes in patterns of and influences on disclosure. Additionally, research exploring the relationship between communication and treatment outcomes is warranted to provide a richer, deeper understanding of the impact of patient care dynamics. Such understanding could arguably provide the scaffolding for robust, effective, efficient public health policy and practice guidelines.

#### *2.2.5.1 Limitations of this review*

The findings from our review need to be considered within the context of certain limitations. The varied nature and lack of a consistent international definition of CM lend a high degree of heterogeneity to the collection of studies appraised (281). Likewise, while the wide variation in disclosure rates is likely to be partially due to confounding factors relating to differences among target populations (e.g. age, gender), settings (e.g. hospital, community clinics), geographical location (e.g. country/region), and sample sizes, the absence of a standard, validated tool for measuring disclosure also impacts the analysis and reporting on disclosure rates. The heterogeneity produced by these limitations reduced the number of papers suitable for meta-analysis and prevented a more robust, fixed-model meta-analysis on this topic, as well as

prohibiting meta-analyses of CM categories other than biologically-based CM due to insufficient data. Additionally, identifying a comprehensive selection of studies to review was difficult due to disclosure frequently being reported as a secondary outcome and thus not being mentioned in the paper's title, abstract or keywords. However, these limitations have been minimised where possible by following systematic review best practice, and while remaining mindful of the limitations of our review, the importance of the findings presented here for contemporary healthcare practice and provision should not be underestimated.

### **2.3.6 Conclusion**

The rate of disclosure regarding CM use to medical providers remains low and it appears that disclosure is still a major challenge facing health care providers. This review, alongside previous research, suggests that patient decision-making regarding disclosure and non-disclosure of CM use to a medical provider is impacted by the nature of patient-provider communication during consultation and perceptions of provider knowledge of CM. The initiation of conversations about CM with patients and provision of consultations characterised by person-centred, collaborative communication by medical providers may contribute towards increased disclosure rates and mitigate against the potential direct and indirect risks of un-coordinated concurrent CM and conventional medical care. This is a topic which should be treated with gravity; it is central to wider patient management and care in contemporary clinical settings, particularly for primary care providers acting as gatekeeper in their patients' care.

## 2.5 CHAPTER SUMMARY

This chapter explores what is currently known about the three topic areas that contribute to the research aim of this thesis, namely the *use of CM practitioner services by individuals with chronic conditions*, *patient experiences of PCC for chronic illness management* and *clinical communication about concomitant CM and conventional medicine use*. Each review provides a foundation from which to address the corresponding research objectives embedded within this thesis and elucidates where this project can best respond to gaps in the existing knowledge base. Primarily, these gaps relate to: care-seeking behaviours and motivations of those with chronic conditions who consult CM practitioners, perceptions of PCC in clinical consultation with CM practitioners by patients with chronic conditions, and patient communication with CM practitioners regarding concomitant use of CM and conventional/pharmaceutical medicines. There is also a need to examine these factors within the wider scope of health care provision for those with chronic conditions in Australia, in order to understand the role of CM clinical care for these patients alongside the conventional medical care they receive, within a localised context. Accordingly, the following chapter will outline the methodological approach of this project to address these gaps and generate new knowledge in alignment with the project's research aim.

## **3. METHODOLOGY**

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### **3.1 CHAPTER INTRODUCTION**

This project falls within the multidisciplinary field of health services research, which uses empirical investigation to examine health-related phenomena that span across domains from individual experiences to population health needs and outcomes, with the ultimate goal of informing clinical practice and public health policy (282). The project employs a cross-sectional survey design, drawing data from two settings in a two-phase sequence: a broad national sample of the general population (Phase One), and a clinical national sample of individuals consulting CM practitioners (Phase Two). The results of the first phase inform the conduct of the second (see Figure 3.1 below). Rationale and conduct of the project methodology are outlined in this chapter.

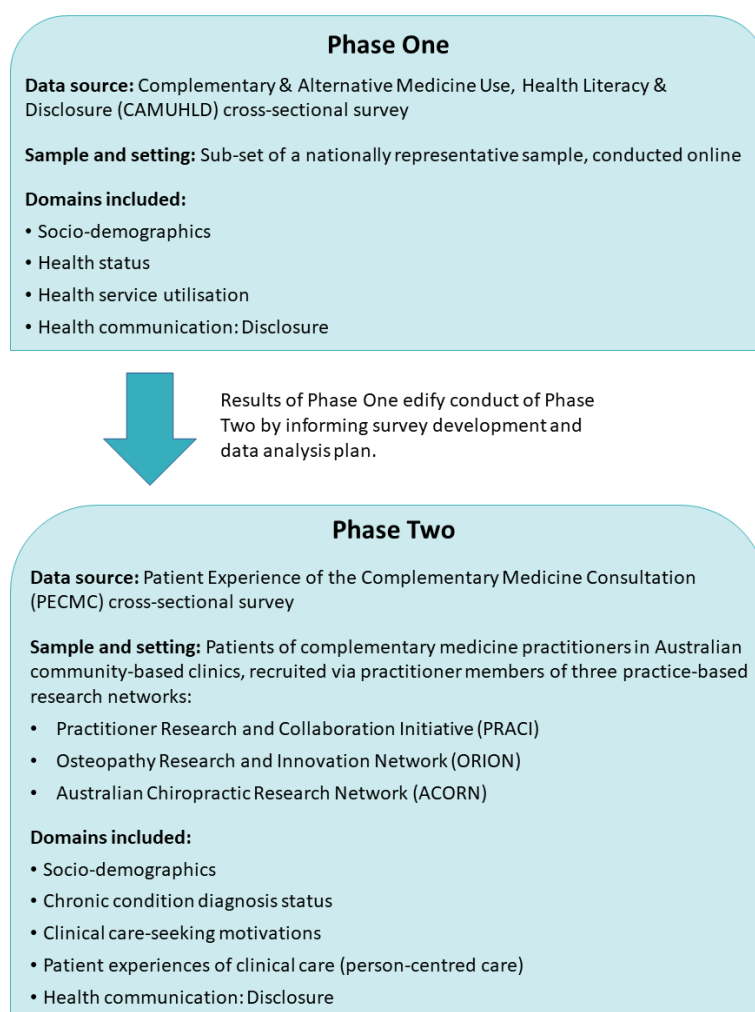
#### **3.1.1 Phase One overview**

Phase One is nested within a broader project – the Complementary and Alternative Medicine Use, Health Literacy and Disclosure (CAMUHLD) project. The CAMUHLD project utilises an online research company database to administer the survey and achieve a sample broadly representative of the Australian population. Phase One draws on selected domains from the CAMUHLD dataset to address Research Objectives 1-4. Specifically, the results produced by analyses conducted within Phase One will describe the characteristics of individuals with chronic conditions who consult CM practitioners in Australia (Objective 1), the reasons motivating these individuals to consult with CM practitioners, and predictors of the use of CM practitioner services by individuals with chronic conditions (Objective 2) (see Chapter 4). In addition, Phase One will describe communication behaviours of individuals with chronic conditions regarding disclosure of CM use to conventional medicine providers (Objective 3) and of conventional medicine use to CM practitioners (Objective 4) (see Chapter 7). Details of Phase One and of the CAMUHLD survey are outlined below in section 3.2.

#### **3.1.2 Phase Two overview**

Phase Two is structured with reference to the findings of Phase One, building on identification of factors surrounding the use of CM practitioner services by individuals with chronic conditions in Australia. The Patient Experiences of the Complementary Medicine Consultation (PECMC) survey utilises three pre-existing practitioner-based research networks (PBRNs) to contact CM practitioners around Australia in order to

survey patients consulting with the CM practitioners in community-based clinical settings. Data from Phase Two both complements and extends upon data from Phase One, addressing Research Objectives 1-6. In complement to the broader national data from Phase One, analyses from Phase Two will describe the characteristics of individuals with chronic conditions who consult with CM practitioners in clinical settings (Objective 1) and their reasons for consultation (Objective 2) (see Chapter 5), as well as communication behaviours regarding disclosure of CM use to conventional medical providers (Objective 3) and disclosure of conventional medicine use to CM practitioners (Objective 4) (see Chapter 7). Phase Two extends upon this to examine the patient experience of the clinical consultation, assessing the extent to which PCC is experienced by patients with chronic conditions during consultation with CM practitioners (Objective 5) and how this experience differs when compared to consultations with conventional medical providers (Objective 6) (see Chapter 6). Full details of Phase Two and the PECMC survey are outlined below in section 3.3.



**Figure 3.1 Sequential outline of project phases**

### **3.1.3 Survey research design**

Survey research has a long history and well-established place in public health research and it is widely considered a suitable method for application in descriptive health services research (283). Surveys provide a systematic, uniform method of collecting information from members of a target population to assess the characteristics, perceptions and experiences of that population relevant to the research question through direct inquiry and response (283). This documentation of prevailing phenomena, which represents a form of observation of natural settings, optimises external validity and generalisability of results (283).

As the current project aims to describe the characteristics, perceptions and experiences of individuals, a cross-sectional survey framework has been chosen for both Phase One and Phase Two. Cross-sectional surveys collect data at a single time-point and consequently are not suitable for identifying causation, but may be used to document patterns and correlations, or to develop hypotheses of causation for further study (283). By sampling from two complementary sampling frames representing the target population at different levels – one from the broader general population and one from a more specific clinical level – a degree of triangulation can be employed to account for the weaknesses inherent to each setting, providing a more complete picture of the phenomena under examination (283).

## **3.2 PHASE ONE: THE COMPLEMENTARY AND ALTERNATIVE MEDICINE USE, HEALTH LITERACY AND DISCLOSURE (CAMUHLD) SURVEY**

Phase One of the project draws upon data from the CAMUHLD project (see Appendix 3.1), within which it is nested. The following sections describe the CAMUHLD survey and the scope of Phase One of this thesis within the CAMUHLD project. The CAMUHLD survey was developed at the University of Technology Sydney, by the Australian Research Centre in Complementary and Integrative Medicine (UTS:ARCCIM), in partnership with Endeavour College of Natural Health (ECNH), to assess complementary medicine use, health literacy and disclosure of use, alongside other health service utilisation and socio-demographic details within a broadly nationally representative sample of the Australian general population. The online setting of the survey provided accessibility to a large national sample through an unobtrusive, anonymous medium (283), ideal for gaining a broad snapshot of current characteristics regarding the engagement of the Australian population with CM. Phase One of this thesis is structured from data taken from a sub-set of the CAMUHLD



sample and from a sub-set of the CAMUHLD instrument domains, as detailed in the following sections.

### **3.2.1 CAMUHLD sample and Phase One chronic conditions sub-set**

The CAMUHLD survey participants were adults (aged 18 years and over), who spoke English and were active members of the Qualtrics® online research company database through which recruitment was outsourced. Adult database members were invited by email to participate voluntarily in the survey via a weblink, with recruitment occurring between 26 July and 28 August 2017. Purposive convenience sampling was employed to achieve a sample representative of the Australian general population regarding gender, age and state of residence in accordance with 2016 Australian Census data (284). As required numbers for each demographic level were achieved, new survey respondents from within that demographic were screened out of participation until all demographic categories were adequately met. Participants provided informed consent after reading a project information sheet which outlined the research team, research topic, expected time and inconvenience involved, the anonymous and voluntary nature of the survey and who to contact in the event of concerns or questions. Participants received a small financial compensation for their time, as per Qualtrics standard remuneration structure. The survey took an average of approximately 15 minutes to complete.

A sample of 2,000 was sought for the CAMUHLD project, with calculations based on previous rates of reported CM use in Australian settings (43) in order to afford sufficient statistical power for inferential analyses. An initial pool of 2,025 completed surveys were returned and subjected to screening for missing and disengaged responses. Identification of discrepancies and incongruities, lack of variation and repeated patterns within responses led to six observations being removed as the data were deemed unreliable. This produced a sample of 2,019 in the final CAMUHLD data set. The sample used for Phase One of this thesis project was a sub-set of the CAMUHLD sample comprised of respondents who indicated having one or more chronic conditions, totalling 1,314 participants.

### **3.2.2 CAMUHLD instrument**

The CAMUHLD survey was comprised of fifty items in total, covering domains of participant socio-demographics, health status, health service utilisation (of both CM and conventional medicine services), health literacy (surrounding CM products and services), and health communication (disclosure of treatment use to care providers). The sub-set of survey data applicable to this project (Phase One) was taken from items

relating to participant socio-demographics, health status, health service utilisation, and health communication, which are outlined in the sections below. The online survey was tested repeatedly by the research team and piloted with a convenience sample of seven Australian adults to ensure full technical usability and functionality of survey logic, with minor amendments made to survey structure in response to feedback. The survey was logically structured to display items which were relevant to participants on the basis of their previous responses to avoid unnecessary questioning and reduce survey fatigue.

### 3.2.2.1 Socio-demographics

Socio-demographic items asked participants about their gender, age, location, education, financial manageability, employment status, marital status, private health insurance (PHI) coverage and possession of a Health Care Card (card provided to low-income earners in Australia for health and medical financial concessions). The questions relating to socio-demographics are shown in Figure 3.2. Specifically, gender was categorised as *Female*, *Male* or *Unspecified*. Age was presented categorically in ranges of ten years (*18-29*, *30-39*, *40-49*, *50-59*, *60 and over*). Participants indicated their location by provided a residential postcode which was used to denote state of residence.

Education was categorised through the qualification level completed, presenting participants with options of *No formal qualifications*, *Year 10 or equivalent*, *Year 12 or equivalent*, *Trade/apprenticeship*, *Certificate/diploma*, *University degree*, and *Higher university degree (e.g. Masters, PhD)*. Participants were asked how they were managing financially at the time with response options detailing *It is impossible*, *It is difficult all of the time*, *It is difficult some of the time*, *It is not too bad*, and *It is easy*. Employment status was categorised through response options *Full time work (35 or more hours per week)*, *Part time work (less than 35 hours per week)*, *Casual/temp work (irregular hours)*, *Looking for work*, and *Not in the paid workforce*. Participants denoted their marital status as *Never married*, *Married*, *De facto (opposite sex)*, *De facto (same sex)*, *Separated*, *Divorced*, or *Widowed*.

PHI coverage was determined first through a binary variable asking *Do you currently have private health insurance (yes/no)*, then through a list presented to those who responded yes to determine which ancillary services were covered (*I do not have private health insurance for ancillary services*, *Yoga/pilates/meditation*, *Physiotherapy*, *Psychology services*, *Chiropractic*, *Osteopathy*, *Acupuncture*, *Chinese medicine/herbs*, *Homeopathy*, *Naturopathy*, *Western herbal medicine*, *Remedial massage/massage*

therapy, Nutrition/dietetics, Not sure). Possession of a Health Care Card was presented as a simple binary option (yes/no).

CAMUHLD survey socio-demographic items	
<b>What is your gender? Please select the response that best applies to you.</b>	
<input type="radio"/> Female <input type="radio"/> Male <input type="radio"/> Unspecified	
<b>What is your age range?</b>	
<input type="radio"/> 18-29 <input type="radio"/> 30-39 <input type="radio"/> 40-49 <input type="radio"/> 50-59 <input type="radio"/> 60 and over	
<b>What is your residential postcode?</b>	Postcode <input type="text"/>
<b>How do you manage financially at the moment?</b>	
<input type="radio"/> It is impossible <input type="radio"/> It is difficult all the time <input type="radio"/> It is difficult some of the time <input type="radio"/> It is not too bad <input type="radio"/> It is easy	
<b>What is the highest qualification you have completed?</b>	
<input type="radio"/> No formal qualification <input type="radio"/> Year 10 or equivalent <input type="radio"/> Year 12 or equivalent <input type="radio"/> Trade/apprenticeship <input type="radio"/> Certificate/diploma <input type="radio"/> University degree <input type="radio"/> Higher university degree (e.g. Masters, PhD)	
<b>Do you currently have private health insurance?</b>	
<input type="radio"/> Yes <input type="radio"/> No	
<b>Do you currently have a Health Care Card?</b>	
<input type="radio"/> Yes <input type="radio"/> No	
<b>What best describes your employment status? (Mark one only)</b>	
<input type="radio"/> Full time work (35 hours or more per week) <input type="radio"/> Part time work (less than 35 hours per week) <input type="radio"/> Casual/temp work (irregular hours) <input type="radio"/> Looking for work <input type="radio"/> Not in the paid workforce	
<b>What is your present marital status?</b>	
<input type="radio"/> Never married <input type="radio"/> Married <input type="radio"/> De facto (opposite sex) <input type="radio"/> De facto (same sex) <input type="radio"/> Separated <input type="radio"/> Divorced <input type="radio"/> Widowed	
<b>If you currently have private health insurance for ancillary services, please indicate which services are covered:</b>	
<input type="checkbox"/> I do not have private health insurance for ancillary services <input type="checkbox"/> Yoga/pilates/meditation <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Psychology services <input type="checkbox"/> Chiropractic <input type="checkbox"/> Osteopathy <input type="checkbox"/> Acupuncture <input type="checkbox"/> Chinese medicine/herbs <input type="checkbox"/> Homeopathy <input type="checkbox"/> Naturopathy <input type="checkbox"/> Western herbalism <input type="checkbox"/> Remedial massage/massage therapy <input type="checkbox"/> Nutrition/dietetics <input type="checkbox"/> Not sure	

**Figure 3.2** Items relating to socio-demographics in the CAMUHLD survey.

### 3.2.2.2 Health status

Health status items used in this study included the diagnosis and number of chronic conditions which had been diagnosed or treated within the preceding three years. The time frame of three years was chosen to reflect the prolonged nature of chronic conditions, recognising that some participants may be living with a chronic condition that is not currently requiring active treatment. Respondents were presented with a list of 30 common chronic conditions as well as an open-text option, as displayed in Figure 3.3.

CAMUHLD survey chronic condition status item	
In the last 3 years, have you been diagnosed or treated for: (mark all that apply)	
<input type="checkbox"/> Type 1 diabetes	<input type="checkbox"/> Non-insulin dependent type 2 diabetes
<input type="checkbox"/> Insulin dependent type 2 diabetes	<input type="checkbox"/> Cancer - benign
<input type="checkbox"/> Cancer - malignant	<input type="checkbox"/> Heart disease
<input type="checkbox"/> Hypertension (high blood pressure)	<input type="checkbox"/> Dislipidaemia (high cholesterol)
<input type="checkbox"/> Osteoarthritis	<input type="checkbox"/> Other musculoskeletal disorder
<input type="checkbox"/> Asthma	<input type="checkbox"/> Bronchitis
<input type="checkbox"/> Other respiratory disorder	<input type="checkbox"/> Endometriosis
<input type="checkbox"/> Polycystic ovarian syndrome	<input type="checkbox"/> Other female reproductive disorder
<input type="checkbox"/> Benign prostatic hyperplasia	<input type="checkbox"/> Other male reproductive disorder
<input type="checkbox"/> Irritable bowel syndrome	<input type="checkbox"/> Inflammatory bowel disease
<input type="checkbox"/> Celiac disease	<input type="checkbox"/> Gastro-oesophageal reflux disease
<input type="checkbox"/> Chronic constipations	<input type="checkbox"/> Other gastrointestinal/digestive disorder
<input type="checkbox"/> Mood disorder (e.g. depression)	<input type="checkbox"/> Anxiety disorder
<input type="checkbox"/> Sleep disorder	<input type="checkbox"/> Substance use disorder
<input type="checkbox"/> Schizophrenia or other psychotic disorder	<input type="checkbox"/> Other mental health disorder
<input type="checkbox"/> Other health condition - please specify	
<input type="checkbox"/> None of the above	

**Figure 3.3 Health status item identifying chronic condition diagnoses in the CAMUHLD survey.**

Additionally, participants' self-perceived health status was assessed using twenty items from the Short Form-20 (SF-20) measure, which first asks participants to rate their general health on a five-point Likert scale from *Excellent* to *Poor*, then explores health status further through six dimensions: physical functioning, role functioning, social functioning, mental health, health perception, and bodily pain (285). The SF-20 is a modified, shortened, validated instrument developed from the Medical Outcomes Study, a multi-year project involving patients with chronic conditions, and is designed to reduce respondent survey fatigue while still achieving precision in data integrity (285).

The physical functioning dimension includes six items with ask respondents about their limitation in performing physical activities using a three-point Likert scale from *Limited for more than 3 months* to *Not limited at all*. The role functioning dimension uses the same three-point scale and includes two items asking about the impact of health on ability to fulfil roles at work, home or school. The social functioning domain is a single

item which asks respondents about how severely their health has limited their social activities during the previous month using a six-point Likert scale ranging from *All of the time* to *None of the time*. The mental health dimension uses the same six-point Likert scale across five items relating to anxiety, depression, loss of behavioural-emotional control and psychological wellbeing. Health perception is assessed across four items designed to balance favourably/unfavourably worded statements to control for acquiescent and oppositional response biases using a five-point Likert scale ranging from *Definitely true* to *Definitely false*. Bodily pain is a single item asking about severity of bodily pain within the previous four weeks, using a six-point Likert scale ranging from *None* to *Very severe*. The section of the survey covering health status items is shown in Figure 3.4.

CAMUHLD survey health status items: SF-20											
<p><b>[General health]</b> In general, would you say your health is:</p> <p><input type="radio"/> Excellent   <input type="radio"/> Very good   <input type="radio"/> Good   <input type="radio"/> Fair   <input type="radio"/> Poor</p>											
<p><b>[Physical functioning]</b> For how long (if at all) has your health limited you in each of the following activities?</p> <table border="1"> <thead> <tr> <th></th> <th>Scale response options</th> </tr> </thead> <tbody> <tr> <td>The kinds of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports</td> <td rowspan="5"> <input type="radio"/> Limited for more than 3 months  <input type="radio"/> Limited for less than 3 months  <input type="radio"/> Not limited at all                 </td> </tr> <tr> <td>The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling</td> </tr> <tr> <td>Walking uphill or climbing a few flights of stairs</td> </tr> <tr> <td>Bending, lifting or stooping</td> </tr> <tr> <td>Walking one block</td> </tr> <tr> <td>Eating, dressing, bathing, or using the toilet</td> <td></td> </tr> </tbody> </table>			Scale response options	The kinds of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	<input type="radio"/> Limited for more than 3 months <input type="radio"/> Limited for less than 3 months <input type="radio"/> Not limited at all	The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling	Walking uphill or climbing a few flights of stairs	Bending, lifting or stooping	Walking one block	Eating, dressing, bathing, or using the toilet	
	Scale response options										
The kinds of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	<input type="radio"/> Limited for more than 3 months <input type="radio"/> Limited for less than 3 months <input type="radio"/> Not limited at all										
The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling											
Walking uphill or climbing a few flights of stairs											
Bending, lifting or stooping											
Walking one block											
Eating, dressing, bathing, or using the toilet											
<p><b>[Role functioning]</b></p> <table border="1"> <thead> <tr> <th></th> <th>Scale response options</th> </tr> </thead> <tbody> <tr> <td>Does your health keep you from working at a job, doing work around the house, or going to school?</td> <td> <input type="radio"/> YES, for more than 3 months  <input type="radio"/> YES, for 3 months or less                 </td> </tr> <tr> <td>Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?</td> <td><input type="radio"/> NO</td> </tr> </tbody> </table>			Scale response options	Does your health keep you from working at a job, doing work around the house, or going to school?	<input type="radio"/> YES, for more than 3 months <input type="radio"/> YES, for 3 months or less	Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?	<input type="radio"/> NO				
	Scale response options										
Does your health keep you from working at a job, doing work around the house, or going to school?	<input type="radio"/> YES, for more than 3 months <input type="radio"/> YES, for 3 months or less										
Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?	<input type="radio"/> NO										
<p>For each of the following questions, please mark the circle for the one answer that comes closest to the way you have been feeling during the <b>past month</b></p> <p><b>[Social functioning]</b>      Scale response options</p> <p>How much of the time, during the past month, has your health limited your social activities (like visiting with friends or close relatives)?</p> <p><b>[Mental health]</b></p> <p>How much of the time, during the past month, have you been a very nervous person?      <input type="radio"/> All of the time  <input type="radio"/> Most of the time  <input type="radio"/> A good bit of the time  <input type="radio"/> Some of the time  <input type="radio"/> A little of the time  <input type="radio"/> None of the time</p> <p>During the past month, how much of the time have you felt calm and peaceful?      <input type="radio"/> A little of the time  <input type="radio"/> None of the time</p> <p>How much of the time, during the past month, have you felt downhearted and blue?      <input type="radio"/> A little of the time  <input type="radio"/> None of the time</p> <p>During the past month, how much of the time have you been a happy person?      <input type="radio"/> A little of the time  <input type="radio"/> None of the time</p> <p>How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?      <input type="radio"/> A little of the time  <input type="radio"/> None of the time</p> <p><b>[Health perception]</b> Please select the answer that describes whether the following statements are true or false for you.</p> <table border="1"> <thead> <tr> <th></th> <th>Scale response options</th> </tr> </thead> <tbody> <tr> <td>I am somewhat ill</td> <td rowspan="4"> <input type="radio"/> Definitely true  <input type="radio"/> Mostly true  <input type="radio"/> Not sure  <input type="radio"/> Mostly false  <input type="radio"/> Definitely false                 </td> </tr> <tr> <td>I am as healthy as anybody I know</td> </tr> <tr> <td>My health is excellent</td> </tr> <tr> <td>I have been feeling bad lately</td> </tr> </tbody> </table> <p><b>[Bodily pain]</b> How much bodily pain have you had during the past 4 weeks:</p> <p><input type="radio"/> None   <input type="radio"/> Very mild   <input type="radio"/> Mild   <input type="radio"/> Moderate   <input type="radio"/> Severe   <input type="radio"/> Very severe</p>			Scale response options	I am somewhat ill	<input type="radio"/> Definitely true <input type="radio"/> Mostly true <input type="radio"/> Not sure <input type="radio"/> Mostly false <input type="radio"/> Definitely false	I am as healthy as anybody I know	My health is excellent	I have been feeling bad lately			
	Scale response options										
I am somewhat ill	<input type="radio"/> Definitely true <input type="radio"/> Mostly true <input type="radio"/> Not sure <input type="radio"/> Mostly false <input type="radio"/> Definitely false										
I am as healthy as anybody I know											
My health is excellent											
I have been feeling bad lately											

**Figure 3.4 Health status items for the SF-20 in the CAMUHLD survey.**

### 3.2.2.3 Health service utilisation

Items used in this thesis pertaining to health service utilisation covered prevalence and frequency of visits to CM practitioners commonly accessed in Australia (chiropractor, osteopath, massage therapist, acupuncturist, naturopath, Western herbalist, traditional Chinese medicine practitioner, homeopath, aromatherapist, yoga teacher) (6, 43) and conventional medicine service utilisation (GP, specialist, hospital doctor, pharmacist, counsellor/mental health worker, community nurse, physiotherapist) within the

preceding twelve months. Participants' reasons for consulting each profession were also reported from a selection of four options: *For an acute illness/condition*, *To treat a long-term health condition*, *To improve wellbeing* or open-text option *Other (please specify)*. These items were adapted from the International Complementary and Alternative Medicine Questionnaire (I-CAM-Q) – a measure designed to capture standardised core aspects of CM use such as frequency and purpose (286). The list of CM professions included in the I-CAM-Q items for the CAMUHLD measure was modified to provide relevance in the Australian cultural context. This section of the survey is shown in Figure 3.5.

CAMUHLD survey health service utilisation items	
What was the frequency of your visits to the following health professionals in the <u>previous 12 months</u> ?	What was the reason for visiting [health professional] in the <u>previous 12 months</u> ?
<b>Conventional medical providers</b>	Item response options  <input type="checkbox"/> For an acute illness/condition, one that lasted less than one month  <input type="checkbox"/> To treat a long-term health condition (one that lasted more than one month) or its symptoms  <input type="checkbox"/> To improve wellbeing  <input type="checkbox"/> Other (please specify)
<input type="radio"/> A family doctor or another General Practitioner (GP)	
<input type="radio"/> A specialist doctor	
<input type="radio"/> A hospital doctor (in outpatients or casualty)	
<input type="radio"/> A pharmacist	
<input type="radio"/> A counsellor or other mental health worker	
<input type="radio"/> A community nurse	
<input type="radio"/> A physiotherapist	
<b>Complementary medicine practitioners</b>	
<input type="radio"/> A chiropractor	
<input type="radio"/> An osteopath	
<input type="radio"/> A massage therapist	
<input type="radio"/> An acupuncturist	
<input type="radio"/> A naturopath	
<input type="radio"/> A Western herbalist	
<input type="radio"/> A traditional Chinese medicine practitioner	
<input type="radio"/> A homeopath	
<input type="radio"/> An aromatherapist	
<input type="radio"/> A yoga teacher	
<input type="radio"/> Other (please specify): <input type="text"/>	

**Figure 3.5 Health service utilisation items and response options for the CAMUHLD survey, detailing health care professions consulted, and reasons for consultation.**

#### 3.2.2.4 Health communication: Disclosure

Health communication measures included the Complementary Medicine Disclosure Index (CMDI – measuring disclosure/non-disclosure of CM use to medical doctors) and the Conventional Medicine Disclosure Index (CONMED-DI – measuring disclosure/non-disclosure of conventional medicine use to CM practitioners), with each index comprised of a measure of disclosure rates, and two separate sets of items encompassing the domains of: a) reasons for disclosure and b) reasons for non-disclosure. The indices covered disclosure communication with care providers over the preceding twelve months. The CMDI asked participants whether they had disclosed CM use to a GP, specialist doctor, hospital doctor or pharmacist. The CONMED-DI asked participants whether they had disclosed conventional medicine use to a CM practitioners from a selection of CM professions identified in previous research as being commonly consulted in Australia (43) – a massage therapist, acupuncturist, naturopath, Western herbalist, traditional Chinese medicine practitioner, homeopath or chiropractor.

The CMDI and CONMED-DI each measured rates of disclosure with an initial question recording rates as full disclosure (*I disclosed ALL*), partial disclosure (*I disclosed SOME*) or non-disclosure (*I did NOT disclose*), alongside an *I did not visit this type of health professional* response. Reasons for disclosure and non-disclosure were then presented to participants as two respective sets of items, listed with a five-point Likert scale ranging from *Strongly agree* (value of 5) to *Strongly disagree* (value of 1). Participants who indicated full disclosure were presented with the set of items relating to reasons for disclosing, those who indicated non-disclosure were presented with the set of items outlining reasons for not disclosing, while participants who indicated partial disclosure were presented with both sets of items. Presentation of the indices was skipped for participants who had not visited the associated health professional.

These indices were developed from thorough examination of existing literature related to disclosure (287) and were subjected to validation analysis by researchers working on the CAMUHLD project (288, 289). As the CMDI and CONMED-DI are formative measures, construct validity was assessed through structural equation modeling to produce variance inflation factors (VIF), whereby values less than 3.3 indicate sufficient construct validity (290). Within the CMDI, items regarding disclosure ranged from VIF 1.21 to 2.47, while items regarding non-disclosure ranged from 1.04 to 2.37 (289). Within the CONMED-DI, VIF values ranged from 1.04 to 2.47 for disclosure items, and

1.09 to 2.65 for non-disclosure items (288). Further details of CMDI and CONMED-DI can be seen below in Figure 3.6 and Figure 3.7, respectively.

Complementary Medicine Disclosure Index (CMDI) items					
The following question relates to the disclosure of information about your use of health treatments to health professionals providing your health care in the previous 12 months. Please select the response that best reflects your experience with the following health professionals...					
	I told them about ALL the complementary and alternative medicines I was using	I only told them about SOME of my complementary and alternative medicine use	I DID NOT tell them about my complementary and alternative medicine use	I did not visit this type of health professional	
A family doctor or general practitioner (GP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
A specialist doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The following questions relate to your interactions with <i>your usual GP/Specialist doctor</i> , over the last 12 months. Please indicate your level of agreement with the following statements.					
I DID NOT disclose my complementary medicine use to my GP/Specialist doctor because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
They did not ask me about my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary medicines are safe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried the wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried the would try to discourage my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not approve of my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I DISCLOSED my complementary medicine use to my GP/Specialist doctor because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about drug interactions with the complementary medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing complementary medicine with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would be willing to discuss my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They support my use of complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Figure 3.6 Health communication items and response options for the CAMUHLD survey, detailing Complementary Medicine Disclosure Index (CMDI).**



Pharmaceutical Medicine Disclosure Index (PMDI) items					
The following question relates to the disclosure of information about your use of health treatments to health professionals providing your health care in the previous 12 months. Please select the response that best reflects your experience with the following health professionals...					
	I told them about ALL the conventional medicines I was using	I only told them about SOME of my conventional medicine use	I DID NOT tell them about my conventional medicine use	I did not visit this type of health professional	
A massage therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
A chiropractor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
An acupuncturist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
A naturopath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The following questions relate to your interactions with <i>your complementary and alternative health practitioner</i> , in the last 12 months. Please indicate your level of agreement with the following statements.					
I DID NOT disclose my conventional medicine use to my complementary medicine practitioner because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
They did not ask me about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think it was important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forgot to mention it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would try to discourage my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not approve of my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not use conventional medicines regularly enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Q19. I DISCLOSED my conventional medicine use to my complementary medicine practitioner because...</b>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about drug interactions with the conventional medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing conventional medicine with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would be willing to discuss my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They support my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about side-effects of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Figure 3.7 Health communication items and response options for the CAMUHLD survey, detailing Conventional Medicine Disclosure Index (CONMED-DI).**

### 3.2.3 CAMUHLD data handling and analysis

Data from the online CAMUHLD survey were downloaded to a spreadsheet for cleaning and coding. Open-text responses to variables with *Other (please specify)* options were systematically examined and either recoded into existing suitable categories or coded into new categories within the variable as appropriate. Likert scale variables were recoded to reflect a positive response direction where required to streamline analysis. Chronic condition diagnosis variables were collapsed from specific diagnoses into broader categories of conditions to produce adequate cell sizes for inferential analyses, as shown in Table 3.1. Categorical variables, such as health professions consulted, were used to generate binary variables for the purposes of some analyses. A binary variable was also generated for presence of any chronic condition diagnosis.

Statistical analyses were undertaken with StataIC-14 (StataCorp LC 2015) software. Chi-square tests were employed to confirm the sample as being representative of the Australian general population with reference to 2016 Census data (284). For descriptive statistics, frequencies and percentages were calculated to present the relative frequency observed in categorical and binary variables, while means and standard deviations were calculated to demonstrate the central tendency and measure of variability in continuous variables (291).

Associations between categorical and binary variables were identified using chi-square tests, with effect size determined by Cramer's V where possible, and associations involving continuous variables were assessed using independent t-tests. Chi-square analyses are applied to test whether there is a significant difference in outcomes between two or more groups, and is applicable when expected cell frequencies exceed 5 and all cell frequencies exceed 1 (291). The substantial sample size of the CAMUHLD dataset provided adequate cell sizes for chi-square to be undertaken. Cramer's V represents the strength of association in chi-square analyses by measuring the intercorrelation of nominal variables (292), allowing for more substantive interpretation of results.

**Table 3.1 Categorisation of Chronic Conditions into Collapsed Variables for Analysis**

<b>Collapsed categories</b>	<b>Specific conditions as listed on survey</b>
<b>Cardiovascular</b>	Heart disease Hypertension Dyslipidaemia
<b>Diabetes</b>	Type 1 diabetes Non-insulin dependent type 2 diabetes Insulin dependent type 2 diabetes
<b>Cancer</b>	Cancer (benign) Cancer (malignant)
<b>Female reproductive</b>	Endometriosis Polycystic ovarian syndrome Other female reproductive disorder
<b>Male reproductive</b>	Benign prostatic hyperplasia Other male reproductive disorder
<b>Respiratory</b>	Asthma Bronchitis Other respiratory disorder
<b>Gastrointestinal</b>	Irritable bowel syndrome (IBS) Inflammatory bowel disease (Crohn's disease, ulcerative colitis) Coeliac disease Gastro-oesophageal reflux disease (GORD/GERD) Chronic constipation Other gastrointestinal/digestive disorder
<b>Mental Health</b>	Mood disorder (e.g. depression) Anxiety disorder Sleep disorder Substance use disorder Schizophrenia or other psychotic disorder Other mental health disorder
<b>Musculoskeletal</b>	Osteoarthritis Other musculoskeletal disorder
<b>Other</b>	Other chronic health condition/s (not listed above)

Potential predictors for outcomes of interest were identified through reverse stepwise logistic regression. Stepwise regression models involve evaluation of the contributions of different variables to the regression model, allowing for identification of effect modifiers by systematically testing the impact of each included variable on the model's statistical significance and numerical stability (293). This approach results in the most parsimonious model to best describe the data (294). Reverse stepwise logistic

regression achieves this by removing the variable which has the least statistically significant impact on the model and comparing the resulting model to the previous version (293). Reverse stepwise logistic regression was applied to this project's data in the following manner:

1. Potential effect modifying variables (independent variables) were selected through clinical expertise, followed by Pearson chi-square or Fisher's exact tests of association with the outcome of interest (dependent variable). Independent variables with a statistical significance of  $p < 0.25$  were included in the initial application of the regression model for the associated outcome of interest.
2. The initial model was examined and the independent variable with the weakest association with the outcome of interest was removed before the regression was conducted again.
3. The two models were subject to a likelihood ratio test to assess whether removal of the independent variable was appropriate. Appropriate removal was defined by a value of  $p > 0.05$ .
4. The process of removing the independent variable with the weakest association was repeated until all retained independent variables returned a value of  $p < 0.05$ , presenting the most parsimonious model of predictors for the outcome of interest.

### **3.3 PHASE TWO: PATIENT EXPERIENCES OF THE COMPLEMENTARY MEDICINE CONSULTATION (PECMC) SURVEY**

Phase Two of the project builds upon Phase One by assessing similar parameters within a clinical rather than general population setting, and extending to assessment of patient experiences of clinical care, using the PECMC survey (see Appendix 3.2). The design of the PECMC survey was informed by results of the CAMUHLD project; the CM professions selected for investigation were determined from those most commonly consulted in clinical settings by CAMUHLD participants with chronic conditions, while survey domains were structured to complement CAMUHLD findings. Domains included in the PECMC encompassed patient characteristics, CM service utilisation, patient experience and disclosure behaviours of individuals with chronic conditions who consult with CM practitioners. The approach of surveying patients in existent clinical settings was chosen to produce findings translational to patients and practitioners in

real-world clinical practice – and relevant to policymakers invested in the implications of such practice – in accordance with the goals of health services research (282).

### **3.3.1 PECMC setting and sampling**

The PECMC survey was administered to patients of CM practitioners. The CM professions included in this phase of the project were selected based on findings from the CAMUHLD survey. This selection encompassed the five CM professions most commonly accessed in clinical settings by CAMUHLD participants with chronic conditions: massage therapy, chiropractic, acupuncture, naturopathy and osteopathy (see Chapter 4). While yoga was initially placed within these five most accessed CM professions from the CAMUHLD survey, it was excluded from the PECMC study as it is not typically provided within a clinical setting involving individualised consultation.

A pragmatic way to conduct research in existent clinical settings is through practice-based research networks (PBRNs), which provide collaborative infrastructure to connect researchers with health/medical practitioners and their patients in the community (295). PBRN infrastructure generally consists of fifteen or more ambulatory clinical practices whose practitioners affiliate with academic institutions and researchers, explicitly with the mission of conducting research with the participation of member practitioners and their patients (296). Administrative and directorial staff, alongside suitable advisory boards, direct the functioning of the PBRN and communication with relevant community stakeholders (296). PBRNs are valuable in health services research as they elicit research findings that are directly translatable to real world practice. This translation is especially desirable in the field of CM research in Australia, which has faced challenges in bridging the divide between evidence and applied practice (297). The professional CM landscape in Australia includes three PBRNs which were accessed for this project, as outlined below.

#### ***3.3.1.1 Practitioner Research and Collaboration Initiative (PRACI)***

The multi-modality Practitioner Research and Collaboration Initiative (PRACI) is the largest national PBRN for CM practitioners in the world, representing fourteen CM professions (298). PRACI was established in 2014 by Endeavour College of Natural Health, with the support of UTS:ARCCIM (299) and has since provided infrastructure for the conduct of various projects from clinical trials to observational studies (300). The PRACI database includes 1,053 CM practitioner members, representing the breadth and diversity of CM practice in Australia (298). The innovative framework and wide

reach of the PRACI PBRN lends strength to this project's aim to illustrate the actuality of patient experiences in CM consultation around Australia.

#### *3.3.1.2 Osteopathy Research and Innovation Network (ORION)*

The Osteopathy Research and Innovation Network (ORION) comprises a nationally representative collective of osteopathic practitioners in Australia (301). The development of ORION began in 2015, funded by Osteopathy Australia, the predominant professional association for the osteopathic profession in Australia, and conducted independently by researchers at UTS:ARCCIM (302). ORION is the world's first PBRN exclusive to the osteopathic profession and its development was contributed to by almost half (49.1%, n=992) of the Australian osteopathic profession (301). Sub-studies conducted through ORION have contributed a number of important publications to the growing evidence base for osteopathy (302). The rich, nationally representative resource presented by the ORION PBRN provides confidence that data taken from this setting will reflect the experiences of osteopathy patients in Australia.

#### *3.3.1.3 Australian Chiropractic Research Network (ACORN)*

The Australian Chiropractic Research Network (ACORN) constitutes a nationally representative collective of chiropractic practitioners (303). ACORN was established in 2014 with funding from the Australian Chiropractors' Association and was developed independently by a research team from UTS:ARCCIM (303). Since its inception, ACORN has provided a foundation for several sub-studies, generating numerous publications and novel contributions to the field of chiropractic practice and its evidence in Australia. The ACORN database encompasses approximately 36% of the Australian chiropractic workforce, amounting to 1,680 members in the PBRN (303). This extensive coverage of the profession provides a reliable network through which to examine the reality of chiropractic consultation for patients in Australia.

#### *3.3.1.4 Recruitment*

The PRACI, ACORN and ORION PBRNs were contacted to connect with suitable practitioners of the five selected CM professions. Members of the three PBRNs who were active in clinical practice were invited by email to submit an online expression of interest and consent form (Appendix 3.3) to assist with recruitment of their patients to the survey. Practitioners were then selected on the basis of their clinic location to ensure a wide geographical spread; for each profession, an attempt was made to include at least one practitioner from each of the larger Australian states (New South

Wales, Victoria, Queensland, South Australia, Western Australia) and at least one practitioner from any of the smaller states (Tasmania, Northern Territory, Australian Capital Territory). Priority was placed on selecting practitioners who consulted with ten or more patients per week to facilitate efficiency in recruitment.

After confirming their involvement by email or phone, hardcopy study materials were posted to selected practitioners. Materials included: patient information sheets (Appendix 3.4) and surveys to distribute, practitioner information sheets (Appendix 3.3), and detailed instructions regarding the study protocol, recruitment process and communication about the study with patients (Appendix 3.5) to promote consistency in patient recruitment. The selected practitioners each provided 15 consecutive eligible patients with an information sheet about the study and a hardcopy of the survey instrument with a consent form attached. The information sheet outlined the research team, the purpose of the research, the anonymous and voluntary nature of the survey, expected time to complete the survey, risks and inconvenience involved, and contact details in case of concerns or questions. The consent form directed the participant to read the information sheet before participating. If the patient chose to participate, the hardcopy (paper) survey was self-administered without assistance at a location of their convenience to allow anonymity around participation, with surveys returned by post. This approach reduced selection bias, allowed patients to provide or withhold consent without coercion, and blinded practitioners to recruitment outcomes in order to preserve the integrity of patient-practitioner relationships (practitioners were not aware of who did or did not participate).

Patients of the recruiting practitioners were considered eligible to participate in the survey if they were adults (aged 18 years and over) who spoke English, were capable of freely providing consent, and had not already participated in the survey in a previous consultation. Each survey package included a postage-paid envelope to send completed surveys to the research team at no cost to patients or practitioners. Also included was a page directing participants to a separate online form where a draw could be entered to win a \$100 gift voucher as an incentive to participate. Personal details collected through the online form included only a name and contact point (phone or email), with the winner chosen randomly.

Sample size calculations were informed by previous pilot studies of the validated measures included in the PECMC survey (88, 304), alongside a conservative estimate of prevalence of chronic conditions (65% - based on previous studies in multi-profession CM clinics in Australia) (88). Allowing for a 5.0% margin of error, this

calculation produced a desired sample of  $n=377$ , which was rounded to four hundred participants being sought to allow for potential missing or unreliable responses. The number of CM practitioners sought to assist with recruitment (forty) and the number of surveys printed for distribution (six hundred) were calculated based on response rates from previous research in similar settings (88) in an attempt to achieve the desired sample size.

The final number of CM practitioners who participated in the process of recruitment was thirty-nine (seven chiropractors, eight practitioners from each other profession). Each recruiting practitioner emailed the research team a confirmation that all surveys had been distributed, totalling 585 surveys distributed to patients. Of these, 199 surveys were returned by post, producing a 34.0% response rate. Five of the returned surveys were incomplete and were excluded on this basis, while three others were excluded due to contradictory responses (responses to some items were inconsistent with responses to others), providing a final sample of  $n=191$  patients.

### **3.3.2 PECMC instrument**

The PECMC survey contained twenty-nine questions relating to the domains of socio-demographics, diagnosed chronic condition/s, clinical care-seeking factors, experiences of person-centredness in clinical care received (from CM practitioners and from medical doctors (MDs)), and communication about treatments used by patients. Respondents who reported having no chronic condition diagnosis were asked to complete only socio-demographic items; this allowed identification of the prevalence of chronic condition diagnoses amongst the sample and of potential socio-demographic differences between respondents with or without chronic conditions. All other items were completed only by participants with chronic conditions. The survey was assessed by two researchers with a background in CM practice for general face validity, and piloted with six diverse volunteers to ensure the logic and content were sensible to individuals from the general population.

#### ***3.3.2.1 Socio-demographics and chronic condition status***

Items covering socio-demographics included gender, age, state of residence, relationship status, educational status, employment status, financial manageability, PHI coverage, and Health Care Card possession status. Current chronic condition diagnoses were identified by respondents from a list, with additional options for open-text responses alongside a “none of the above” option.



The questions relating to socio-demographics are shown in Figure 3.8. Specifically, age was presented categorically in ranges of ten years (*18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75 and over*). Gender was categorised as *Female, Male, Transgender* or *Other*. Participants provided a residential postcode to denote state of residence. Relationship status response options included *Never married, Married, De facto, Separated, Divorced, or Widowed*.

Educational status was categorised according to the level of qualification completed, which included *No formal qualifications, Year 10 or equivalent, Year 12 or equivalent, Trade or apprenticeship, Certificate or diploma, University degree (e.g. Bachelor), and Higher university degree (e.g. Masters, PhD)*. Employment status response options covered *Full time work (35 hours or more per week), Part time work (less than 35 hours per week), Casual or temporary work (irregular hours), Currently looking for work, and Not currently in the paid workforce nor looking*. Financial manageability was categorised as *It is impossible, It is difficult all of the time, It is difficult some of the time, It is not too bad, or It is easy*.

A binary variable first determined PHI coverage through the question *Do you currently have private health insurance (yes/no)*. A list was then provided for those who responded yes to determine which ancillary services were covered with the following response options: *Yoga or pilates, Physiotherapy, Psychology services, Chiropractic, Osteopathy, Acupuncture, Chinese herbal medicine, Homeopathy, Naturopathy, Western herbal medicine, Massage therapy, Nutrition or dietetics, Myotherapy or musculoskeletal therapy, My private health insurance doesn't cover ancillary services, and I don't know/can't remember*. Health Care Card possession was identified with a simple binary item asking *Do you currently have a Health Care Card (yes/no)*.

Chronic condition status was determined by presenting a list of common chronic conditions and asking respondents to *"please select all conditions you currently have, that have been diagnosed by a doctor or other health professional"*. The list included twenty-seven options encompassing a range of common chronic health conditions, as well as an open-text option and a *None of the above* option (see Figure 3.9). Those who selected *None of the above* were directed to return the survey without completing any further questions.

PECMC survey socio-demographic items			
<b>What is your age?</b>			
<input type="radio"/> 18-24	<input type="radio"/> 25-34	<input type="radio"/> 35-44	<input type="radio"/> 45-54
<input type="radio"/> 55-64	<input type="radio"/> 65-74	<input type="radio"/> 75 and over	
<b>What is your gender?</b>			
<input type="radio"/> Female	<input type="radio"/> Male	<input type="radio"/> Transgender	<input type="radio"/> Other
<b>What is your residential postcode?</b>			
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>What is your relationship status?</b>			
<input type="radio"/> Never married	<input type="radio"/> Married	<input type="radio"/> De facto	
<input type="radio"/> Separated	<input type="radio"/> Divorced	<input type="radio"/> Widowed	
<b>What is the highest qualification you have completed?</b>			
<input type="radio"/> No formal qualification	<input type="radio"/> Year 10 or equivalent		
<input type="radio"/> Year 12 or equivalent	<input type="radio"/> Trade or apprenticeship		
<input type="radio"/> Certificate or diploma	<input type="radio"/> University degree (e.g. Bachelor)		
<input type="radio"/> Higher university degree (e.g. Masters, PhD)			
<b>What best describes your employment status?</b>			
<input type="radio"/> Full time work (35 hours or more per week)	<input type="radio"/> Part time work (less than 35 hours per week)		
<input type="radio"/> Casual or temporary work (irregular hours)	<input type="radio"/> Currently looking for work		
<input type="radio"/> Not currently in the paid workforce, nor looking			
<b>How do you manage financially at the moment?</b>			
<input type="radio"/> It is impossible	<input type="radio"/> It is difficult all the time		
<input type="radio"/> It is difficult some of the time	<input type="radio"/> It is not too bad		
<input type="radio"/> It is easy			
<b>Do you currently have private health insurance?</b>			
<input type="radio"/> No	<input type="radio"/> Yes		
<b>Q8a. If Yes, which of the following ancillary services does your private health insurance cover?</b>			
<input type="checkbox"/> Yoga or pilates	<input type="checkbox"/> Physiotherapy		
<input type="checkbox"/> Psychology services	<input type="checkbox"/> Chiropractic		
<input type="checkbox"/> Osteopathy	<input type="checkbox"/> Acupuncture		
<input type="checkbox"/> Chinese herbalism	<input type="checkbox"/> Homeopathy		
<input type="checkbox"/> Naturopathy	<input type="checkbox"/> Western herbalism		
<input type="checkbox"/> Massage therapy	<input type="checkbox"/> Nutrition or dietetics		
<input type="checkbox"/> Myotherapy or musculoskeletal therapy			
<input type="checkbox"/> My private health insurance doesn't cover ancillary services			
<input type="checkbox"/> I do not know/can not remember			
<b>Do you currently have a Health Care Card?</b>			
<input type="radio"/> No	<input type="radio"/> Yes		

**Figure 3.8** Items relating to socio-demographics in the PECMC survey.

PECMC survey chronic condition status item			
<b>From the following list, please select <i>all</i> conditions you currently have, that have been <i>diagnosed by a doctor or other health professional</i></b>			
Arthritis	<input type="checkbox"/>	Alzheimer's disease or dementia	<input type="checkbox"/>
Asthma	<input type="checkbox"/>	Congenital condition (e.g. cystic fibrosis)	<input type="checkbox"/>
Cancer or post-cancer treatment complications	<input type="checkbox"/>	Chronic kidney disease	<input type="checkbox"/>
COPD (chronic obstructive pulmonary disease)	<input type="checkbox"/>	Endometriosis	<input type="checkbox"/>
Diabetes (type 1)	<input type="checkbox"/>	PCOS (polycystic ovarian syndrome)	<input type="checkbox"/>
Diabetes (type 2)	<input type="checkbox"/>	Other female reproductive disorder	<input type="checkbox"/>
Heart disease/cardiovascular disease	<input type="checkbox"/>	Prostatic hyperplasia	<input type="checkbox"/>
Hypertension/high blood pressure	<input type="checkbox"/>	Other male reproductive disorder	<input type="checkbox"/>
Musculoskeletal condition	<input type="checkbox"/>	Inflammatory bowel disease (Crohn's disease or ulcerative colitis)	<input type="checkbox"/>
Chronic pain	<input type="checkbox"/>	IBS (irritable bowel syndrome)	<input type="checkbox"/>
Depression	<input type="checkbox"/>	Fibromyalgia or CFS/ME (chronic fatigue syndrome/myalgic encephalomyelitis)	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	Other autoimmune disease (not listed)	<input type="checkbox"/>
Other mental health condition	<input type="checkbox"/>	Other chronic condition/s (not listed above)	
Insomnia or other sleep disorder	<input type="checkbox"/>	Please specify: _____	<input type="checkbox"/>
Obesity	<input type="checkbox"/>	_____	
		None of the above	<input type="radio"/>

**Figure 3.9.** Health status item identifying chronic condition diagnoses in the PECMC survey.

### 3.3.2.2 Clinical care-seeking

Regarding the CM practitioner the respondent had consulted with, continuity of care-seeking and reasons for care-seeking were assessed. Continuity was measured by asking respondents how many times they had consulted with the practitioner and presenting five response options: *This was my first visit, 2 times, 3 times, 4 times, or 5 or more times*. Reasons for care-seeking with the CM practitioner were presented as twelve items with a five-point Likert scale (ranging from *Strongly disagree = 1 to Strongly agree = 5*) alongside a *Doesn't apply* option. The reasons presented in the twelve items were informed by the I-CAM-Q (286) and further extended through examination of existing research (6, 305) and subjected to face validity testing by researchers with expertise in the subject matter (see Figure 3.10).

Respondents were also asked about care-seeking in regards to consulting with MDs for their chronic condition/s. This item identified whether respondents had consulted with a GP or specialist doctor and directed them to continue the survey if they had done so. Respondents who had not consulted a MD were advised they had completed the survey at this point and were directed to return it.

PECMC survey clinical care-seeking items	
The following questions relate specifically to your experience with the <i>health professional you are visiting today</i> .	
At the conclusion of your visit today, how many times will you have visited this practitioner?	
<input type="radio"/> 1 - This was my first visit <input type="radio"/> 2 times <input type="radio"/> 3 times <input type="radio"/> 4 times <input type="radio"/> 5 or more times	
How much do you agree or disagree with the following statements about your reasons for consulting the health professional you are visiting today?	
	Response options
To seek treatment for an acute illness lasting less than 1 month	
To seek treatment for a long-term illness lasting more than 1 month	
I was dissatisfied with my conventional medical treatment and wanted to try something different	
To reduce side-effects of my current medical treatments/medicines	
To enhance the effectiveness of my current medical treatments/medicines	<input type="radio"/> Strongly Disagree <input type="radio"/> Disagree <input type="radio"/> Neutral <input type="radio"/> Agree <input type="radio"/> Strongly Agree <input type="radio"/> Doesn't apply
To improve general wellbeing and prevent future health problems	
I was seeking holistic/natural treatments	
This type of health care suits my personal belief system	
I believe this type of health care is safe	
This type of health care gives me hope about my future health	
This type of health care gives me a sense of control about my health	
This health care professional is supportive and compassionate	

**Figure 3.10 Clinical care-seeking items in the PECMC survey**

### 3.3.2.3 Patient experiences of clinical care

In order to examine the extent of person-centredness present in care provided to respondents with chronic conditions, measures were incorporated to assess patient perceptions of care received during consultation. Measures pertaining to patient experiences of clinical care included the Patient-Centred Care Scale (PCCS), Perceived Provider Support Scale (PPSS), Empowerment Scale and the Patient Assessment of Chronic Illness Care (PACIC) measure. The PCCS, PPSS and Empowerment Scale are designed to be co-administered interdependently and were developed to measure provider support specifically in CM settings (304). These three interdependent measures have been previously validated in a sample of patients from a diverse range of CM professions, demonstrating high internal consistency based on Cronbach's  $\alpha$ s (PCCS  $\alpha = 0.87$ , PPSS  $\alpha = 0.90$ , Empowerment Scale  $\alpha = 0.85$ ). The measures were chosen for their sensitivity to the holistic context of CM consultations, and for their demonstrated validity across a variety of CM professions (304).

To complement these scales with a measure specific to assessing provision of care tailored to those with chronic conditions, the PACIC measure was included. The PACIC has been designed and validated to assess delivery of PCC to patients with chronic conditions in primary care settings (306). It has been implemented and validated with repeatedly high internal consistency in a number of languages and settings, and across populations of patients with a variety of chronic conditions including diabetes (307), hypertension (308), coronary heart disease (309), and osteoarthritis (310). The PACIC has also been subjected to some preliminary use and validation in CM settings involving chiropractic (90) and homeopathic care, continuing to demonstrate high internal consistency (Cronbach's  $\alpha$  0.86 overall and 0.65 to 0.82 for individual subscales) (311).

The PCCS (ten items) and PPSS (seven items) allow respondents to rate their perceptions of PCC and emotional support from the provider (respectively) using a five-point Likert scale ranging from *Strongly disagree* (value of 1) to *Strongly agree* (value of 5), while the Empowerment Scale (five items) allows respondents to rate how the consultation has affected their perceptions of health-related empowerment using a three-point scale of *No* (value of 1), *Yes a little* (value of 2), and *Yes a lot* (value of 3) (304). The PACIC measure is comprised of twenty items which use a five-point scale ranging from *Almost never* (value of 1) to *Almost always* (value of 5), allowing respondents to rate five domains of clinical care. These domains cover aspects of PCC as they relate specifically to management of patients with chronic conditions (patient

activation, delivery system design/decision support, goal setting/tailoring, contextual problem-solving, follow-up/coordination) (306).

The survey presented these four measures to respondents in relation to both the CM consultation they had just attended, and to their most recent consultation with their MD (general practitioner or specialist doctor) if applicable. The measures were used without alteration to wording, with the exception of replacing the titles “practitioner” or “doctor” in accordance with the relevant consultation context. Full details of the PCCS, PPSS and Empowerment Scale items are presented in Figure 3.11, and those from the PACIC are presented in Figure 3.12.

PECMC survey items on patient experiences of care: interdependent measures	
When thinking about your most recent consultation <i>with</i> [profession], how much do you agree or disagree with the following statements:	
[Patient-centred care scale]	Response options
I feel seen and heard as a unique individual by my practitioner/doctor	<input type="radio"/> Strongly Disagree <input type="radio"/> Disagree <input type="radio"/> Neutral <input type="radio"/> Agree <input type="radio"/> Strongly Agree <input type="radio"/> Doesn't apply
My practitioner/doctor has a full picture of me as an individual	
My practitioner/doctor is really interested in finding and addressing my health problems	
The root causes of my problems are identified by my practitioner/doctor	
The root causes of my problems are being treated by my practitioner/doctor	
The treatment is individualised for me at each session	
My practitioner/doctor receives feedback from my body that guides treatment	
My practitioner/doctor asks me for feedback from my body that guides treatment	
I know what to expect during treatment sessions	
My practitioner/doctor teaches me ways to relieve symptoms myself	
[Perceived provider support scale]	Response options
My practitioner/doctor cares about me	<input type="radio"/> Strongly Disagree <input type="radio"/> Disagree <input type="radio"/> Neutral <input type="radio"/> Agree <input type="radio"/> Strongly Agree <input type="radio"/> Doesn't apply
I feel cared for during treatment	
My practitioner/doctor accepts me as I am	
I receive personal attention during treatment	
I can talk openly with my practitioner/doctor	
My practitioner/doctor gives me hope	
I trust my doctor	
When thinking about what has happened for you as a result of your most recent consultation with your [profession], how would you describe the following?:	
[Empowerment scale]	Response options
Do you feel more in control of your health?	<input type="radio"/> No <input type="radio"/> Yes, a little <input type="radio"/> Yes, a lot
Do you know what to do to take care of your health problem?	
Do you believe that your health problem will improve?	
Do you advocate more for yourself?	
Do you have techniques you can use when your symptoms get worse?	

**Figure 3.11 Interdependent measures of patient experiences of care**

**PECCM survey items on patient experiences of care: Patient Assessment of Chronic Illness Care (PACIC) Measure**

Think about the health care you've received for your chronic condition/s over the past 6 months (If you've been seeing this practitioner for less than 6 months, think about the care you've received since you started seeing them).	
Over the past 6 months, when receiving medical care for my chronic condition, I was:	Response options
Asked for my ideas when we made a treatment plan	<input type="radio"/> Almost never <input type="radio"/> Generally not <input type="radio"/> Sometimes <input type="radio"/> Most of the time <input type="radio"/> Almost always
Given choices about treatment to think about	
Asked to talk about any problems with my medicines/treatments or their effects	
Given a written list of things I should do to improve my health	
Satisfied that my care was well organised	
Shown how what I did to take care of my illness influenced my condition	
Asked to talk about my goals in caring for my illness	
Helped to set specific goals to improve my eating or exercise	
Given a copy of my treatment plan	
Encouraged to go to a specific group or class to help me cope with my chronic illness	
Asked questions, either directly or on a survey, about my health habits	
Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me	
Helped to make a treatment plan that I could do in my daily life	
Helped to plan ahead so I could take care of my illness even in hard times.	
Asked how my chronic illness affects my life	
Contacted after a visit to see how things were going	
Encouraged to attend programs in the community that could help me	
Referred to a dietitian, health educator, or counsellor	
Told how my visits with other types of practitioners, like doctors, surgeons or specialists, helped my treatment	
Asked how my visits with other doctors/practitioners were going	

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**Figure 3.12 Patient Assessment of Chronic Illness Care (PACIC) Measure**

**3.3.2.4 Clinical communication: Disclosure**

Communication between patients and practitioners about treatments being used by the patient participants was measured using the CMDI and CONMED-DI, in alignment with the CAMUHLD survey. As all participants had consulted a CM practitioner, the CONMED-DI was presented first, asking participants about their disclosure of conventional medicine use to the CM practitioner they had just consulted with. An initial question assessed rates of disclosure over the preceding twelve months and response options were identical to those in the CAMUHLD survey – recorded as full disclosure (*I disclosed ALL*), partial disclosure (*I disclosed SOME*) or non-disclosure (*I did NOT disclose*) – with the additional option of *I am not currently taking any conventional medicines*. Participants who were not taking any conventional medicines (and thus had nothing to disclose) were directed to skip the CONMED-DI items. Participants who reported full disclosure were directed to complete only the CONMED-DI items listing

reasons for disclosing, those who reported non-disclosure were directed to complete only the CONMED-DI items listing reasons for non-disclosure, while those who reported partial disclosure were directed to complete both domains of items. Participants who indicated they were also consulting with a GP or specialist doctor for their chronic condition/s were directed to complete the CMDI in the same fashion regarding their most recent consultation with that provider. Reasons listed in the CONMED-DI and CMDI were scored as a five point Likert scale ranging from *Strongly agree* (value of 5) to *Strongly disagree* (value of 1). Full details of the CONMED-DI and CMDI can be seen in Figure 3.7 and Figure 3.6, respectively.

### **3.3.3 PECMC data handling and analysis**

As completed surveys were received by post, each one was assessed for missing and unreliable responses (e.g. responses to different items that were contradictory or inconsistent). Surveys with excessive missing or unreliable responses were excluded from the sample to preserve integrity of the data, as described in section 3.3.1 above. Data were then manually input to a spreadsheet and simultaneously coded before importing to StataC-14 (StataCorp LC 2015) for analysis.

Some variables were recoded through collapsing of categories to produce adequate cell sizes for inferential analyses, where appropriate. This included some socio-demographic variables (age, relationship status, educational qualifications, employment status, financial manageability), and chronic condition variables, which were collapsed from specific conditions into broader categories (e.g. musculoskeletal conditions, mental health conditions etc.) and coded as binaries. Binary variables were also generated for presence of chronic conditions (did or did not report a chronic condition diagnosis), the CM profession consulted and the type of medical doctor consulted to enable between-group comparisons and tests of association.

Frequencies and percentages were calculated to present descriptive results for categorical and binary variables including socio-demographics, chronic condition diagnosis categories, CM profession consulted, number of visits with the CM practitioner, reasons for consulting the CM practitioner, and disclosure rates. Missing responses were excluded from analysis, as were *Does not apply* responses for items describing reasons for consultation. Both descriptive results and summary statistics were calculated for measures relating to patient perceptions of clinical care (PCCS, PPSS, Empowerment Scale, PACIC).

Summary statistics were calculated as means and standard deviations to determine the central tendency and measure of variability for variables measured with Likert scales.

Summary statistics were produced for each individual item in the PCCS, PPSS, Empowerment Scale, CONMED-DI and CMDI, excluding missing responses. The PACIC measure was scored with summary statistics for each item, each domain, and for the overall measure to, in accordance with its intended use and previous validation (306). During calculation of PACIC domain scores and overall summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations for items with recorded values. Chi-square analysis was conducted with socio-demographic variables to assess for differences between participants whose observations were and were not included in the PACIC summary score calculations, but no statistically significant differences were identified.

Fisher's exact test was employed to test associations between socio-demographics, chronic conditions diagnoses, number of consultation visits and disclosure rates across groups delineated by chronic condition presence or CM profession consulted. Fisher's exact test was selected to optimise accuracy, due to expected cell sizes being small (291). One-way analysis of variance (ANOVA) was conducted to assess the relationship between patients' disclosure rates and perceptions of PCC, examining the difference between PACIC summary scores across different disclosure behaviours for consultations with both CM practitioners and with medical doctors. One-way ANOVA was selected as it is the most appropriate test to assess whether there is a statistically significant difference between the means (PACIC summary scores) of three or more groups (disclosed all, disclosed some, did not disclose) (291).

### **3.4 ETHICAL CONSIDERATIONS**

The CAMUHLD project received ethical approval from the Human Research and Ethics Committees (HREC) of the University of Technology Sydney (ETH17-1564) (see Appendix 3.6), Endeavour College of Natural Health (20170242) (Appendix 3.7) and Charles Sturt University (H17048) (Appendix 3.8). The identity and contact details of participants were known only to Qualtrics and survey responses were deidentified at the point of data collection; no identifying information was collected and survey responses were not traceable to participants. All data materials are electronic and stored in password protected files accessible only the research team. Informed consent was a prerequisite to participation and included informing participants of the voluntary, anonymous nature of the survey and their right to withdraw participation at any time.



The PECMC Survey was approved by the HREC of the University of Technology Sydney (ETH18-2769) (Appendix 3.9). As participants were recruited by their consulting CM practitioners, the recruitment protocol was designed to prevent the study from impacting the patient-practitioner relationship. Provision of hardcopy survey materials for patients to take away from the consultation enabled anonymous provision or withholding of participation to protect patients from perceived coercion to participate. Patients were provided with information sheets enabling informed consent and assuring them of their right to withdraw participation at any time without penalty. A declaration of consent was included on the front of each survey (Appendix 3.2) It was considered possible that some participants may experience emotional distress when reporting on experiences of care, prompting inclusion of contact details for support services such as Lifeline in the information sheet. No identifying data were collected in the survey. The separate online link where participants could enter a draw as an incentive was not connected to the survey data in any way, and all details submitted through the form were deleted after the winner had confirmed receipt of their gift card. Hardcopy data is stored in a locked filing cabinet at Endeavour College of Natural Health, while electronic copies are stored in password protected folders accessible only to the research team.

### **3.5 CHAPTER SUMMARY**

The cross-sectional survey design employed for this thesis draws from two samples, providing data on the research questions from multiple settings which offer different strengths. By surveying the target population at both a nationally representative level and a clinical consultation level, more comprehensive consideration is given to the subject matter. The breadth and depth afforded by this approach reflect the nature of person-centred care, complementary medicine practice and chronic illness, producing rich insights into these topics of increasing importance to public health.

## **4. INDIVIDUALS WITH CHRONIC CONDITIONS WHO CONSULT CM PRACTITIONERS: RESULTS FROM A NATIONAL POPULATION-BASED SURVEY**

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### **4.1 RATIONALE FOR THIS ANALYSIS**

The Research Aim of this thesis as defined in Chapter 1 (section 1.2) requires an understanding of the characteristics of individuals with chronic conditions who consult with CM practitioners in Australia and their use of CM practitioner services.

Identification of such qualities amongst these individuals provides insight into the factors that make them unique from other groups of health care consumers and drive their particular health care-seeking behaviours. Both the challenges faced by health systems and care providers in providing optimal care to the growing population of patients with chronic conditions, and the high prevalence of CM use by such patients (as discussed in section 1.2), lend weight to an examination of the prevalence of CM practitioner consultation amongst those with chronic conditions, as well as who amongst those with chronic conditions use CM practitioner services in Australia, which CM professions are being consulted and why those services are sought.

Accordingly, this chapter utilises data from a sub-set of participants in the CAMUHLD survey who reported one or more chronic condition diagnoses as part of Phase Two analyses. This chapter reports on the prevalence of CM practitioner consultation within the sub-set of participants with chronic conditions, alongside socio-demographics, chronic condition diagnoses and health status, drawing comparisons between those who did or did not report consulting CM practitioners. In addition, this chapter identifies the CM professions being consulted by those with chronic conditions in Australia and presents the reasons for consulting CM practitioners reported by participants who did so, alongside reasons given by participants for consulting conventional medical providers. Predictors for consulting with CM practitioners are also explored. These analyses respond to Research Questions 1, 2 and 3, addressing Research Objective 1 and Research Objective 2 of this thesis.

### **4.2 PUBLICATION OF RESULTS**

The results presented within this chapter have been published as follows:

Foley H, Steel A, McIntyre E, Harnett J, Sibbritt D, Wardle J & Adams J.

Complementary medicine practitioner consultations amongst 1,314 individuals with chronic conditions: Characteristics of users, reasons for and predictors of use.

Complement Ther Clin Pract. 2020. 40:101194

A copy of the full published article is included below. The journal-formatted version can be viewed in Appendix 4.

### **4.3 COMPLEMENTARY MEDICINE PRACTITIONER CONSULTATIONS AMONGST 1,314 INDIVIDUALS WITH CHRONIC CONDITIONS: CHARACTERISTICS OF USERS, REASONS FOR AND PREDICTORS OF USE**

#### **4.3.1 Introduction**

Chronic conditions are prolonged health conditions, often involving complex causes, requiring ongoing medical care, and limiting an individual's functional capacity (9). Rates of chronic conditions are rising, increasingly contributing to the burden of disease and incurring substantial economic, personal and social costs to public health systems, individuals and their communities (2). The rising prevalence of chronic conditions is influenced by post-industrial shifts in societal lifestyle and dietary habits not conducive to health maintenance (1), alongside advancements in medical science resulting in reduced burden from acute and infectious diseases, and subsequently increased life expectancy (1).

Recognition of the burden of chronic conditions has led to their prioritisation in public health policy (1, 2). Even so, the complex, protracted nature of chronic conditions (which, unlike acute conditions, often include multiple morbidities) presents challenges to health care models built on strategies targeting acute, infectious diseases (11). Individuals with chronic conditions often require multifactorial, coordinated approaches to care accounting for the various difficulties impacting on health and daily life (2), particularly in multimorbidity where concurrent conditions add to complexity of needs and care (312). For many individuals with chronic conditions, the challenges of their health needs are further compounded by socioeconomic consequences arising from reduced capacity to engage in employment and social activities (29). Combined, the challenges facing both health systems and individuals regarding management of chronic conditions can result in unmet health-related needs for the chronically ill (2).

Efforts made by people living with chronic conditions to address their own unmet needs can lead to seeking additional care outside of conventional medicine, often in the form of complementary medicine (CM)—practices, paradigms and products defined as “complementary” by their general exclusion from the medical curriculum and mainstay of conventional medical practice (37). While CM can be self-prescribed, they are also provided by practitioners trained in CM professions, and are included in treatment by some conventional medical providers (37). Use of CM in the Australian general population is high, with 12-month prevalence estimates over 60% and consultation with CM practitioners reported by more than half of CM users (313). Individuals with chronic conditions have shown higher rates of CM use, including CM practitioner services (6). CM practitioners may be especially attractive to individuals with complex needs due to the holistic approach inherent to many CM philosophies (7), which seek to address the varied factors directly and indirectly influencing health and wellbeing (314).

The value of formally including CM in management and prevention of chronic conditions has been acknowledged in international public health guidelines (8). Nevertheless, such inclusion remains ad-hoc and beyond formal practice in Australia, particularly regarding services delivered by CM practitioners, leaving patients to coordinate their own care with little guidance (5). To date, what is known about the context and nature of service delivery by CM practitioners in Australia or the role it plays in wider care for those with chronic conditions is limited (6). Empirically examining CM practitioner use by this clinical sub-population is imperative to develop and evaluate possibilities of more formal integrated care in accordance with current evidence-based, person-centred guidelines (2). In direct response to this empirical gap, this paper describes the characteristics and CM practitioner consultation behaviours of individuals with chronic conditions.

### **4.3.2 Materials and methods**

#### *4.3.2.1 Study design and setting*

The Complementary and Alternative Medicine Use, Health Literacy and Disclosure (CAMUHLD) project was conducted as a cross-sectional survey, online, between 26 July and 28 August, 2017. This paper reports analyses of data provided by respondents who indicated having chronic conditions.

#### *4.3.2.2 Participants and recruitment*

Participants were adults (aged 18 and over), invited to participate through membership with research recruitment company Qualtrics. Purposive convenience sampling was employed to achieve a sample broadly representative of the Australian population regarding gender, age and state of residence. As part of the benefits involved with being a Qualtrics database member, participants who completed the survey were provided a small financial compensation. Participants provided consent after reading an information sheet. Survey completion time was approximately 15 minutes. A sample of 2,025 was drawn, producing 2,019 cases after removal of six respondents, deemed unreliable due to discrepancies in their data. This final sample size was considered adequate to provide statistical power for inferential analyses, based on previous literature reporting CM use in Australia (6). Of the 2,019 respondents included in the CAMUHLD project, 1,314 reported having one or more chronic conditions to comprise the sample for analyses reported here.

#### 4.3.2.3 Instrument

The survey was comprised of 50 items encompassing socio-demographics, health status, health service utilisation, health literacy and health communication. Items applicable to analyses presented here included socio-demographics, health status and health service utilisation.

Socio-demographics covered gender, age, state of residence, financial manageability, educational qualification, employment status, marital status, private health insurance (PHI) coverage, and possession of a Health Care Card (provided to low-income earners and welfare recipients in Australia for financial concessions on health care and medicines). Respondents indicated (yes/no) which chronic condition/s they had been diagnosed with or treated for within the preceding 3 years from a list of common chronic health conditions, alongside an open-text option of *other health condition (please specify)*, and an option for *none of the above* (details in Table 4.1). Health status was assessed with the 20-item short-form health survey (SF-20) which assesses self-perceived health status across six domains (physical functioning, role functioning, social functioning, mental health, current health perceptions, pain) (285). The SF-20 has been shown to be a valid and reliable measure of self-perceived health status that balances breadth and depth of measurement in a short form (285).

Health service utilisation items asked respondents whether they had consulted with a range of conventional medicine providers and CM practitioners within the previous 12 months, and the reasons for consultation. These items were adapted from the International Complementary and Alternative Medicine Questionnaire (I-CAM-Q) (286),

with modifications to ensure cultural relevance in the Australian context and suitability for online delivery. The I-CAM-Q was developed to allow consistency in collection of information about CM use across different populations (286). Formatting of the online instrument encouraged respondents to complete all items relevant to the individual and allowed for open-text responses where suitable, limiting occurrence of missing responses.

**Table 4.1 Chronic Conditions Presented in Survey and Categorisation of Conditions for Analysis**

<b>Condition categories</b>	<b>Specific conditions as listed on survey</b>
<b>Cardiovascular</b>	Heart disease Hypertension Dyslipidaemia
<b>Diabetes</b>	Type 1 diabetes Non-insulin dependent type 2 diabetes Insulin dependent type 2 diabetes
<b>Cancer</b>	Cancer (benign) Cancer (malignant)
<b>Female reproductive</b>	Endometriosis Polycystic ovarian syndrome Other female reproductive disorder
<b>Male reproductive</b>	Benign prostatic hyperplasia Other male reproductive disorder
<b>Respiratory</b>	Asthma Bronchitis Other respiratory disorder
<b>Gastrointestinal</b>	Irritable bowel syndrome (IBS) Inflammatory bowel disease (Crohn's disease, ulcerative colitis) Coeliac disease Gastro-oesophageal reflux disease (GORD/GERD) Chronic constipation Other gastrointestinal/digestive disorder
<b>Mental Health</b>	Mood disorder (e.g. depression) Anxiety disorder Sleep disorder Substance use disorder Schizophrenia or other psychotic disorder Other mental health disorder
<b>Musculoskeletal</b>	Osteoarthritis Other musculoskeletal disorder
<b>Other</b>	Other chronic health condition/s (not listed above)

#### 4.3.2.4 Data analysis

Analyses were conducted with StataC-14 (StataCorp LC 2015) software. Categorical variables detailing service utilisation of health care providers were recoded to binaries (consulted/did not consult), and a binary variable was generated to describe the presence of chronic condition/s (yes/no). Chronic condition variables were also collapsed into categories (e.g. cardiovascular, gastrointestinal) for analyses, as shown in Table 4.1.

Associations between having consulted a CM practitioner and socio-demographic/health status variables were assessed using chi-square tests (categorical/binary variables) and independent t-tests (continuous variables). Potential predictors for having consulted with the most commonly accessed CM professions were determined using reverse stepwise logistic regression, producing adjusted odds ratios (aOR) in the most parsimonious model accounting for the influence of socio-demographic and health status factors. Statistical significance was set at  $p < 0.05$ . Missing data were excluded from analysis.

#### 4.3.2.5 Ethics

Ethical approval was obtained from the [institution blinded for review purposes] Human Research Ethics Committee ([HREC/approval number blinded for review purposes]). The study was approved and conducted in accordance with the Declaration of Helsinki.

### 4.3.3 Results

#### 4.3.3.1 Participant characteristics

Amongst respondents with chronic conditions ( $n = 1,314$ ) a slight majority were female (54.0%). The most commonly reported age group was 60 and over (31.9%), and most respondents resided in the states of New South Wales (27.3%), Victoria (25.2%) or Queensland (24.7%). They were most commonly married (43.7%), not in the paid workforce (42.4%) and held a post-secondary school trade or vocational qualification as their highest educational level (36.0%). When asked how they were managing financially, the most frequently recorded response was *it is difficult some of the time* (37.8%). PHI was held by 47.7% of the sample, with 31.8% including cover for CM services, and Health Care Cards were held by 38.3%.

Of the 1,314 respondents, 505 (38.4%) had consulted a CM practitioner one or more times in the preceding 12 months, while 809 (61.6%) had not. The two groups were significantly different across all socio-demographic domains excluding possession of a

Health Care Card ( $p = .212$ ). Those who had consulted a CM practitioner were more commonly: female ( $p = .004$ ), of younger age (49 years or below) ( $p < .001$ ), located in New South Wales or Victoria ( $p = .01$ ), in possession of university-level qualifications ( $p < .001$ ), employed ( $p < .001$ ), managing better financially ( $p = .041$ ), and single or married (as opposed to de facto, separated, divorced or widowed) ( $p = .048$ ). Those who consulted CM practitioners more commonly had PHI ( $p < .001$ ) and higher rates of PHI coverage for CM services ( $p < .001$ ). Full socio-demographics are presented in Table 4.2.

#### 4.3.3.2 *Participant health status*

The most commonly reported category of chronic conditions was mental health (48.8%), followed by cardiovascular (33.9%), respiratory (26.9%), musculoskeletal (24.1%) and gastrointestinal (22.3%) conditions. Multimorbidity was common with almost two-thirds (65.3%) reporting two or more concurrent chronic conditions (see Table 4.3).

Compared to respondents who did not consult CM practitioners, those who did consult had lower rates of reported cardiovascular disease ( $p = .016$ ), and higher rates of reported female reproductive ( $p < .001$ ), gastrointestinal ( $p < .001$ ), mental health ( $p = .004$ ) and respiratory conditions ( $p = .019$ ), as well as higher odds of reporting multimorbidity involving five or more conditions ( $p = .001$ ). While those who consulted with CM practitioners reported higher levels of general health status ( $p = .011$ ), they also reported lower scores of physical functioning ( $p = .006$ ), social functioning ( $p < .001$ ) and mental health ( $p < .001$ ), and higher levels of bodily pain ( $p = .002$ ) (see Table 4.3).



**Table 4.2 Socio-demographics of Participants with Chronic Conditions**

Socio-demographic category	Full sample <i>n</i> = 1,314	Consulted CM practitioner <i>n</i> = 505 (38.4%)	Didn't consult CM practitioner <i>n</i> = 809 (61.6%)	Chi <sup>2</sup> <i>P</i> value
<b>Gender</b>				
Female	709 (54.0%)	298 (59.0%)	411 (50.8%)	<i>.004</i>
Male	604 (46.0%)	207 (41.0%)	397 (49.1%)	
Other†	1 (0.1%)	0 (0.0%)	1 (0.1%)	
<b>Age</b>				
18-29	264 (20.1%)	133 (26.3%)	131 (16.2%)	< <i>.001</i>
30-39	182 (13.9%)	90 (17.8%)	92 (11.4%)	
40-49	229 (17.4%)	99 (19.6%)	130 (16.1%)	
50-59	220 (16.7%)	74 (14.7%)	146 (18.1%)	
60 and over	419 (31.9%)	109 (21.6%)	310 (38.3%)	
<b>State</b>				
NSW	359 (27.3%)	145 (28.7%)	214 (26.5%)	<i>.01</i>
VIC	331 (25.2%)	145 (28.7%)	186 (23.0%)	
QLD	325 (24.7%)	125 (24.8%)	200 (24.7%)	
SA	122 (9.3%)	44 (8.7%)	78 (9.6%)	
NT	4 (0.3%)	1 (0.2%)	3 (0.4%)	
WA	125 (9.5%)	31 (6.1%)	94 (11.6%)	
TAS	31 (2.4%)	7 (1.4%)	24 (3.0%)	
ACT	17 (1.3%)	7 (1.4%)	10 (1.2%)	
<b>Managing financially</b>				
It is impossible	50 (3.8%)	13 (2.6%)	37 (4.6%)	<i>.041</i>
It is difficult all of the time	273 (20.8%)	90 (17.8%)	183 (22.6%)	
It is difficult some of the time	496 (37.8%)	197 (39.0%)	299 (37.0%)	
It is not too bad	420 (32.0%)	170 (33.7%)	250 (30.9%)	
It is easy	75 (5.7%)	35 (6.9%)	40 (4.9%)	
<b>Education level</b>				
Up to year 10	236 (18.0%)	66 (13.1%)	170 (21.0%)	< <i>.001</i>
Year 12 or equivalent	260 (19.8%)	88 (17.4%)	172 (21.3%)	
Trade/VET	473 (36.0%)	177 (35.1%)	296 (36.6%)	
University degree	345 (26.3%)	174 (34.5%)	171 (21.1%)	
<b>Employment status</b>				
Full time work	327 (24.9%)	176 (34.9%)	151 (18.7%)	< <i>.001</i>
Part time work	236 (18.0%)	109 (21.6%)	127 (15.7%)	
Casual/temporary work	84 (6.4%)	33 (6.5%)	51 (6.3%)	
Looking for work	110 (8.4%)	28 (5.5%)	82 (10.1%)	
Not in paid workforce	557 (42.4%)	159 (31.5%)	398 (49.2%)	
<b>Marital status</b>				
Never married	328 (25.0%)	139 (27.5%)	189 (23.4%)	<i>.048</i>
Married	574 (43.7%)	231 (45.7%)	343 (42.4%)	
De facto (opposite sex)	139 (10.6%)	46 (9.1%)	93 (11.5%)	
De facto (same sex)	21 (1.6%)	9 (1.8%)	12 (1.5%)	
Separated/divorced/widowed	252 (19.2%)	80 (15.8%)	172 (21.3%)	
<b>PHI status</b>				
Has PHI	627 (47.7%)	301 (59.6%)	326 (40.3%)	< <i>.001</i>
PHI covers any CM	417 (31.8%)	242 (47.9%)	175 (21.6%)	< <i>.001</i>
<b>HCC status</b>	503 (38.3%)	204 (40.4%)	299 (37.0%)	<i>.212</i>

†Excluded from analyses of gender due to small cell size

**Table 4.3 Health Status and Personal Wellbeing of Participants who did and did not Consult with CM Practitioners**

	Full sample <i>n</i> = 1,314	Consulted CM practitioner <i>n</i> = 505 (38.4%)	Did not consult CM practitioner <i>n</i> = 809 (61.6%)	<i>P</i> value <sup>†</sup>
<b>Condition</b>				
<b>Cardiovascular</b>	445 (33.9%)	151 (29.9%)	294 (36.3%)	.016
<b>Diabetes</b>	176 (13.4%)	70 (13.9%)	106 (13.1%)	.694
<b>Cancer</b>	132 (10.1%)	52 (10.3%)	80 (9.9%)	.811
<b>Female reproductive</b>	112 (8.5%)	61 (12.1%)	51 (6.3%)	< .001
<b>Male reproductive</b>	48 (3.7%)	20 (4.0%)	28 (3.5%)	.639
<b>Respiratory</b>	353 (26.9%)	154 (30.5%)	199 (24.6%)	.019
<b>Gastrointestinal</b>	293 (22.3%)	141 (27.9%)	152 (18.8%)	< .001
<b>Mental Health</b>	641 (48.8%)	272 (53.9%)	369 (45.6%)	.004
<b>Musculoskeletal</b>	317 (24.1%)	124 (24.6%)	193 (23.9%)	.774
<b>Other</b>	148 (11.3%)	52 (10.3%)	96 (11.9%)	.381
<b>Multimorbidity</b>				
<b>1 condition</b>	455 (34.6%)	165 (32.7%)	290 (35.9%)	
<b>2 conditions</b>	284 (21.6%)	92 (18.2%)	192 (23.7%)	
<b>3 conditions</b>	184 (14.0%)	81 (16.0%)	103 (12.7%)	.001
<b>4 conditions</b>	145 (11.0%)	49 (9.7%)	96 (11.9%)	
<b>5+ conditions</b>	246 (18.7%)	118 (23.4%)	128 (15.8%)	
<b>SF-20</b>				
<b>General health</b>	45.22 ± 26.96	47.62 ± 28.20	43.73 ± 26.06	.011
<b>Physical functioning</b>	66.20 ± 32.05	63.15 ± 31.36	68.10 ± 32.34	.006
<b>Role functioning</b>	61.43 ± 42.04	59.06 ± 40.50	62.92 ± 42.92	.053
<b>Social functioning</b>	71.60 ± 30.36	65.82 ± 31.63	75.20 ± 28.99	< .001
<b>Mental health</b>	59.91 ± 23.79	57.12 ± 21.71	61.65 ± 24.86	< .001
<b>Health perception</b>	48.04 ± 26.12	47.71 ± 25.94	48.24 ± 26.24	.72
<b>Pain</b>	57.99 ± 25.67	55.17 ± 25.70	59.75 ± 25.50	.002

†Chi-square association used for binary and categorical variables (condition, multimorbidity), independent t-test used for continuous variables (SF-20 scores).

#### 4.3.3.3 Health service utilisation and reasons for consultation

Of the CM professions consulted, the most common was massage therapy (*n* = 284, 21.6%), followed by chiropractic (*n* = 188, 14.3%), acupuncture (*n* = 123, 9.4%), yoga (*n* = 118, 9.0%), naturopathy (*n* = 94, 7.2%) and osteopathy (*n* = 91, 6.9%). The least commonly utilised CM professions were traditional medicine (other than traditional Chinese medicine) (*n* = 2, 0.2%) and “other” natural medicine professions (*n* = 8, 0.6%).

Consulting with CM practitioners to support general wellbeing was common, being the most frequently reported reason for consulting with traditional medicine practitioners (100%), yoga teachers (77.0%), massage therapists (62.0%), aromatherapists (59.7%), traditional Chinese medicine practitioners (58.3%), Western herbalists (54.4%) and naturopaths (54.3%). Seeking treatment for long-term conditions was the most frequently reported reason for consulting with acupuncturists (63.4%), osteopaths (55.0%), chiropractors (53.7%) and homeopaths (38.0%). Seeking treatment for acute conditions or for “other” reasons were less commonly reported across all CM professions.

Conventional medical services were heavily utilised within the sample with the most commonly consulted profession being general practitioners (GPs) (n = 1,257, 95.7%), followed by pharmacists (n = 1,105, 84.1%), specialist doctors (n = 719, 54.7%) and hospital doctors (n = 472, 35.9%). Across all four conventional medical professions, the most frequently reported reason for consultation was to seek treatment for a long-term condition. Further details in Table 4.4.

#### 4.3.3.4 Predictors of consultation with CM professions

The regression model found respondents who consulted with CM practitioners had approximately half the odds of being from older age groups of 50-59 years (aOR = 0.52) or 60 years and older (aOR = 0.48) than those who did not consult with CM practitioners. The odds of them being unemployed were also lower (*looking for work* aOR = 0.39 or *not in the workforce* aOR = 0.57) and they had twice the odds of managing well financially (*it is not too bad* aOR = 2.10; *it is easy* aOR = 2.68).

Respondents who consulted with CM practitioners had increased odds by almost half of reporting gastrointestinal conditions (aOR = 1.49) and by more than one-third of reporting mental health conditions (aOR = 1.35). They were approaching three times the odds of PHI coverage for CM services (aOR = 2.85). Further details in Table 4.5.

Respondents consulting a chiropractor had increased odds by almost two-thirds of being male (aOR = 1.64) and by more than three-quarters of having five or more multimorbid conditions (aOR = 1.77), while their odds of being from older age groups were reduced by more than half (50-59 years aOR = 0.46; 60 years and older aOR = 0.41). Having consulted an osteopath was associated with decreased odds by more than half of reporting cardiovascular conditions (aOR = 0.47) and of being from older age groups (50-59 years aOR = 0.40; 60 years and older aOR = 0.22).

**Table 4.4 Health Professions Consulted and Reasons for Consultation**

	Profession Consulted		Reasons for consulting with a CM practitioner									
			Long-term condition		Acute condition		Wellbeing		Other		No. reasons <sup>†</sup>	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	Mean	SD
<b>Complementary medicine</b>												
<b>Massage therapist</b>	284	21.6	108	38.0	47	16.6	176	62.0	6	2.1	1.20	0.46
<b>Chiropractor</b>	188	14.3	101	53.7	46	24.5	69	36.7	6	3.2	1.18	0.47
<b>Acupuncturist</b>	123	9.4	78	63.4	27	22.0	36	29.3	1	0.8	1.17	0.44
<b>Yoga teacher</b>	118	9.0	32	27.1	13	11.0	91	77.0	0	0.0	1.15	0.44
<b>Naturopath</b>	94	7.2	43	45.7	17	18.1	51	54.3	1	1.1	1.19	0.49
<b>Osteopath</b>	91	6.9	50	55.0	23	25.3	27	29.7	2	2.2	1.15	0.39
<b>TCM practitioner</b>	72	5.5	32	44.4	19	26.4	42	58.3	0	0.0	1.29	0.59
<b>Aromatherapist</b>	62	4.7	24	38.7	14	22.6	37	59.7	0	0.0	1.21	0.48
<b>Western herbalist</b>	57	4.3	17	29.8	15	26.3	31	54.4	0	0.0	1.12	0.31
<b>Homeopath</b>	50	3.8	19	38.0	15	30.0	18	36.0	0	0.0	1.06	0.24
<b>Other natural medicine</b>	8	0.6	4	50.0	1	12.5	6	75.0	0	0.0	1.38	0.74
<b>Traditional medicine</b>	2	0.2	0	0.0	0	0.0	2	100.0	0	0.0	1.00	0.00
<b>Conventional medicine</b>												
<b>GP</b>	1,257	95.7	804	64.0	332	26.4	358	28.5	96	7.6	1.26	0.52
<b>Specialist doctor</b>	719	54.7	539	75.0	137	19.1	145	20.2	27	3.8	1.18	0.44
<b>Hospital doctor</b>	472	35.9	229	48.5	226	47.9	69	14.6	12	2.5	1.14	0.40
<b>Pharmacist</b>	1,105	84.1	642	58.1	250	22.6	327	29.6	140	12.7	1.23	0.52

<sup>†</sup>Average number of reasons provided by participants

Respondents who had visited a massage therapist had decreased odds by almost half of being from older age groups (50-59 years aOR = 0.57; 60 years and older aOR = 0.51) and by more than half of being unemployed (*looking for work* aOR = 0.41 or *not in the workforce* aOR = 0.49). More than twice the odds of reporting a cancer diagnosis (aOR = 2.32) and almost three times the odds of reporting male reproductive conditions (aOR = 2.93) were found amongst respondents consulting an acupuncturist. Their odds of being married were twice that of being single (aOR = 2.01), while their odds of being from older age groups were substantially reduced (50-59 years aOR = 0.37; 60 years and older aOR = 0.22).

Respondents who had utilised the services of a yoga teacher had reduced odds by almost half of being male (aOR = 0.52) and substantially reduced odds of being unemployed (*looking for work* aOR = 0.34 or *not in the workforce* aOR = 0.24) or casually/temporarily employed (aOR = 0.33). They were found to have reduced odds by half of being aged 30-39 (aOR = 0.50) and by more than two-thirds of being aged 50-59 (aOR = 0.28), while their odds of holding university-level qualifications were increased by more than two-fold (aOR = 2.64) and odds of holding a Health Care Card were reduced by almost half (aOR = 0.52).

Odds of being *not in the workforce* were reduced by more than two-thirds (aOR = 0.29) for respondents consulting a naturopath. While holding PHI generally was not found to be a predictor of consulting a CM practitioner, the odds of having PHI coverage for the specific profession utilised was increased across all six professions, ranging from aOR = 2.63 for yoga to aOR = 6.09 for osteopathy. Full details of adjusted odds ratios are presented in Table 4.5.

**Table 4.5 Predictors of Consulting with Complementary Medicine (CM) Practitioners: Results of Reverse Stepwise Logistic Regression**

		Any CM			Chiropractic			Osteopathic			Massage therapy			Acupuncture			Yoga			Naturopathy		
		aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI
<b>Gender</b>																						
	Female	Ref	-	-	Ref	-	-	-	-	-	-	-	-	-	-	-	-	-	Ref	-	-	
	Male				1.64	.006	1.16, 2.34									0.52	.005	0.33, 0.82				
<b>Age range</b>																						
	18-29	Ref	-	-	Ref	-	-	-	-	-	-	-	-	-	-	-	-	-	Ref	-	-	
	30-39	1.04	.855	0.68, 1.59	0.86	.591	0.50, 1.48	1.46	.302	0.71, 2.98	1.38	.158	0.88, 2.15	0.64	.175	0.33, 1.22	0.50	.025	0.27, 0.92			
	40-49	0.77	.217	0.52, 1.16	0.71	.195	0.42, 1.19	0.77	.491	0.36, 1.63	0.98	.935	0.64, 1.52	0.67	.191	0.36, 1.22	0.62	.115	0.35, 1.12			
	50-59	0.52	.003	0.33, 0.79	0.46	.007	0.27, 0.81	0.40	.049	0.16, 1.00	0.57	.026	0.35, 0.93	0.37	.006	0.18, 0.76	0.28	.002	0.12, 0.62			
	60+	0.48	.001	0.32, 0.74	0.41	<.001	0.25, 0.66	0.22	.002	0.08, 0.60	0.51	.008	0.31, 0.84	0.22	<.001	0.11, 0.45	0.48	.061	0.23, 1.03			
<b>Employment status</b>																						
	Full time work	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
	Part time work	1.04	.826	0.72, 1.52							0.99	.942	0.66, 1.46				0.68	.168	0.39, 1.17	0.96	.895	0.55, 1.70
	Casual/temp work	0.70	.195	0.41, 1.20							0.57	.077	0.31, 1.06				0.33	.013	0.13, 0.79	0.58	.252	0.23, 1.47
	Looking for work	0.39	.001	0.23, 0.67							0.41	.004	0.22, 0.75				0.34	.013	0.15, 0.79	0.63	.259	0.28, 1.41
	Not in workforce	0.57	.003	0.40, 0.83							0.49	.001	0.32, 0.73				0.24	<.001	0.12, 0.49	0.29	<.001	0.16, 0.54
<b>Managing financially</b>																						
	It is impossible	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
	Difficult all the time	1.40	.365	0.67, 2.92																		
	Difficult sometimes	1.96	.065	0.96, 4.00																		
	It is not too bad	2.10	.047	1.01, 4.35																		
	It is easy	2.68	.03	1.10, 6.52																		
<b>Educational qual</b>																						
	Up to year 10	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
	Year 12 or equivalent															0.95	.908	0.38, 2.38				

	Any CM			Chiropractic			Osteopathic			Massage therapy			Acupuncture			Yoga			Naturopathy		
	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI
Trade/Vocational															1.55	.291	0.69, 3.52				
University															2.64	.021	1.16, 6.00				
<b>Marital status</b>																					
Never married	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Married													2.01	.011	1.17, 3.44						
De facto, opposite sex													0.41	.08	0.15, 1.11						
De facto, same sex													1.19	.831	0.25, 5.65						
Separated/ Divorced/ Widowed													1.85	.072	0.95, 3.60						
<b>Cardiovascular condition</b>							0.47	.025	0.25, 0.91												
<b>Cancer diagnosis</b>													2.32	.006	1.28, 4.21						
<b>Male reproductive condition</b>													2.93	.016	1.22, 7.03						
<b>Gastrointestinal condition</b>	1.49	.008	1.11, 2.00																		
<b>Mental health condition</b>	1.35	.029	1.03, 1.77																		
<b>Multimorbidity</b>																					
1 condition	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
2 conditions				1.04	.877	0.64, 1.68															
3 conditions				1.35	.268	0.80, 2.28															
4 conditions				0.62	.173	0.32, 1.23															
5+ conditions				1.77	.026	1.07, 2.94															
<b>PHI covers this</b>	2.85	<.001	2.17, 3.72	3.25	<.001	2.28, 4.63	6.09	<.001	3.42, 10.85	3.69	<.001	2.62, 5.21	3.68	<.001	2.29, 5.91	2.63	.003	1.39, 5.00	2.64	.003	1.40, 4.95
<b>Health Care Card holder</b>															0.52	.007	0.33, 0.84				

aOR = Odds ratio adjusted for socio-demographic and health status variables

#### 4.3.4. Discussion

This paper is the first to present a detailed description of the characteristics of individuals with chronic conditions who consult with CM practitioners in Australia, alongside indications of the motivation for seeking such care. This provides insight into the dynamics of the relationship between chronic illness and CM use in the Australian health care landscape. There appear to be a number of socio-demographic factors influencing both utilisation of CM practitioner services generally, and utilisation of specific CM professions, which speak to the complex interplay of physical, economic and psychosocial determinants of health associated with living with chronic conditions.

The finding that participants consulting any CM practitioner had higher odds of being younger, employed, able to manage financially and in possession of PHI coverage for CM is consistent with what is known about CM practitioner service users in the general population (6). Differences, however, were noted regarding use of specific CM professions, highlighting the nuanced nature of the field of CM and significant heterogeneity between CM professions and practices. Additionally, while employment status predicted utilisation of some CM professions by study participants, financial management status did not, nor did general PHI cover status. Considered together, these economic factors suggest a more complex relationship between financial status and CM use than a direct correlation with income. Previous research shows the economic burden of managing chronic conditions can affect an individual's financial management and create greater perceived necessity for PHI coverage, regardless of income or employment status (315). Consequently, it may be that individuals in our study were encouraged to consult CM practitioners by the potential cost-reduction afforded by PHI coverage for CM. Additionally, participant employment could possibly have been influential, as CM practitioners often build a client-base via word-of-mouth referrals (316, 317), which are more likely to occur during social interaction such as the interaction that occurs when working with others in employment.

We also found the associations between consultation behaviour and chronic condition categories differed depending on which CM professions were consulted, indicating potential relationships between profession-specific treatments and condition-specific needs. Those consulting with osteopaths had lower odds than other respondents of reporting cardiovascular conditions, which is not unexpected given the general focus of osteopaths on musculoskeletal conditions (301). Nonetheless, these lower odds may represent missed opportunities for cardiovascular management, considering that osteopaths report provision of patient education on modifiable factors that contribute to



cardiovascular disease such as exercise, stress management and nutrition (301). Participants who had consulted with acupuncturists had higher odds than those who had not consulted acupuncturists of reporting cancer. This may be due to growing recognition of acupuncture as a suitable adjunct treatment with low risk of conventional treatment interactions for numerous cancer symptoms (318), as well as its inclusion in some Australian oncology centre programs (319-321). Male reproductive conditions were also reported at higher odds amongst those who had consulted acupuncturists compared to those who had not, possibly a result of men with conditions such as benign prostatic hyperplasia seeking alternatives to pharmacological treatment, which has low adherence due to drug side-effects impacting on sexual function (322). Participants consulting with chiropractors exhibited higher odds of multimorbidity (five or more conditions), which may relate to the high incidence of back pain in those with multimorbidities (17), reflecting the prevalence of back problems amongst chiropractic users (323) as well as the diverse therapeutic tools employed by chiropractors in Australia (303).

Odds of consulting any CM practitioner were higher for those with gastrointestinal and mental health conditions—two fields in which patients receiving conventional medical care often have unmet needs (25, 26, 123, 324). In fact, prevalence of mental health problems is particularly high amongst individuals with chronic conditions, which is likely a bidirectional relationship, exacerbated by the burden and reduced quality of life associated with prolonged illness (325). Yet, individuals with chronic conditions report difficulty in addressing comorbid mental health problems through conventional care due to limited consultation time, perceived provider reliance on pharmaceuticals, and poor patient-provider communication (326). Such difficulties may lead these individuals to seek care from CM practitioners specifically to address mental health needs, as CM practitioners are often perceived as being notably empathic and supportive (7).

It was common for people in our study to seek care from CM practitioners to treat long-term conditions. However, seeking support for general wellbeing was a more frequently reported reason for CM consultation, particularly amongst participants visiting health professionals for whom there were no increased odds of users reporting any specific chronic condition (massage therapy, naturopathy, yoga). As perceptions of wellness reflect health-related quality of life (327), care sought to improve general wellbeing may be addressing unmet quality of life needs. The identification of wellness as a predominant motivator could also suggest users of these professions consider them to be personal treats or luxuries (328). The legitimacy of CM professions as therapeutic resources may be undermined by prevailing perceptions of health care as disease

treatment, rather than as an holistic means of addressing the many factors that contribute to a state of health and overall quality of life (328). Despite this, there is emerging evidence for effectiveness of some CM in certain chronic conditions; for example, massage therapy for various symptoms in fibromyalgia (329) and other pain-related conditions (330); naturopathy for management of anxiety, menopausal symptoms (331) and diabetes (332); and yoga for chronic obstructive pulmonary disease (333) and post-traumatic stress disorder (334).

While the findings of our study add to current knowledge of the role of CM practitioners in chronic health management in Australia, study limitations must be considered. Due to the unavailability of existing data describing the socio-demographic profile of individuals with chronic conditions as a comprehensive group in Australia, it was not possible to determine the representativeness of the sub-sample used in these analyses. The full CAMUHL sample was broadly representative of the national population, yet due to the online and self-report nature of the study, responder and recall bias may still be present. Survey items regarding health service utilisation were limited to the preceding 12 months to reduce recall bias, with the exception of the item asking about chronic condition diagnosis, which extended to 3 years to reflect the temporal reality of chronic illness. Additionally, chronic conditions were grouped into categories for analysis—such categorisation differs between studies when conditions broach more than one category, limiting the accuracy of comparisons with other relevant research. Lastly, the cross-sectional design and lack of post-treatment health outcome measures of our dataset prevents speculation about the value of treatments provided by CM practitioners. Understanding of the intersection of chronic disease and use of CM practitioner services would benefit from research using longitudinal design to further explore the role and value of CM in the care of those with chronic conditions. Such research could include more extensive evaluation of effectiveness, safety, and the psychosocial impact of patient-practitioner relationships in CM clinical care on health-related quality of life.

#### **4.3.5. Conclusion**

The use of CM practitioner services by individuals with chronic conditions is highly prevalent and appears to be driven by socio-demographic factors relating to social determinants of health, alongside a desire for improved wellbeing. CM practitioners providing these services may be addressing unmet needs within a population that represents a growing burden to a public health system challenged by the complexity and protracted nature of their health needs. The current and future contributions of CM

professions should be systematically acknowledged and examined as potentially invaluable resources for managing the changing landscape of health care as it becomes increasingly dominated by chronic illness. There is a pressing need for public health practice to better align with policy acknowledging the potential value of integrated medicine for chronic health management.

#### **4.4 CHAPTER SUMMARY**

The results from this chapter identify a substantial prevalence of CM consultation amongst those with chronic conditions. This chapter also discusses the socio-demographic and health-related characteristics which differentiate individuals with chronic conditions who consult with CM practitioners from those with chronic conditions who do not consult CM practitioners, including characteristics which predict such consultation. To fully interpret these results, researchers and policymakers must also have an understanding of the potential connections between condition-specific patient needs and the profession-specific strengths of different CM practitioner services, not only surrounding treatment of conditions but also of associated wellbeing and/or quality of life factors. The findings in this chapter uncover gaps in knowledge regarding the aspects of care, both generally and profession-specific, in CM services that are perceived by patients with chronic conditions as suitable for fulfilling their health and wellbeing needs. Exploration of which aspects of CM care are valued by patients requires closer examination of the relationships between different chronic condition diagnoses and care-seeking behaviours regarding specific CM professions, including motivations to consult and experiences of care received. Additional research is also required to discern how the role and experience of CM practitioner services may differ from that of conventional medicine services for individuals with chronic conditions.

## **5. INDIVIDUALS WITH CHRONIC CONDITIONS WHO CONSULT CM PRACTITIONERS: RESULTS FROM THREE NATIONAL PRACTICE-BASED RESEARCH NETWORKS**

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### **5.1 RATIONALE FOR THIS ANALYSIS**

The previous chapter identified a high prevalence of CM practitioner consultation amongst individuals with chronic conditions in an Australian national sample, which appears to be influenced by socio-demographic factors related to social determinants of health. Chapter 4 also ascertained that chronic condition patients are motivated to seek CM practitioner services predominantly for improved wellbeing and preventive care, alongside direct treatment of their chronic conditions. Analyses exploring predictors of having consulted with a CM practitioner noted apparent associations between categories of diagnosed chronic conditions and the type of CM professions consulted. The findings of the previous chapter inform analyses conducted in the present chapter, providing a foundation from which to further develop understanding of the characteristics of individuals with chronic conditions who consult with CM practitioners and the nature of their care-seeking behaviours, in accordance with the Research Aim of this thesis (see section 1.2).

The present chapter utilises data from participants of the Phase Two PECMC survey. It complements the previous chapter's broad national sample with a sample drawn from CM clinical practices embedded in three national PBRNs. The CM clinical practices included reflect the CM professions most commonly accessed by Australians with chronic conditions – as described in the previous chapter – thereby focusing this study to the clinical settings most relevant to the target population. While the CAMUHLD survey data used in the previous chapter relied on participant recall of events from the preceding twelve months, the PECMC survey was administered to patients shortly following their CM consultation. This complementary approach to data collection and analysis aims to develop a deeper understanding of the relationship between having a chronic condition and consulting with a CM practitioner by drawing from the breadth of the CAMUHLD survey findings to apply depth of exploration in a more specific clinical setting.

Accordingly, this chapter examines the characteristics of individuals with chronic conditions who consult with CM practitioners, their reasons for doing so and associations between chronic condition diagnoses and CM professions consulted in greater detail. In addition, this chapter assesses the continuity of consultation (number of consultations from one to five or more) with CM practitioners by those with chronic conditions to add greater insight regarding care-seeking behaviours. Specifically, a comparison is made between the socio-demographics of those with and without chronic conditions amongst individuals consulting with CM practitioners to further define the characteristics of the target population. The reasons for consultation are extended beyond those used in Phase One to elicit more nuanced descriptions of patient motivations, and both reasons for consultation and chronic condition diagnoses are compared between groups delineated by the CM profession consulted. The number of consultations each participant had with their CM practitioner is also examined to determine the extent of continuity of care in the patient-practitioner relationship. These analyses add weight to the foundations of the preceding chapter to more completely address Research Objective 1 and Research Objective 2 in response to Research Questions 1, 2 and 3 (outlined in section 1.2).

## **5.2 PUBLICATION OF RESULTS**

The results presented within this chapter have been published as follows:

Foley H, Steel A & Adams J. Consultation with complementary medicine practitioners by individuals with chronic conditions: Characteristics and reasons for consultation in Australian clinical settings. Health Soc Care Comm. 2020. In press.

A copy of the manuscript can be viewed in Appendix 5.

## **5.3 CONSULTATION WITH COMPLEMENTARY MEDICINE PRACTITIONERS BY INDIVIDUALS WITH CHRONIC CONDITIONS: CHARACTERISTICS AND REASONS FOR CONSULTATION IN AUSTRALIAN CLINICAL SETTINGS**

### **5.3.1 Introduction**

Chronic conditions – which limit functional capacity and require prolonged medical management over time (9) – present a substantial and growing burden of disease (1). More than half of the Australian population live with at least one chronic condition (2). Prevalence of chronic conditions is increasing as the landscape of disease shifts away

from acute and infectious diseases toward chronic and non-communicable conditions, precipitated by post-industrial lifestyle and environmental changes, and increased life expectancy (1). However, health systems face many challenges in meeting the complex, ongoing health needs of individuals with chronic conditions (1, 2).

Those with chronic conditions report a number of physical, psychosocial and financial challenges and unmet needs impacting on their health, health care experiences, and quality of life (27, 29, 30). The complexity and protracted nature of chronic conditions creates a need for multi-factorial approaches to care and self-management (2) which often leads individuals to supplement medical care with additional services, such as those provided by complementary medicine (CM) practitioners (57). CM refers to health practices, paradigms and products generally found outside of mainstream medical practice and training (37). CM may be self-prescribed, but is also commonly provided by practitioners of CM professions, as well as some conventional medical providers (37). Australians demonstrate particularly high rates of CM use – estimated at approximately 63% for CM use overall and 36% for CM practitioner use (313). Consultations with CM practitioners appear to be even higher amongst Australians with chronic conditions (313).

The decision to consult with CM practitioners is reportedly driven by a number of motivations, including the patient's attraction to the holistic approach of many CM professions which seek to "treat the whole person" (305). Holistic approaches may be particularly useful in chronic condition management as they involve a person-centred consideration of the many ways in which a patient's daily life is affected by their condition, rather than solely treating the disease process (89). Other motivations which have been reported by patients as reasons to consult a CM practitioner include a desire to take an active role in their own health, dissatisfaction with conventional medicine or its side-effects, a desire for preventive health care, a perception of CM as safe, a perceived ability of CM to provide hope and control, and a perception of CM practitioners as being especially supportive (6, 305).

The high prevalence of CM use by those with chronic conditions suggests many amongst these sufferers perceive value in CM for managing their health, and this potential value has been acknowledged in global public health guidelines (37). Limited research has explored some drivers of CM utilisation in Australia by individuals with specific chronic conditions, such as diabetes and cardiovascular disease (335). Yet the factors surrounding CM practitioner consultation by individuals with chronic conditions as a wider clinical population in Australia have not been examined thus far (6, 57).

Understanding the profile and motivations of those with chronic conditions who consult with CM practitioners is integral in order to develop more comprehensive models of care delivery to this increasingly important clinical population, as well as to ensure the health needs of those with chronic conditions are adequately met. Consequently, the aim of the study reported here is to describe the characteristics and reasons for consultation amongst those with chronic conditions who consult with CM practitioners in clinical settings.

### **5.3.2 Methods**

#### *5.3.2.1 Study design and setting*

A cross-sectional survey was conducted in community-based CM clinics throughout Australia between November 2018 and March 2019. The five most-commonly consulted clinical CM professions in Australia – massage therapy, chiropractic, acupuncture, naturopathy and osteopathy – were selected based on previous research (313). Practitioners of these professions were invited to assist with patient recruitment through three practitioner-based research networks (PBRNs): the Practitioner Research and Collaboration Initiative (PRACI)(298), the Osteopathy Research and Innovation Network (ORION)(301, 302), and the Australian Chiropractic Research Network (ACORN) (303).

#### *5.3.2.2 Participants and recruitment*

CM practitioners who were active clinicians and members of one of the participating PBRNs completed an online expression of interest and consent form to participate in the study. Seven to eight practitioners of each profession were selected on the basis of geographical location and were provided with hardcopy study materials (information sheets, surveys, and detailed instructions regarding the study protocol, the recruitment process and communication about the study with patients to ensure consistency in patient recruitment). The selected practitioners each provided 15 consecutive eligible patients with an information sheet about the study, a consent form and a hardcopy of the survey instrument, to be self-administered from home if the patient chose to participate. Participation was anonymous. This approach reduced selection bias, allowed patients to provide or withhold consent without coercion, and blinded practitioners to recruitment outcomes in order to preserve the integrity of patient-practitioner relationships (practitioners were not aware of who did or did not participate). Patients were considered eligible to participate if they were adults (aged

18 and over), fluent English speakers, capable of providing informed consent, and had not already participated during previous consultations with the recruiting practitioner.

Each survey was provided with a reply-paid postage envelope to return completed surveys to the research team at no cost to practitioners or patients. The surveys also included a link to a separate online form where participants could choose to enter a draw to win a \$100 gift voucher as an incentive to participate. Personal details collected through the online form included only a name and contact point (phone or email), with the winner chosen randomly. A sample of 400 patients was sought to achieve a 5.0% margin of error, calculated using conservative estimates of chronic condition prevalence and response rates based on previous research in a similar population (88).

### 5.3.2.3 Instrument

The survey was comprised of 29 questions, covering socio-demographics, chronic condition diagnoses, details of CM care-seeking, experiences of care received, and communication about treatments used by patients. Respondents who did not have a chronic condition diagnosis completed only socio-demographic items; this data was taken in order to establish the prevalence of chronic condition diagnoses amongst those consulting with CM practitioners and to identify potential socio-demographic differences between those with or without chronic conditions. All other variables were responded to only by participants with chronic conditions. Items applicable to the analyses presented here included socio-demographics, chronic condition diagnoses and details of CM care-seeking.

Socio-demographics encompassed age, gender, state of residence, marital status, educational qualification level, employment status, financial manageability, private health insurance coverage, and possession of a Health Care Card (card provided to low-income earners in Australia for health and medical financial concessions). Current chronic condition diagnoses were identified by respondents from a list, with additional options for open-text responses alongside a “none of the above” option. Care-seeking items included profession of the CM practitioner who provided the survey, number of visits ever attended with the CM practitioner consulted (to determine whether the patient-practitioner relationship is new or ongoing), and a list of reasons for seeking care from the CM practitioner. The list of reasons was informed by existing research (6, 305), subjected to face validity testing by researchers with expertise in the subject matter, and scored using a five-point Likert scale from *Strongly disagree* to *Strongly agree* with an additional *Doesn't apply* option.



#### *5.3.2.4 Data handling and analysis*

Data analysis was undertaken with StataIC 14 (StataCorp LC 2015). In order to produce adequate cell sizes, some variables were recoded to collapse response options where appropriate (age, marital status, educational qualification, employment status, financial manageability). Chronic condition diagnoses, including those reported by participants in open text responses, were recoded from specific conditions into broader condition categories as binary variables. Professions consulted were coded as binaries to allow comparison between participants who had consulted with a particular profession and participants who had not consulted that profession.

Descriptive statistics were tabulated as frequencies and percentages, and Fisher's exact test was used to test associations and compare groups. Comparisons were drawn between participants with and without chronic conditions for socio-demographics, and between groups delineated by the profession consulted by those with chronic conditions for all variables. Missing responses were excluded from analysis, as were *Does not apply* responses for items describing reasons for consultation.

#### *5.3.2.5 Ethics*

Ethical approval was granted by the Human Research Ethics Committee, University of Technology Sydney (ETH18-2769). This study conforms to the standards of the Declaration of Helsinki.

### **5.3.3 Results**

A total of 39 CM practitioners participated in the recruitment process (seven chiropractors and eight practitioners from each other profession) and confirmed distribution of the survey materials by emailing the research team. Of the 585 surveys distributed to patients, 199 were returned, providing a 34.0% response rate. Five returned surveys were excluded due to being incomplete and three others were excluded due to inconsistent responses which challenged reliability of the data (responses to some items contradicted responses to others), producing a final sample of 191 patients.

#### *5.3.3.1 Participant characteristics*

Within the full sample, 153 (80.1%) patients reported at least one diagnosed chronic condition. Participants with chronic conditions were more commonly female (82.4%)

compared to participants with no chronic conditions (68.4%) ( $p = .042$ ). Participants with chronic conditions also reported higher rates of Health Care Card cover (37.6%) compared to those with no chronic conditions (15.8%) ( $p = .007$ ). No other statistically significant socio-demographic differences were found between the two groups (see Table 5.1).

Participants who reported at least one chronic condition diagnosis were most commonly female (82.4%), aged 65 years and over (29.0%), residing in New South Wales (27.2%), married (55.9%), vocational or trade qualified (40.1%) and employed (30.9% full time, 25.0% part time, 6.6% casually/temporarily). Participants most commonly reported financial manageability as *not too bad* (48.0%), held private health insurance cover generally (79.0%) and held private health insurance cover specifically for CM (71.1%), with 37.6% reporting Health Care Card cover. Full socio-demographic details are presented in Table 5.1.

Table 5.1 Socio-demographics of full sample

	All respondents n = 191 (100%)	Chronic condition/s n = 153 (80.1%)	No chronic condition n = 38 (19.9%)	P value
<b>Gender (n = 191)</b>				
<i>Female</i>	152 (79.6%)	126 (82.4%)	26 (68.4%)	.042
<i>Male</i>	38 (19.9%)	26 (17.0%)	12 (31.6%)	
<i>Transgender†</i>	1 (0.5%)	1 (0.7%)	0 (0.0%)	
<b>Age (n = 190)</b>				
<i>18-34</i>	22 (11.6%)	15 (9.9%)	7 (18.4%)	.358
<i>35-44</i>	31 (16.3%)	25 (16.5%)	6 (15.8%)	
<i>45-54</i>	44 (23.2%)	35 (23.0%)	9 (23.7%)	
<i>55-64</i>	43 (22.6%)	33 (21.7%)	10 (26.3%)	
<i>65+</i>	50 (26.3%)	44 (29.0%)	6 (15.8%)	
<b>State (n = 185)</b>				
<i>ACT</i>	8 (4.3%)	4 (2.7%)	4 (10.5%)	.181
<i>NSW</i>	48 (26.0%)	40 (27.2%)	8 (21.1%)	
<i>VIC</i>	33 (17.8%)	26 (17.7%)	7 (18.4%)	
<i>QLD</i>	43 (23.2%)	31 (21.1%)	12 (31.6%)	
<i>SA</i>	16 (8.7%)	13 (8.8%)	3 (7.9%)	
<i>WA</i>	10 (5.4%)	10 (6.8%)	0 (0.0%)	
<i>TAS</i>	27 (14.6%)	23 (15.7%)	4 (10.5%)	
<i>NT</i>	0 (0.0%)	0 (0.0%)	0 (0.0%)	
<b>Relationship status (n = 190)</b>				
<i>Never married</i>	29 (15.3%)	25 (16.5%)	4 (10.5%)	.198
<i>Married</i>	109 (57.4%)	85 (55.9%)	24 (63.2%)	
<i>De facto</i>	22 (11.6%)	15 (9.9%)	7 (18.4%)	
<i>Separated/divorced/widowed</i>	30 (15.9%)	27 (17.8%)	3 (7.9%)	
<b>Education (n = 190)</b>				
<i>Up to year 12</i>	42 (22.1%)	36 (23.7%)	6 (15.8%)	.569
<i>VET/trade</i>	77 (40.5%)	61 (40.1%)	16 (42.1%)	
<i>Higher education</i>	71 (37.4%)	55 (36.2%)	16 (42.1%)	
<b>Employment status (n = 189)</b>				
<i>Full time work</i>	64 (33.9%)	47 (30.9%)	17 (46.0%)	.211
<i>Part time work</i>	47 (24.9%)	38 (25.0%)	9 (24.3%)	
<i>Casual/temporary work</i>	13 (6.9%)	10 (6.6%)	3 (8.1%)	
<i>Not in paid workforce</i>	65 (34.4%)	57 (37.5%)	8 (21.6%)	
<b>Financial status (n = 187)</b>				
<i>It is impossible/difficult all of the time</i>	18 (9.6%)	16 (10.7%)	2 (5.4%)	.641
<i>It is difficult some of the time</i>	39 (20.9%)	33 (22.0%)	6 (16.2%)	
<i>It is not too bad</i>	92 (49.2%)	72 (48.0%)	20 (54.1%)	
<i>It is easy</i>	38 (20.3%)	29 (19.3%)	9 (24.3%)	
<b>PHI cover (n = 190)</b>	148 (77.9%)	120 (79.0%)	28 (73.7%)	.309
<b>PHI cover for CM (n = 190)</b>	135 (71.1%)	108 (71.1%)	27 (71.1%)	.573
<b>Health care card (n = 187)</b>	62 (33.2%)	56 (37.6%)	6 (15.8%)	.007

†Excluded from analyses of gender due to small cell size

For each of the five professions, a substantial majority of participants reported a chronic condition diagnosis, ranging from 76.3% of those who had consulted a massage therapist to 93.3% of those who had consulted a chiropractor. Between-group comparisons based on the profession consulted found a higher proportion of men amongst those who consulted chiropractors compared to those consulting the other four professions ( $p = .024$ ). Those who consulted a massage therapist had lower rates of Health Care Card coverage ( $p = .027$ ) compared to those consulting with the other four professions. Participants who had consulted a naturopath had a higher representation from the 65 years and over age group ( $p = .023$ ) and significantly lower rates of private health insurance coverage, both generally ( $p < .001$ ) and for CM ( $p = .001$ ). Full details in Table 5.2.

#### *5.3.3.2 Health service utilisation*

A majority of participants were repeat patients to their CM practitioner with 75.0% indicating they had attended five or more consultations. Between group comparisons found a significant difference in number of consults for those who had consulted a naturopath as only 56.7% of participants consulting this profession had attended five or more consultations. No other significant differences were seen in the frequency of service utilisation (see Table 5.3).

#### *5.3.3.3 Chronic condition diagnoses*

The most commonly reported chronic condition diagnoses were musculoskeletal conditions (60.8%), mental health conditions (47.7%), cardiovascular conditions (27.5%) and gastrointestinal conditions (18.3%). There were few statistically significant differences in the categories of conditions reported by participants across the different professions – higher rates of female reproductive conditions were found amongst those who had consulted an acupuncturist ( $p = .042$ ), while those who had consulted a naturopath demonstrated higher rates of reported mental health conditions ( $p < .001$ ) and gastrointestinal conditions ( $p = .043$ ) (see Table 5.3).

**Table 5.2 Socio-demographics of respondents with chronic conditions, by profession consulted**

	Acupunc ture n = 24 (77.4%)†	P	Chiropra ctic n = 28 (93.3%)†	P	Massa ge n = 29 (76.3 %)†	P	Naturop athy n = 33 (80.5%)†	P	Osteopa thy n = 39 (76.5%) †	P
<b>Gender (n = 153)</b>										
Female	21 (87.5%)	.37 6	19 (67.9%)	.02 4	26 (89.7 %)	.21 6	28 (84.9%)	.31 3	32 (82.1%)	.52 3
Male	3 (12.5%)		9 (32.1%)		3 (10.3 %)		4 (12.1%)		7 (17.9%)	
Transgender‡	0 (0.0%)		0 (0.0%)		0 (0.0%)		1 (3.0%)		0 (0.0%)	
<b>Age (n = 152)</b>										
18-34	3 (12.5%)	.84 9	3 (10.7%)	.45 5	3 (10.3 %)	.15 3	2 (6.1%)	.02 3	4 (10.5%)	.07 1
35-44	3 (12.5%)		6 (21.4%)		4 (13.8 %)		6 (18.2%)		6 (15.8%)	
45-54	5 (20.8%)		9 (32.1%)		11 (37.9 %)		7 (21.2%)		3 (7.9%)	
55-64	7 (29.2%)		5 (17.9%)		7 (24.1 %)		2 (6.1%)		12 (31.6%)	
65+	6 (25.0%)		5 (17.9%)		4 (13.8 %)		16 (48.5%)		13 (34.2%)	
<b>Relationship status (n = 152)</b>										
Never married	2 (8.3%)	.38 8	3 (10.7%)	.24 7	7 (24.1 %)	.21 9	5 (15.2%)	.08 8	8 (21.1%)	.24 3
Married	13 (54.2%)		20 (71.4%)		13 (44.8 %)		15 (45.5%)		24 (63.2%)	
De facto	2 (8.3%)		3 (10.7%)		5 (17.2 %)		2 (6.1%)		3 (7.9%)	
Separated/divorced/ widowed	7 (29.2%)		2 (7.1%)		4 (13.8 %)		11 (33.3%)		3 (7.9%)	
<b>Education (n = 152)</b>										
Up to year 12	6 (25.0%)	.45 4	7 (25.0%)	1.0 0	3 (10.3 %)	.17 5	8 (24.2%)	.72 3	12 (31.6%)	.42 4
VET/trade	7 (29.2%)		11 (39.3%)		14 (48.3 %)		15 (45.5%)		14 (36.8%)	
Higher education	11 (45.8%)		10 (35.7%)		12 (41.4 %)		10 (30.3%)		12 (31.6%)	
<b>Employment status (n = 152)</b>										
Full time work	10 (41.7%)	.23 1	12 (42.9%)	.35 0	12 (41.4 %)	.11 1	7 (21.2%)	.16 3	6 (15.8%)	.10 9
Part time work	5 (20.8%)		4 (14.3%)		10 (34.5 %)		7 (21.2%)		12 (31.6%)	

<i>Casual/temporary work</i>	3 (12.5%)		2 (7.1%)		1 (3.5%)		1 (3.0%)		3 (7.9%)	
<i>Not in paid workforce</i>	6 (25.0%)		10 (35.7%)		6 (20.7%)		18 (54.6%)		17 (44.7%)	
<b>Financial manageability (n = 150)</b>										
<i>It is impossible/difficult all of the time</i>	3 (12.5%)		3 (11.1%)		2 (6.9%)		5 (15.6%)		3 (7.9%)	
<i>It is difficult some of the time</i>	8 (33.3%)	.18	7 (25.9%)	.89	6 (20.7%)	.69	7 (21.9%)	.62	5 (13.2%)	.37
<i>It is not too bad</i>	7 (29.2%)	1	13 (48.2%)	5	17 (58.6%)	8	13 (40.6%)	0	22 (57.9%)	5
<i>It is easy</i>	6 (25.0%)		4 (14.8%)		4 (13.8%)		7 (21.9%)		8 (21.1%)	
<b>Health care cost subsidies</b>										
<i>PHI cover (n = 152)</i>	22 (91.7%)	.07	24 (85.7%)	.24	24 (82.8%)	.39	18 (54.6%)	<.00	32 (84.2%)	.25
<i>PHI for this profession (n = 152)</i>	19 (86.4%)	.62	24 (96%)	.08	22 (92.7%)	.29	10 (55.6%)	.00	29 (90.6%)	.28
<i>Health care card (n = 149)</i>	8 (33.3%)	.41	10 (38.5%)	.54	6 (20.7%)	.02	16 (48.5%)	.10	16 (43.2%)	.26

†Percentage of participants who consulted this profession

‡Excluded from analysis of gender due to small cell size

**Table 5.3 Service utilisation frequency and chronic condition diagnoses**

	All CM professions	Acupuncture	<i>P</i>	Chiropractic	<i>P</i>	Massage	<i>P</i>	Naturopathy	<i>P</i>	Osteopathy	<i>P</i>
<b>Number of visits (n = 148)</b>											
<i>First visit</i>	13 (8.8%)	3 (12.5%)		1 (3.7%)		2 (7.1%)		5 (16.7%)		2 (5.1%)	
<i>Two times</i>	9 (6.1%)	1 (4.2%)		0 (0.0%)		1 (3.6%)		3 (10.0%)		4 (10.3%)	
<i>Three times</i>	6 (4.1%)	1 (4.2%)	.933	0 (0.0%)	.314	0 (0.0%)	.827	4 (13.3%)	.008	1 (2.6%)	.147
<i>Four times</i>	9 (6.1%)	1 (4.2%)		1 (3.7%)		1 (3.6%)		1 (3.3%)		5 (12.8%)	
<i>Five or more</i>	111 (75.0%)	18 (75.0%)		25 (92.6%)		24 (85.7%)		17 (56.7%)		27 (69.2%)	
<b>Condition category (n = 153)</b>											
<i>Musculoskeletal conditions</i>	93 (60.8%)	14 (58.3%)	.479	16 (57.1%)	.408	20 (69.0%)	.216	19 (57.6%)	.408	24 (61.5%)	.534
<i>Mental health conditions</i>	73 (47.7%)	9 (37.5%)	.193	10 (35.7%)	.115	13 (44.8%)	.446	26 (78.8%)	< .001	15 (38.5%)	.124
<i>Cardiovascular conditions</i>	42 (27.5%)	5 (20.8%)	.301	7 (25.0%)	.474	10 (34.5%)	.235	11 (33.3%)	.259	9 (23.1%)	.313
<i>Gastrointestinal conditions</i>	28 (18.3%)	6 (25.0%)	.254	5 (17.9%)	.594	3 (10.3%)	.168	10 (30.3%)	.043	4 (10.3%)	.099
<i>Respiratory conditions</i>	25 (16.3%)	5 (20.8%)	.349	6 (21.4%)	.291	6 (20.7%)	.324	4 (12.1%)	.328	4 (10.3%)	.175
<i>Female reproductive conditions</i>	23 (15.0%)	7 (29.2%)	.042	3 (10.7%)	.354	3 (10.3%)	.323	6 (18.2%)	.371	4 (10.3%)	.245
<i>Cancer or related complications</i>	8 (5.3%)	1 (4.2%)	.634	2 (7.1%)	.449	1 (3.5%)	.531	1 (3.0%)	.453	3 (7.7%)	.332
<i>Diabetes mellitus (type I or II)</i>	6 (3.9%)	0 (0.0%)	.353	1 (3.6%)	.698	3 (10.3%)	.082	1 (3.0%)	.616	1 (2.6%)	.520
<i>Male reproductive conditions</i>	4 (2.6%)	1 (4.2%)	.498	1 (3.6%)	.558	1 (3.5%)	.573	0 (0.0%)	.374	1 (2.6%)	.731
<i>Other conditions</i>	59 (38.6%)	9 (37.5%)	.549	9 (32.1%)	.292	13 (44.8%)	.286	13 (39.4%)	.533	15 (38.5%)	.572

#### 5.3.3.4 Reasons for consultation

Of the 153 participants with chronic conditions, 150 (98.04%) selected at least one reason for their consultation. The reason with which respondents most commonly reported they strongly agreed or agreed was *This health care professional is supportive and compassionate* (n = 136). A majority of respondents also strongly agreed or agreed with the items: *I believe this type of health care is safe* (n = 131), *To improve general wellbeing and prevent future health problems* (n = 125), *This type of health care gives me hope about my future health* (n = 108) and *This type of health care gives me a sense of control about my health* (n = 105). The reason with which respondents most commonly reported they strongly disagreed or disagreed was *To seek treatment for an acute illness lasting less than one month* (n = 42), followed by *To reduce side-effects of my current medical treatments/medicines* (n = 38) and *I was dissatisfied with my conventional medical treatment and wanted to try something different* (n = 27). Full details in Table 5.4.

##### 5.3.3.4.1 REASONS FOR CONSULTING AN ACUPUNCTURIST

All 24 participants who had consulted an acupuncturist selected at least one reason for consultation. Amongst those who had consulted an acupuncturist, the reason for which respondents most commonly selected Strongly agree or Agree was *This health care professional is supportive and compassionate* (n = 22), followed by *I believe this type of health care is safe* (n = 21) and *To improve general wellbeing and prevent future health problems* (n = 21). The reasons with which respondents consulting an acupuncturist most commonly strongly disagreed or disagreed were *To seek treatment for an acute illness lasting less than one month* (n = 10) and *To reduce side-effects of my current medical treatments/medicines* (n = 8) (see Table 5.4).



**Table 5.4 Reasons for consultation**

Reason	All professions (n = 150)			Acupuncture (n = 24)			Chiropractic (n = 27)			Massage (n = 29)			Naturopathy (n = 31)			Osteopathy (n = 39)		
	Strongly agree/ Agree	Neutral	Disagree/ Strongly	Strongly agree/ Agree	Neutral	Disagree/ Strongly	Strongly agree/ Agree	Neutral	Disagree/ Strongly	Strongly agree/ Agree	Neutral	Disagree/ Strongly	Strongly agree/ Agree	Neutral	Disagree/ Strongly	Strongly agree/ Agree	Neutral	Disagree/ Strongly
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
To seek treatment for an acute illness lasting less than one month (n = 81)	33 (40.7)	6 (7.4)	42 (51.9)	5 (31.3)	1 (6.3)	10 (62.5)	6 (35.3)	2 (11.8)	9 (52.9)	5 (31.3)	1 (6.3)	10 (62.5)	3 (33.3)	2 (22.2)	4 (44.4)	14 (60.9)	0 (0.0)	9 (39.1)
To seek treatment for a long-term illness lasting more than one month (n = 119)	98 (82.4)	7 (5.9)	14 (11.8)	14 (82.4)	0 (0.0)	3 (17.7)	17 (77.3)	3 (13.6)	2 (9.1)	17 (73.9)	1 (4.4)	5 (21.7)	25 (92.6)	1 (3.7)	1 (3.7)	25 (83.3)	2 (6.7)	3 (10.0)
I was dissatisfied with my conventional medical treatment and wanted to try something different (n = 108)	55 (50.9)	26 (24.1)	27 (25.0)	7 (36.8)	6 (31.6)	6 (31.6)	6 (33.3)	4 (22.2)	8 (44.4)	7 (36.8)	6 (31.6)	6 (31.6)	17 (63.0)	6 (22.2)	4 (14.8)	18 (72.0)	4 (16.0)	3 (12.0)
To reduce side-effects of my current medical treatments/ medicines (n = 87)	33 (37.9)	16 (18.4)	38 (43.7)	3 (23.1)	2 (15.4)	8 (61.5)	3 (16.7)	2 (11.1)	13 (72.2)	7 (38.9)	3 (16.7)	8 (44.4)	14 (70.0)	3 (15.0)	3 (15.0)	6 (33.3)	6 (33.3)	6 (33.3)
To enhance the effectiveness of my current medical treatments/ medicines (n = 104)	73 (70.2)	14 (13.5)	17 (16.4)	13 (68.4)	2 (10.5)	4 (21.1)	9 (42.9)	2 (9.5)	10 (47.6)	16 (76.2)	4 (19.1)	1 (4.8)	20 (87.0)	3 (13.0)	0 (0.0)	15 (75.0)	3 (15.0)	2 (10.0)
To improve general wellbeing and prevent future health problems (n = 140)	125 (89.3)	9 (6.4)	6 (4.3)	21 (91.3)	1 (4.4)	1 (4.4)	22 (91.7)	1 (4.2)	1 (4.2)	22 (81.5)	4 (14.8)	1 (3.7)	25 (89.3)	1 (3.6)	2 (7.1)	35 (92.1)	2 (5.3)	1 (2.6)
I was seeking holistic/natural treatments (n = 125)	92 (73.6)	23 (18.4)	10 (8.0)	17 (77.3)	5 (22.7)	0 (0.0)	10 (45.5)	6 (27.3)	6 (27.3)	19 (82.6)	2 (8.7)	2 (8.7)	25 (86.2)	3 (10.3)	1 (3.5)	21 (72.4)	7 (24.1)	1 (3.5)

This type of health care suits my personal belief system (n = 123)	94 (76.4)	21 (17.1)	8 (6.5)	14 (73.7)	5 (26.3)	0 (0.0)	11 (52.4)	5 (23.8)	5 (23.8)	19 (79.2)	3 (12.5)	2 (8.3)	25 (86.2)	4 (13.8)	0 (0.0)	25 (83.3)	4 (13.3)	1 (3.3)
I believe this type of health care is safe (n = 137)	131 (95.6)	5 (3.7)	1 (0.7)	21 (95.5)	1 (4.5)	0 (0.0)	20 (95.2)	1 (4.8)	0 (0.0)	26 (96.3)	0 (0.0)	1 (3.7)	28 (93.3)	2 (6.7)	0 (0.0)	36 (97.3)	1 (2.7)	0 (0.0)
This type of health care gives me hope about my future health (n = 126)	108 (85.7)	17 (13.5)	1 (0.8)	17 (85.0)	3 (15.0)	0 (0.0)	16 (80.0)	4 (20.0)	0 (0.0)	21 (87.5)	2 (8.3)	1 (4.2)	25 (89.3)	3 (10.7)	0 (0.0)	29 (85.3)	5 (14.7)	0 (0.0)
This type of health care gives me a sense of control about my health (n = 129)	105 (81.4)	22 (17.1)	2 (1.6)	16 (80.0)	4 (20.0)	0 (0.0)	14 (66.7)	6 (28.6)	1 (4.8)	18 (78.3)	4 (17.4)	1 (4.4)	27 (93.1)	2 (6.9)	0 (0.0)	30 (83.3)	6 (16.7)	0 (0.0)
This health care professional is supportive and compassionate (n = 140)	136 (97.1)	2 (1.4)	2 (1.4)	22 (95.7)	1 (4.4)	0 (0.0)	21 (95.5)	1 (4.6)	0 (0.0)	26 (92.9)	0 (0.0)	2 (7.1)	29 (100.0)	0 (0.0)	0 (0.0)	38 (100.0)	0 (0.0)	0 (0.0)

#### 5.3.3.4.2 REASONS FOR CONSULTING A CHIROPRACTOR

Of the 28 respondents who had consulted a chiropractor, 27 provided at least one reason for consultation. Respondents consulting a chiropractor most commonly selected strongly agree or agree for items *To improve general wellbeing and prevent future health problems* (n = 22), *This health care professional is supportive and compassionate* (n = 21) and *I believe this type of health care is safe* (n = 20). The items for which they most commonly selected strongly disagree or disagree were *To reduce side-effects of my current medical treatments/medicines* (n = 13) and *To enhance the effectiveness of my current medical treatments/medicines* (n = 10) (see Table 5.4).

#### 5.3.3.4.3 REASONS FOR CONSULTING A MASSAGE THERAPIST

At least one reason for consultation was provided by all 29 respondents who had visited a massage therapist. The reasons for which respondents consulting a massage therapist most commonly selected strongly agree or agree were *This health care professional is supportive and compassionate* (n = 26) and *I believe this type of health care is safe* (n = 26), followed by *To improve general wellbeing and prevent future health problems* (n = 22) and *This type of health care gives me hope about my future health* (n = 21). The item for which respondents consulting a massage therapist most commonly selected strongly disagree or disagree was *To seek treatment for an acute illness lasting less than one month* (n = 10), followed by *To reduce side-effects of my current medical treatments/medicines* (n = 8), *I was dissatisfied with my conventional medical treatment and wanted to try something different* (n = 6), and *To seek treatment for a long-term illness lasting more than one month* (n = 5) (see Table 5.4).

#### 5.3.3.4.4 REASONS FOR CONSULTING A NATUROPATH

Of the 33 participants who had visited a naturopath, 31 provided at least one reason for the consultation. Amongst respondents consulting a naturopath, the reasons most commonly selected as strongly agree or agree were *This health care professional is supportive and compassionate* (n = 29), *I believe this type of health care is safe* (n = 28) and *This type of health care gives me a sense of control about my health* (n = 27). Very few respondents in this group selected strongly disagree or disagree for any items, with the most common being *To seek treatment for an acute illness lasting less than one month* (n = 4) and *I was dissatisfied with my conventional medical treatment and wanted to try something different* (n = 4) (see Table 5.4).

#### 5.3.3.4.5 REASONS FOR CONSULTING AN OSTEOPATH

All 39 respondents consulting an osteopath provided at least one reason for their consultation. Those respondents who had consulted an osteopath most commonly strongly agreed or agreed with the reasons *This health care professional is supportive and compassionate* (n = 38), *I believe this type of health care is safe* (n = 36), *To improve general wellbeing and prevent future health problems* (n = 35) and *This type of health care gives me a sense of control about my health* (n = 30). The reasons with which respondents in this group most commonly strongly disagreed or disagreed were *To seek treatment for an acute illness lasting less than one month* (n = 9) and *To reduce side-effects of my current medical treatments/medicines* (n = 6) (see Table 5.4).

### 5.3.4 Discussion

This paper presents novel insights into the characteristics and motivations surrounding CM practitioner consultations in Australia by individuals with chronic conditions – a substantial clinical population representing a growing public health burden (2). Our results suggest that Australians with chronic conditions who consult CM practitioners do so repeatedly over time and with a wide range of conditions. Patients visiting CM practitioners are motivated by a desire for supportive, compassionate, safe health care to improve their wellbeing. While there were many commonalities amongst our participants, there were also some key differences in characteristics between those consulting with practitioners of different CM professions.

There appears to be little difference in socio-demographic characteristics between CM practitioner service users with and without chronic condition diagnoses. However, the high prevalence of chronic conditions within our sample and across the sub-groups consulting with each of the five professions, together with the high rates of repeat consultation, indicate CM practitioners may be an important resource for some people living with chronic conditions. Indeed, recent Australian-based research identified that individuals with chronic conditions are more likely to consult CM practitioners than individuals with no chronic conditions (313). While seeking treatment specifically for a chronic condition was a widely reported reason for CM practitioner consultation, seeking improved wellbeing and preventive care was more consistently reported. This indicates our participants also use the services of CM practitioners to manage their general health and improve their wider quality of life, rather than exclusively as a form of direct disease treatment. Such use reflects an understanding of CM as a health resource used as a complement to conventional medicine and implies CM practitioners

may be addressing gaps in wider care provision (27). These patterns of use and motivation are also reflective of the philosophical focus on wellbeing and preventive care inherent to many CM professions (336). Such a philosophical focus may hold special appeal to individuals who face challenges around wellbeing while living with chronic conditions, particularly as health systems face their own challenges in addressing quality of life needs for this population (2).

Regarding the consistency with which participants indicated they visit their CM practitioner due to viewing them as supportive and compassionate, it may be that individuals with chronic conditions seek CM practitioners for care regarding psychosocial health needs (337). This is also reflected in our participants' perceptions that the CM practitioner instils hope and a sense of control for the individual over their own health; the CM clinician may influence self-efficacy amongst their patients. Due to the protracted and often complex nature of chronic conditions, alongside the impact on an individual's capacity to engage in work and social activities, health-related psychosocial challenges are frequently faced within this population (2, 131, 338). The holistic philosophies of CM professions which seek to treat the "whole person" (89), as well as the typically longer consultation times provided by CM professionals (339, 340), may produce an environment conducive to addressing psychosocial needs by allowing patients the time and space to be heard. This environment could facilitate exploration of potential solutions to challenges outside of direct, immediate medical needs.

Patients consulting naturopaths more frequently reported having been diagnosed with mental health conditions, which require substantial psychosocial support, as well as gastrointestinal conditions, which often impact on psychosocial wellbeing (341). While patients with such conditions have previously reported having needs which are not met by conventional medical treatment (25, 324), there is emerging evidence to support the efficacy of naturopathic whole practice and associated treatments, such as herbal medicines, in the treatment of mental health and gastrointestinal conditions (342, 343). There was also substantive agreement among our respondents consulting with a naturopath that their clinician is supportive and compassionate, which is consistent with previous research (88) and naturopathic training (344). The finding that fewer participants consulting naturopaths had attended five or more consultations, compared to participants consulting the other four professions, is notable and may relate to differences in the models of care provided by the different CM professions. Naturopathy holds, as a core philosophical principle, the intention to educate patients about their health management (89, 345), and thus may facilitate development of greater patient autonomy with a subsequently reduced need for regular consultations.

Further research investigating psychosocial outcomes of treatment, including patient autonomy, in a variety of CM professions would assist in identifying which CM resources might best suit the specific psychosocial needs of individual patients.

CM professions using manual therapeutic approaches (e.g. chiropractic, osteopathy, massage therapy) can be perceived by patients as serving similar treatment purposes (346). However, our findings noted variations in reasons for consulting with practitioners of different manual therapies. Reports of seeking care for acute illnesses were notably low amongst our study participants, with the exception of those consulting osteopaths. With musculoskeletal conditions being the most reported diagnoses in our sample, the acute illnesses experienced by participants consulting osteopaths may have been acute symptom flares of underlying chronic conditions involving musculoskeletal complaints and pain. This is likely, considering that 98% of osteopaths recently surveyed in Australia reported these as the types of conditions most often treated in their clinical practice (301). However, it is unclear as to why these reasons were not reported in a similar manner by respondents consulting chiropractors, as musculoskeletal complaints also predominate within Australian chiropractic practice (303) and chiropractors are one of the most frequently consulted CM practitioners for back pain in Australia (347).

In contrast to osteopaths, participants consulting massage therapists less commonly reported seeking treatment for illness (chronic or acute) as a reason for consultation. This may indicate that some participants using massage therapy perceive this service as a luxury (328). The finding that participants using massage therapy had significantly lower rates of low-income Health Care Card cover implies these participants may also have more disposable income to spend on luxuries – a finding consistent with previous research identifying a correlation between use of massage and greater financial manageability (348). However, there is an emerging body of research to support the use of massage as a therapeutic treatment, particularly for individuals experiencing pain (330) and other musculoskeletal conditions (349). Further research exploring the strengths of different manual therapies and their discrete value in treating different health conditions would be of great benefit to assist patients and medical professionals in decision-making around the use of CM practitioner services, particularly in the context of chronic disease.

#### *5.3.4.1 Limitations*

While our study provides valuable observations about CM practitioner consultation by Australians with chronic conditions and a useful platform from which to develop

research aimed at better serving the needs of this population, certain limitations must be noted in the interpretation of results. The small sample size limits the capacity for generalisation. However, the broad geographical spread of the sample mediates this limitation somewhat. While the recruitment process employed a consecutive approach to participant invitation in order to reduce the risk of sampling bias and a hard-copy instrument to optimise response rates, the anonymity and self-report nature of the survey may still have resulted in sampling bias that failed to include important members of the target population. Identification of the presence of chronic condition diagnoses was achieved through presentation of a list of chronic conditions, however it is not clear whether all respondents had experienced the condition for a prolonged duration at the time of surveying, thus the impact of chronicity may not be accurately reflected in the data. Additionally, missing responses to items relating to reasons for consultation, and the finite nature of the list of reasons presented to participants (which did not allow open text responses), prevent definitive interpretations of this data and statistical validation of the instrument. Nonetheless, as almost all participants responded to at least one item in this measure, it is likely that the responses provided reflect the reasons considered most important by participants. Larger studies using a similar sampling frame, as well as inclusion of open-text response options to reasons for consultation, would be advantageous to develop a deeper and more nuanced understanding of the research topic.

### **5.3.5 Conclusion and implications**

Our findings suggest that for some individuals with chronic conditions, CM practitioners provide an important ongoing service toward the management of chronic conditions, which may be sought especially to improve wellbeing through access to supportive, compassionate care. There appear to be differences in the nature of the services provided by various CM professions, which could be utilised to provide targeted care to address the diverse and specific needs of individuals with chronic conditions. This paper presents an opportunity for further research to examine the utility and value of CM practitioners as an existing, established resource to address the unmet needs experienced by those with chronic conditions. Such examination would facilitate development of policy and health services better positioned to optimally manage the needs of this clinical population.

## 5.4 CHAPTER SUMMARY

The results reported in this chapter determine a high representation of individuals with chronic conditions amongst those consulting CM practitioners in Australian clinical settings and observe a high continuity of consultation with CM practitioners by those individuals. Correlations between select categories of chronic conditions and specific CM professions are identified. The reasons motivating individuals with chronic conditions to seek care from CM practitioners are explored in detail, discerning consistent over-arching themes as well as nuanced specificities for some CM professions. The findings suggest that the care provided by CM practitioners is perceived as valuable and complementary to conventional medicine by the individuals accessing their services. These findings, taken together with those of the preceding chapter, present a replete view of the characteristics of individuals with chronic conditions who consult with CM practitioners in Australia, as well as a comprehensive description of the factors that influence and motivate such care-seeking behaviours within this target population.

Examination of these patient characteristics and foundational care-seeking behaviours raises questions regarding the nature of the care received by individuals with chronic conditions during consultation with CM practitioners. Determining whether the CM consultation experience is responsive to these patient motivations and needs is of import to all stakeholders in chronic condition management, from patients and providers to researchers and policymakers. Furthermore, the position of CM care within the wider context of chronic condition management, which often involves multiple forms of care including both conventional and complementary medicine, must be considered.



## 6. PATIENT EXPERIENCES OF PERSON-CENTRED CARE

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### 6.1 RATIONALE FOR THIS ANALYSIS

The results presented in the previous chapters (Chapter 4 and Chapter 5) identify CM practitioners as playing an important role for many individuals with chronic conditions in Australia, with high rates of ongoing CM consultation within this patient population. Socio-demographic and health-related factors were noted as likely contributors to this use of CM practitioner services, while the associations that were found between chronic condition types and consultation with specific CM professions suggest some services may be perceived by patients as tailored to their particular health needs. The preceding chapters also identified that the motivations of patients with chronic conditions to seek CM practitioner services relate most strongly to a desire for improved quality of life and psychosocial support as well as direct treatment for their chronic conditions. These findings promote the need to examine the nature of the CM consultation for individuals with chronic conditions and whether the patient experience in these consultations is responding to patient motivations for seeking such care. Health services research aims to inform clinical practice and public health policy, which requires an understanding of patient needs and prevailing patient experiences in contemporary clinical settings to determine how practice and policy might optimally meet the needs of individuals and populations. Thus, the present chapter examines the patient experience of consultation with CM practitioners in keeping with the Research Aim of this thesis defined in section 1.2.

This chapter reports on findings from the PECMC survey, focusing on data taken from measures regarding patient experiences of care (as outlined in section 3.3.2.3). It explores patient-reported experiences of consultation with CM practitioners of the most commonly accessed CM professions in Australia (as identified in Chapter 4), drawn from three national PBRNs. This exploration is conducted through the lens of PCC, considering aspects of the consultation such as provider support, empowerment of patients regarding their health management and the tailoring of care to chronic illness needs. Patient experiences are examined as a collective and individually according to the specific CM profession consulted. This examination is also applied to patient reports of experiences with conventional medical doctors in roles typically associated with provision of primary care (GPs and specialist doctors) and a comparison is made between CM and conventional medical settings. These analyses respond to Research

Question 4 and Research Question 5, addressing Research Objective 3 and Research Objective 4 (outlined in section 1.2).

## **6.2 PUBLICATION OF RESULTS**

The results presented within this chapter have been published as follows:

Foley H, Steel A & Adams J. Perceptions of person-centred care amongst individuals with chronic conditions who consult complementary medicine practitioners.

Complement Ther Med. 2020. 52:102518

A copy of the full published article is included below. The journal-formatted version can be viewed in Appendix 6.1.

## **6.3 PERCEPTIONS OF PERSON-CENTRED CARE AMONGST INDIVIDUALS WITH CHRONIC CONDITIONS WHO CONSULT COMPLEMENTARY MEDICINE PRACTITIONERS**

### **6.3.1 Introduction**

Rates of chronic condition diagnoses have risen in recent years and increasingly contribute substantial burden to health care systems globally (1). Chronic conditions are prolonged in duration, typically complex in causes and symptoms, and impact on patients' lives in a variety of ways (9). As well as requiring direct medical intervention, many chronic conditions leave patients with reduced functional, social and economic capacity which can further impact families and communities (2). Optimal chronic disease management requires continuous, individualised and multi-faceted approaches to clinical care beyond treatment of pathology in order to address the prolonged, complex nature of chronic conditions and to account for the pervasive effects on patients' quality of life (2). In particular, comprehensive, individualised consultation approaches (350) and interventions designed to strengthen patient-provider relationships (70) show favourable effects on clinical outcomes in chronic conditions.

Due to the historical and contemporary primary focus of health care systems upon treating acute and infectious diseases – previously presenting the greatest contribution to the burden of disease (1) – there are numerous challenges to adjusting to better manage chronic conditions (141, 351). Person-centred care (PCC) has been recognised in a number of public health policies and guidelines as a paradigm of

clinical care with potential to provide the necessary adjustments to care provision for this purpose (2, 8). PCC seeks to account for the multifactorial aspects of health management by delivering clinical care that is *“respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”* (80). This respect and responsiveness to individual patient circumstances in PCC attends to the complexity of chronic conditions (2) and could facilitate development of the efficiency and sustainability required for health systems to adequately manage increasing chronic illness (8).

An unmet desire for respectful, responsive, individualised clinical care can lead patients with chronic conditions to seek such care outside of mainstream health care systems, often via consultation with complementary medicine (CM) practitioners (352). Those with chronic conditions may seek the care of CM practitioners specifically to address side-effects from, or dissatisfaction with, conventional treatment, as well as for management of their condition from an holistic perspective (6). Many CM professions adhere to practices founded upon the philosophy of holism, which seeks to treat the “whole person” rather than simply addressing a patient’s pathology (89). Holism is well-aligned with PCC due to this whole-person approach (89) which may lead to PCC being consequently delivered in CM clinical practice. As patients with chronic conditions tend to demonstrate higher utilisation of CM practitioner services than the general population (6), it is imperative to determine whether CM clinical practice translates to experiences of PCC for patients.

### **6.3.2 Methods**

The present study sought to determine the extent to which patients with chronic conditions experience PCC during consultation with CM practitioners.

#### *6.3.2.1 Study design and setting*

A cross-sectional survey was conducted between November 2018 and March 2019, in CM clinics throughout Australia. The CM professions chosen for the study were identified through previous research (313) as the five most frequently consulted clinical CM professions in Australia and included chiropractic, massage therapy, osteopathy, acupuncture and naturopathy. Invitations to assist with study patient recruitment were sent to practitioners of these professions through three practitioner-based research networks (PBRNs): the Practitioner Research and Collaboration Initiative (PRACI) (298), the Osteopathy Research and Innovation Network (ORION) (301), and the Australian Chiropractic Research Network (ACORN) (303).

### *6.3.2.2 Participants and recruitment*

Expressions of interest and consent forms were submitted online by CM practitioners who were members of the participating PBRNs and were in active clinical practice. From each of the five professions, seven to eight practitioners were selected based on location to achieve a broad geographical spread. Selected practitioners were provided with hardcopy study materials which included information sheets, surveys to distribute, and instructions detailing the study protocol, recruitment process and scripted guidelines for communicating with patients about the study. Each practitioner then distributed a study information sheet, consent form and hardcopy survey to 15 consecutive eligible patients, who were invited to self-administer the survey at a time and place convenient to them after leaving the clinic. This approach allowed patients to participate (or not) anonymously (blinding practitioners to recruitment outcomes) and without practitioner coercion to reduce selection bias. This recruitment process was chosen to ensure the integrity of patient-practitioner relationships was not affected by the study.

Eligibility criteria for patient participation required that patients be adults (aged 18 and over), fluent in the English language, capable of providing consent, and had not already completed the survey during a previous consultation with the CM practitioner. The surveys included a reply-paid postage envelope for return directly to the research team at no cost to patients or recruiting practitioners. Each survey included a web-link where participating patients could enter a draw to win a \$100 gift-voucher as an incentive to participate. Sample size calculations were undertaken based on response rates from previous research (88) conducted with a similar population and conservative estimates of chronic condition prevalence, resulting in a desired sample of 377 patients being sought to achieve a 5.0% margin of error.

### *6.3.2.3 Instrument*

The survey included 29 questions in total, covering socio-demographics, current chronic condition diagnoses, details of CM practitioner service utilisation, patient experiences of care in CM and conventional medical settings with medical doctors (MDs - general practitioners or specialist doctors), and patient-practitioner communication about patient treatment and medication use. Respondents who did not report a current chronic condition diagnosis were only asked to complete socio-demographic items. Items applicable to the analyses presented here included socio-demographics, chronic condition diagnoses and patient experiences of care.

Socio-demographics covered age, gender, state of residence, relationship status, educational qualification level, employment status, financial manageability, private health insurance (PHI) coverage, and possession of a Health Care Card (provided to low-income earners and welfare recipients in Australia for health and medical financial concessions). Diagnoses of chronic conditions were identified by respondents from a list (arthritis, asthma, cancer or post-cancer treatment complications, chronic obstructive pulmonary disease, diabetes type 1, diabetes type 2, heart disease/cardiovascular disease, hypertension/high blood pressure, musculoskeletal condition, chronic pain, depression, anxiety, other mental health condition, insomnia or other sleep disorder, obesity, Alzheimer's disease or dementia, congenital condition, chronic kidney disease, endometriosis, polycystic ovarian syndrome, other female reproductive disorder, inflammatory bowel disease, irritable bowel syndrome, fibromyalgia of chronic fatigue syndrome/myalgic encephalomyelitis, other autoimmune disease), with additional options for open-text responses.

Measures pertaining to patient experiences of care included the Patient-Centred Care Scale (PCCS), Perceived Provider Support Scale (PPSS), Empowerment Scale and the Patient Assessment of Chronic Illness Care (PACIC) measure. The PCCS, PPSS and Empowerment Scale are designed to be co-administered interdependently (304). The PCCS (ten items) and PPSS (seven items) allow patients to rate aspects of person-centred care and perceived emotional support from the provider (respectively) across a five-point Likert scale from *Strongly disagree* (value of 1) to *Strongly agree* (value of 5), while the Empowerment Scale (five items) allows patients to rate the sense of health-related empowerment resulting from the consultation across a three-point scale of *No* (value of 1), *Yes a little* (value of 2), and *Yes a lot* (value of 3) (304). The PACIC measure includes twenty items using a five-point scale ranging from *Almost never* (value of 1) to *Almost always* (value of 5) which allow patients to rate five domains of actions and clinical care qualities of person-centred care as they relate specifically to management of chronic conditions (patient activation, delivery system design/decision support, goal setting/tailoring, contextual problem-solving, follow-up/coordination) (306). The survey asked patients to complete these four measures in response to the consultation they had just attended with their CM practitioner, as well as in relation to their most recent consultation with their MD (general practitioner or specialist doctor, if applicable).

#### 6.3.2.4 Data handling and analysis

Analyses were completed using StataIC 14 (StataCorp LC 2015). Analyses presented here utilised data from respondents who reported one or more chronic condition diagnoses. Some socio-demographic variables were collapsed and recoded to produce adequate cell sizes, when appropriate (age, relationship status, educational qualification, employment status, financial manageability). CM professions consulted were recoded as binaries to allow comparisons between characteristics of participants who had consulted with different professions using Fisher's exact test.

Descriptive statistics were tabulated as frequencies and percentages, while summary statistics were calculated as means and standard deviations. Summary statistics were calculated for each item in the PCCS, PPSS and Empowerment Scale with missing responses excluded from analysis for that item. The PACIC measure was scored by calculating means for each item and each domain, as well as across the full measure to provide a summary score, in accordance with the measure's intended use and previous validation (306). During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

#### **6.3.2.5 Ethics**

Ethical approval was granted by the Human Research Ethics Committee, University of Technology Sydney (ETH18-2769).

### **6.3.3 Results**

Thirty-nine CM practitioners (seven chiropractors and eight practitioners from each other profession) assisted with recruitment of patients by distributing surveys and confirming recruitment completion. In total, 585 patient surveys were distributed and 199 were returned to the research team (response rate 34.0%). Of the returned surveys, eight were excluded due to an excess of missing responses or contradictory responses which threatened data reliability. Of the remaining 191 surveys, 38 reported no chronic condition diagnoses and were excluded from the present analyses, producing a final sample of 153.

#### **6.3.3.1 Participant characteristics**

Participants with chronic conditions were most commonly female (n = 126, 82.4%), aged 65 years and over (n = 44, 29.0%), married (n = 85, 55.9%), vocationally or trade qualified (n = 61, 40.1%), not in the paid workforce (n = 57, 37.5%) and reported

financial manageability to be *Not too bad* ( $n = 72, 48.0\%$ ). Participants predominantly held PHI cover generally ( $n = 120, 79.0\%$ ) and specifically for the CM profession they were consulting ( $n = 108, 71.1\%$ ), while just over one-third held Health Care Cards ( $n = 56, 37.6\%$ ).

Comparisons between those consulting practitioners from different professions found a higher proportion of men consulting chiropractors ( $p = .024$ ) and a higher proportion of participants from the 65 years and over age group consulting naturopaths ( $p = .023$ ). Those consulting naturopaths also had a significantly lower rate of PHI coverage both generally ( $p < .001$ ) and for the CM profession specifically ( $p = .001$ ). Those consulting massage therapists had lower rates of Health Care Card coverage ( $p = .027$ ). See Table 6.1.

### 6.3.3.2 Patient-centred care

Perceptions of PCC during consultation with CM practitioners were consistently high across the PCCS. For the total sample (consulting any CM practitioner), the highest mean score (of a possible 5.00) was for the item *My practitioner is really interested in finding and addressing my health problems* (mean 4.70), and the lowest was for *The root causes of my problems are being treated by my practitioner* (mean 4.22) (full details in Table 6.2). Those within the total sample who had consulted a MD reported lower perceptions of PCC for MD consultations, with the highest mean at 4.18 for item *My doctor is really interested in finding and addressing my health problems*, ranging to the lowest mean of 3.45 for item *My doctor teaches me ways to relieve symptoms myself*.

Table 6.2 also reports the profession-specific results for whole-system CM professions - acupuncture and naturopathy. Patients consulting acupuncturists reported higher means for items such as *I know what to expect during treatment sessions* and lower means for items such as *My practitioner teaches me ways to relieve my symptoms myself*. Those consulting naturopaths reported a higher mean for the item *My practitioner teaches me ways to relieve my symptoms myself* and a lower mean for *My practitioner receives feedback from my body that guides treatment*. When compared to the total sample, patients of naturopaths reported lower means for their MD consultations across all items of the PCCS.

**Table 6.1 Socio-demographics of respondents with chronic conditions, by profession consulted**

Item	Total sample n = 153 (100%)	Acupuncture n = 24 (77.4%)†	P*	Chiropractic n = 28 (93.3%)†	P*	Massage n = 29 (76.3%)†	P*	Naturopathy n = 33 (80.5%)†	P*	Osteopathy n = 39 (76.5%)†	P*
<b>Gender (n = 153)</b>											
Female	126 (82.4%)	21 (87.5%)	.376	19 (67.9%)	.024	26 (89.7%)	.216	28 (84.9%)	.313	32 (82.1%)	.523
Male	26 (17.0%)	3 (12.5%)		9 (32.1%)		3 (10.3%)		4 (12.1%)		7 (17.9%)	
Transgender‡	1 (0.7%)	0 (0.0%)		0 (0.0%)		0 (0.0%)		1 (3.0%)		0 (0.0%)	
<b>Age (n = 152)</b>											
18-34	15 (9.9%)	3 (12.5%)	.849	3 (10.7%)	.455	3 (10.3%)	.153	2 (6.1%)	.023	4 (10.5%)	.071
35-44	25 (16.5%)	3 (12.5%)		6 (21.4%)		4 (13.8%)		6 (18.2%)		6 (15.8%)	
45-54	35 (23.0%)	5 (20.8%)		9 (32.1%)		11 (37.9%)		7 (21.2%)		3 (7.9%)	
55-64	33 (21.7%)	7 (29.2%)		5 (17.9%)		7 (24.1%)		2 (6.1%)		12 (31.6%)	
65+	44 (29.0%)	6 (25.0%)		5 (17.9%)		4 (13.8%)		16 (48.5%)		13 (34.2%)	
<b>Relationship status (n = 152)</b>											
Never married	25 (16.5%)	2 (8.3%)	.388	3 (10.7%)	.247	7 (24.1%)	.219	5 (15.2%)	.088	8 (21.1%)	.243
Married	85 (55.9%)	13 (54.2%)		20 (71.4%)		13 (44.8%)		15 (45.5%)		24 (63.2%)	
De facto	15 (9.9%)	2 (8.3%)		3 (10.7%)		5 (17.2%)		2 (6.1%)		3 (7.9%)	
Separated/divorced/widowed	27 (17.8%)	7 (29.2%)		2 (7.1%)		4 (13.8%)		11 (33.3%)		3 (7.9%)	
<b>Education (n = 152)</b>											
Up to year 12	36 (23.7%)	6 (25.0%)	.454	7 (25.0%)	1.00	3 (10.3%)	.175	8 (24.2%)	.723	12 (31.6%)	.424
VET/trade	61 (40.1%)	7 (29.2%)		11 (39.3%)		14 (48.3%)		15 (45.5%)		14 (36.8%)	
Higher education	55 (36.2%)	11 (45.8%)		10 (35.7%)		12 (41.4%)		10 (30.3%)		12 (31.6%)	
<b>Employment status (n = 152)</b>											
Full time work	47 (30.9%)	10 (41.7%)	.231	12 (42.9%)	.350	12 (41.4%)	.111	7 (21.2%)	.163	6 (15.8%)	.109
Part time work	38 (25.0%)	5 (20.8%)		4 (14.3%)		10 (34.5%)		7 (21.2%)		12 (31.6%)	
Casual/temporary work	10 (6.6%)	3 (12.5%)		2 (7.1%)		1 (3.5%)		1 (3.0%)		3 (7.9%)	
Not in paid workforce	57 (37.5%)	6 (25.0%)		10 (35.7%)		6 (20.7%)		18 (54.6%)		17 (44.7%)	
<b>Financial manageability (n = 150)</b>											



<i>It is impossible/difficult all of the time</i>	16 (10.7%)	3 (12.5%)		3 (11.1%)		2 (6.9%)		5 (15.6%)		3 (7.9%)
<i>It is difficult some of the time</i>	33 (22.0%)	8 (33.3%)	.181	7 (25.9%)	.895	6 (20.7%)	.698	7 (21.9%)	.620	5 (13.2%)
<i>It is not too bad</i>	72 (48.0%)	7 (29.2%)		13 (48.2%)		17 (58.6%)		13 (40.6%)		22 (57.9%)
<i>It is easy</i>	29 (19.3%)	6 (25.0%)		4 (14.8%)		4 (13.8%)		7 (21.9%)		8 (21.1%)
<b>Health care cost subsidies</b>										
<i>PHI cover (n = 152)</i>	120 (79.0%)	22 (91.7%)	.075	24 (85.7%)	.242	24 (82.8%)	.391	18 (54.6)	< .001	32 (84.2%)
<i>PHI for this profession (n = 152)</i>	108 (71.1%)	19 (86.4%)	.628	24 (96%)	.089	22 (92.7%)	.297	10 (55.6%)	.001	29 (90.6%)
<i>Health care card (n = 149)</i>	56 (37.6%)	8 (33.3%)	.411	10 (38.5%)	.543	6 (20.7%)	.027	16 (48.5%)	.104	16 (43.2%)

†Percentage of the participants who consulted this profession and reported having a chronic condition.

‡Excluded from analysis of gender due to small cell size.

\*P values from Fisher's exact test comparing responses from participants consulting with different professions

**Table 6.2 Interdependent measures.**

Patient-centred care scale, Perceived provider support scale, and Empowerment scale results for total sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.

Measure Items	Consulted Any CM practitioner		Consulted acupuncturists		Consulted naturopaths	
	CM practitioner (n = 149)	Medical doctor (n = 92)	Acupuncturist (n = 23)	Medical doctor (n = 16)	Naturopath (n = 32)	Medical doctor (n = 25)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<b>Patient-centred care scale</b>						
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n = 148)</i>	4.70, 0.50	4.12, 0.89	4.65, 0.57	3.87, 1.06	4.74, 0.45	3.84, 1.03
<i>My practitioner/doctor has a full picture of me as an individual (n = 147)</i>	4.47, 0.68	3.98, 1.03	4.52, 0.59	3.80, 1.15	4.29, 0.78	3.72, 1.14
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n = 148)</i>	4.70, 0.49	4.18, 0.86	4.83, 0.39	4.06, 0.93	4.61, 0.50	3.76, 1.09
<i>The root causes of my problems are identified by my practitioner/doctor (n = 148)</i>	4.22, 0.76	3.78, 1.07	4.00, 0.90	3.63, 1.26	4.16, 0.82	3.48, 1.16
<i>The root causes of my problems are being treated by my practitioner/doctor (n = 148)</i>	4.22, 0.81	3.77, 1.10	4.17, 0.65	3.67, 1.18	4.19, 0.83	3.60, 1.19
<i>The treatment is individualised for me at each session (n = 148)</i>	4.58, 0.56	3.87, 0.91	4.57, 0.59	3.87, 0.83	4.58, 0.56	3.52, 1.00
<i>My practitioner/doctor receives feedback from my body that guides treatment (n = 148)</i>	4.44, 0.66	3.84, 0.94	4.52, 0.51	4.00, 0.93	4.03, 0.75	3.63, 0.82
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n = 148)</i>	4.41, 0.70	3.95, 0.90	4.43, 0.66	3.88, 1.20	4.10, 0.78	3.67, 0.92
<i>I know what to expect during treatment sessions (n = 148)</i>	4.49, 0.61	4.02, 0.79	4.65, 0.49	4.07, 0.59	4.23, 0.62	3.76, 0.93
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n = 148)</i>	4.31, 0.76	3.45, 1.09	3.96, 0.93	3.47, 1.13	4.48, 0.63	3.40, 0.87
<b>Perceived provider support scale</b>						

<i>My practitioner/doctor cares about me (n = 149)</i>	4.62, 0.53	4.24, 0.76	4.70, 0.47	4.13, 0.96	4.66, 0.48	4.16, 0.80
<i>I feel cared for during treatment (n = 149)</i>	4.64, 0.52	4.22, 0.79	4.78, 0.42	4.25, 0.93	4.66, 0.48	4.04, 0.89
<i>My practitioner/doctor accepts me as I am (n = 149)</i>	4.62, 0.53	4.22, 0.72	4.70, 0.56	4.31, 0.79	4.59, 0.50	4.08, 0.70
<i>I receive personal attention during treatment (n = 149)</i>	4.62, 0.51	4.24, 0.75	4.65, 0.49	4.25, 0.68	4.66, 0.48	4.12, 0.78
<i>I can talk openly with my practitioner/doctor (n = 149)</i>	4.62, 0.55	4.24, 0.87	4.70, 0.47	4.13, 1.15	4.56, 0.56	4.08, 1.00
<i>My practitioner/doctor gives me hope (n = 149)</i>	4.39, 0.71	3.77, 1.00	4.43, 0.73	3.63, 1.15	4.38, 0.66	3.58, 1.18
<i>I trust my practitioner/doctor (n = 149)</i>	4.69, 0.46	4.32, 0.77	4.78, 0.42	4.50, 0.73	4.72, 0.46	4.04, 0.89
<b>Empowerment scale</b>						
<i>Do you feel more in control of your health? (n = 124)</i>	2.43, 0.57	2.16, 0.67	2.52, 0.59	2.50, 0.63	2.53, 0.57	1.96, 0.68
<i>Do you know what to do to take care of your health problem? (n = 124)</i>	2.50, 0.53	2.35, 0.58	2.48, 0.59	2.56, 0.51	2.53, 0.57	2.24, 0.60
<i>Do you believe that your health problem will improve? (n = 124)</i>	2.32, 0.70	1.88, 0.68	2.48, 0.67	1.94, 0.68	2.34, 0.70	1.96, 0.79
<i>Do you advocate more for yourself? (n = 120)</i>	2.20, 0.67	2.18, 0.67	2.32, 0.57	2.33, 0.72	2.38, 0.71	2.16, 0.69
<i>Do you have techniques you can use when your symptoms get worse? (n = 122)</i>	2.29, 0.57	2.04, 0.68	2.14, 0.64	2.12, 0.72	2.42, 0.56	2.00, 0.71

Scale values for Patient-Centred Care Scale and Perceived Provider Support Scale: Strongly disagree = 1 (Min), Strongly agree = 5 (Max).

Scale values for Empowerment Scale: No = 1 (Min), Yes a little = 2, Yes a lot = 3 (Max)

Table 6.3 reports the profession-specific results for manual therapy CM professions - massage therapy, osteopathy and chiropractic. Patients of massage therapists reported higher means for MD consultations across all items and patients of osteopaths reported higher means for eight out of ten items. Patients of chiropractors and osteopaths reported higher means for item *The root causes of my problems are identified by my practitioner*, while patients of massage therapists and osteopaths reported higher means for *My practitioner receives feedback from my body that guides treatment*.

### **3.3 Perceived Provider Support**

For the total sample consulting any CM practitioner, perceptions of provider support were strong, with the highest mean (of a possible 5.00) recorded for the item *I trust my practitioner* (mean 4.69) and the lowest mean for *My practitioner gives me hope* (mean 4.39) (full details in Table 6.2). *Strongly agree/agree* responses to the PPSS items were highly consistent, recorded by a majority of respondents across all items. No respondents selected *Strongly disagree/disagree* for any PPSS items regarding consultations with their CM practitioner (see Supplementary Table S1 in Appendix 6.2).

In comparison to CM consultations, respondents who had consulted a MD reported lower means for their medical consultation across all PPSS items. The items attracting the highest and lowest means were *I trust my doctor* (4.32) and *My doctor gives me hope* (3.77) respectively (see Table 6.2).

Compared to the total sample, participants consulting acupuncturists and massage therapists reported higher means across all items of the PPSS for their CM consultation, while all means for those consulting chiropractors were slightly lower. Naturopathy patients reported lower means for all items in response to their consultations with MDs (Table 6.2), while patients of massage therapists and osteopaths reported higher means for their MDs for all items in the PPSS (Table 6.3), compared with the total sample.

**Table 6.3 Interdependent measures.**

Patient-centred care scale, Perceived provider support scale, and Empowerment scale results for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.

Measure Items	Consulted chiropractor		Consulted massage therapist		Consulted osteopath	
	Chiropractor (n = 27)	Medical doctor (n = 16)	Massage therapist (n = 29)	Medical doctor (n = 13)	Osteopath (n = 38)	Medical doctor (n = 22)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<b>Patient-centred care scale</b>						
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n = 148)</i>	4.67, 0.48	4.25, 0.68	4.76, 0.44	4.69, 0.48	4.68, 0.57	4.18, 0.80
<i>My practitioner/doctor has a full picture of me as an individual (n = 147)</i>	4.48, 0.70	4.00, 0.89	4.55, 0.57	4.62, 0.65	4.51, 0.69	4.00, 1.02
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n = 148)</i>	4.59, 0.57	4.19, 0.54	4.69, 0.47	4.77, 0.44	4.76, 0.49	4.41, 0.67
<i>The root causes of my problems are identified by my practitioner/doctor (n = 148)</i>	4.33, 0.68	3.69, 0.87	4.14, 0.79	4.38, 0.77	4.37, 0.63	3.95, 1.00
<i>The root causes of my problems are being treated by my practitioner/doctor (n = 148)</i>	4.22, 0.97	3.50, 0.97	4.07, 0.84	4.38, 0.65	4.37, 0.75	3.86, 1.17
<i>The treatment is individualised for me at each session (n = 148)</i>	4.41, 0.64	3.63, 0.72	4.66, 0.48	4.46, 0.78	4.66, 0.53	4.09, 0.87
<i>My practitioner/doctor receives feedback from my body that guides treatment (n = 148)</i>	4.30, 0.72	4.00, 0.52	4.72, 0.53	4.23, 0.93	4.61, 0.55	3.64, 1.22
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n = 148)</i>	4.41, 0.64	4.00, 0.52	4.62, 0.62	4.23, 0.93	4.47, 0.69	4.09, 0.81
<i>I know what to expect during treatment sessions (n = 148)</i>	4.30, 0.78	3.94, 0.57	4.62, 0.49	4.23, 0.73	4.63, 0.54	4.23, 0.87
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n = 148)</i>	4.22, 0.75	3.50, 1.03	4.34, 0.72	3.62, 1.19	4.42, 0.76	3.36, 1.33
<b>Perceived provider support scale</b>						

<i>My practitioner/doctor cares about me (n = 149)</i>	4.44, 0.64	4.06, 0.57	4.66, 0.48	4.54, 0.66	4.63, 0.54	4.36, 0.79
<i>I feel cared for during treatment (n = 149)</i>	4.44, 0.58	4.06, 0.57	4.72, 0.45	4.62, 0.51	4.63, 0.59	4.29, 0.78
<i>My practitioner/doctor accepts me as I am (n = 149)</i>	4.48, 0.64	4.00, 0.63	4.72, 0.45	4.54, 0.66	4.63, 0.49	4.27, 0.77
<i>I receive personal attention during treatment (n = 149)</i>	4.52, 0.58	4.06, 0.68	4.66, 0.48	4.46, 0.78	4.63, 0.54	4.36, 0.79
<i>I can talk openly with my practitioner/doctor (n = 149)</i>	4.44, 0.64	4.19, 0.66	4.72, 0.45	4.54, 0.66	4.66, 0.58	4.36, 0.73
<i>My practitioner/doctor gives me hope (n = 149)</i>	4.15, 0.82	3.81, 0.91	4.45, 0.74	4.08, 0.76	4.50, 0.65	3.86, 0.89
<i>I trust my practitioner/doctor (n = 149)</i>	4.48, 0.51	4.19, 0.66	4.76, 0.44	4.69, 0.63	4.71, 0.46	4.36, 0.73

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**Empowerment scale**

<i>Do you feel more in control of your health? (n = 124)</i>	2.04, 0.59	1.94, 0.57	2.45, 0.51	2.23, 0.73	2.55, 0.50	2.27, 0.63
<i>Do you know what to do to take care of your health problem? (n = 124)</i>	2.22, 0.42	2.00, 0.52	2.55, 0.51	2.46, 0.52	2.66, 0.48	2.50, 0.60
<i>Do you believe that your health problem will improve? (n = 124)</i>	2.07, 0.62	1.81, 0.66	2.28, 0.80	1.92, 0.49	2.42, 0.68	1.77, 0.69
<i>Do you advocate more for yourself? (n = 120)</i>	1.68, 0.56	1.80, 0.68	2.38, 0.62	2.38, 0.65	2.19, 0.66	2.24, 0.54
<i>Do you have techniques you can use when your symptoms get worse? (n = 122)</i>	2.07, 0.47	1.75, 0.58	2.28, 0.59	2.00, 0.58	2.42, 0.55	2.27, 0.70

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Scale values for Patient-Centred Care Scale and Perceived Provider Support Scale: Strongly disagree = 1 (Min), Strongly agree = 5 (Max).

Scale values for Empowerment Scale: No = 1 (Min), Yes a little = 2, Yes a lot = 3 (Max)

#### 6.3.3.4 Patient empowerment

Responses to the Empowerment Scale for respondents consulting any CM practitioner were typically favourable, with the highest mean (of a possible 3.00) reported for item *Do you know what to do to take care of your health problem* (mean 2.50) and the lowest mean reported for *Do you advocate more for yourself* (mean 2.20) (Table 6.2). The categorical presentation of these items are reported in Supplementary Table S1 (Appendix 6.2).

For participants who responded to the Empowerment Scale regarding consultations with MDs, means were lower than those for CM consultations for all items. The item *Do you know what to do to take care of your health problem* achieved the highest mean (2.35), while item *Do you believe your health problem will improve* achieved the lowest mean (1.88) (Table 6.2).

Higher means were reported for all five items by patients consulting naturopaths (Table 6.2) and for four items by those consulting osteopaths (Table 6.3), compared to the total sample for CM consultations. Regarding MD consultations, higher means were reported by those consulting acupuncturists (Table 6.2), massage therapists and osteopaths, while lower means were reported by those consulting chiropractors (Table 6.3), compared to the total sample.

#### 6.3.3.5 Patient assessment of chronic illness care

The total summary score mean for the PACIC measure, across the total sample, was 3.33 for consultations with any CM practitioner, and 2.95 for consultations with a MD. The highest summary score mean was reported for consultations with naturopaths (4.04) while the lowest was reported by patients of naturopaths for consultations with their MDs (2.84). Of the five PACIC domains, the domain attracting the highest summary score for consultations with CM practitioners was *Delivery and practice* (mean 3.87), while the domain attracting the highest summary score for consultations with MDs was *Patient activation* (mean 3.38). The domain *Follow up and coordination* attracted the lowest summary score for both CM consultations (mean 2.66) and conventional medicine consultations (mean 2.52) (Table 6.4). A general trend demonstrated higher summary scores for consultations with CM practitioners compared to consultations with MDs, with the exception of responses from patients of massage therapists, who reported slightly higher total scores for their MD (mean 3.27) compared to their massage therapist (mean 3.23) (Table 6.5).

Domain summary score means were highest for consultations with naturopaths across all five domains, ranging from 3.34 for *Follow up and coordination* to 4.50 for *Delivery and practice* (Table 6.4). The lowest summary scores for domains *Patient activation* (mean 3.02) and *Delivery and practice* (mean 3.13) were both recorded for MD consultations for chiropractic patients (Table 6.5). The lowest summary scores for domains *Goal setting and tailoring* (mean 2.66) and *Problem-solving and contextual counselling* (mean 2.93) were both recorded for MD consultations for naturopathy patients (Table 6.4), while the lowest summary score for domain *Follow up and coordination* (mean 2.34) was recorded for chiropractic consultations (Table 6.5).



**Table 6.4 Patient Assessment of Chronic Illness Care (PACIC) Measure results for total sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.**

PACIC domain Items	Consulted Any CM practitioner		Consulted acupuncturists		Consulted naturopaths	
	CM practitioner (n = 146)	Medical doctor (n = 90)	Acupuncturist (n = 23)	Medical doctor (n = 14)	Naturopath (n = 31)	Medical doctor (n = 25)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>						
<b>Patient activation</b>						
<i>Asked for my ideas when we made a treatment plan (n = 146)</i>	3.75, 1.09	3.09, 1.22	3.78, 1.17	3.07, 1.33	3.97, 1.02	2.88, 1.13
<i>Given choices about treatment to think about (n = 145)</i>	3.88, 1.09	3.52, 1.06	3.95, 0.95	3.29, 1.07	4.39, 0.80	3.50, 0.93
<i>Asked to talk about any problems with my medicines/treatments of their effects (n = 142)</i>	3.85, 1.22	3.52, 1.26	4.00, 1.20	3.36, 1.55	4.57, 0.68	3.38, 1.13
<b>Patient activation domain score</b>	<b>3.83, 0.97</b>	<b>3.38, 1.05</b>	<b>3.92, 0.98</b>	<b>3.24, 1.26</b>	<b>4.30, 0.67</b>	<b>3.26, 0.89</b>
<b>Delivery and practice</b>						
<i>Given a written list of things I should do to improve my health (n = 143)</i>	3.17, 1.35	2.72, 1.23	3.09, 1.27	2.57, 1.45	4.63, 0.72	3.08, 1.19
<i>Satisfied that my care was well organised (n = 146)</i>	4.53, 0.69	3.79, 1.04	4.52, 0.59	3.79, 1.12	4.71, 0.46	3.44, 1.19
<i>Shown how what I did to take care of my illness influenced my condition (n = 141)</i>	3.92, 1.06	3.24, 1.11	3.68, 1.39	3.14, 1.23	4.17, 0.79	3.24, 0.93
<b>Delivery and practice domain score</b>	<b>3.87, 0.76</b>	<b>3.25, 0.91</b>	<b>3.76, 0.90</b>	<b>3.17, 1.15</b>	<b>4.50, 0.47</b>	<b>3.25, 0.93</b>
<b>Goal setting and tailoring</b>						
<i>Asked to talk about my goals in caring for my illness (n = 143)</i>	3.61, 1.23	2.94, 1.20	3.68, 1.36	3.00, 1.47	4.20, 1.06	2.80, 1.04
<i>Helped to set specific goals to improve my eating or exercise (n = 142)</i>	3.42, 1.28	2.72, 1.22	3.32, 1.55	2.46, 1.51	4.41, 0.82	2.63, 1.10
<i>Given a copy of my treatment plan (n = 142)</i>	2.85, 1.49	2.66, 1.39	2.73, 1.49	2.93, 1.54	4.65, 0.66	2.30, 1.40
<i>Encouraged to go to a specific group or class to help me cope with my chronic illness (n = 138)</i>	2.66, 1.28	2.46, 1.32	1.95, 1.07	2.50, 1.56	3.36, 1.13	2.42, 1.18
<i>Asked questions, either directly or on a survey, about my health habits (n = 144)</i>	3.48, 1.36	3.11, 1.32	3.41, 1.56	2.86, 1.41	4.33, 0.71	3.28, 1.24

<b>Goal setting and tailoring domain score</b>	<b>3.21, 1.03</b>	<b>2.78, 1.04</b>	<b>3.05, 1.20</b>	<b>2.76, 1.32</b>	<b>4.21, 0.58</b>	<b>2.66, 0.95</b>
<b>Problem-solving and contextual counselling</b>						
<i>Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n = 144)</i>	4.09, 1.15	3.52, 1.29	3.86, 1.32	3.29, 1.59	4.67, 0.66	3.64, 1.11
<i>Helped to make a treatment plan that I could do in my daily life (n = 143)</i>	3.71, 1.21	3.03, 1.21	3.27, 1.49	3.14, 1.17	4.52, 0.77	2.71, 1.20
<i>Helped to plan ahead so I could take care of my illness even in hard times (n = 140)</i>	3.56, 1.21	3.05, 1.21	3.14, 1.49	3.07, 1.27	4.29, 0.81	2.59, 1.05
<i>Asked how my chronic illness affects my life (n = 141)</i>	3.79, 1.17	3.21, 1.27	3.77, 1.34	3.07, 1.27	4.14, 1.11	2.91, 1.31
<b>Problem-solving and contextual counselling domain score</b>	<b>3.80, 0.96</b>	<b>3.19, 1.06</b>	<b>3.52, 1.24</b>	<b>3.14, 1.21</b>	<b>4.42, 0.61</b>	<b>2.93, 0.97</b>
<b>Follow-up and coordination</b>						
<i>Contacted after a visit to see how things were going (n = 140)</i>	2.57, 1.28	2.16, 1.29	2.68, 1.29	2.71, 1.64	3.11, 1.23	2.08, 1.38
<i>Encouraged to attend programs in the community that could help me (n = 137)</i>	2.55, 1.25	2.22, 1.24	2.19, 1.25	2.14, 1.17	3.15, 1.16	2.17, 1.19
<i>Referred to a dietician, health educator, or counsellor (n = 137)</i>	2.22, 1.20	2.56, 1.49	2.10, 1.22	2.85, 1.63	3.15, 1.32	2.58, 1.38
<i>Told how my visits with other types of practitioners/doctors helped my treatment (n = 138)</i>	2.83, 1.34	2.75, 1.34	2.67, 1.28	2.64, 1.55	3.71, 1.08	2.90, 1.09
<i>Asked how my visits with other doctors/practitioners were going (n = 142)</i>	3.26, 1.42	2.86, 1.32	3.57, 1.33	2.79, 1.37	3.87, 1.06	3.04, 1.27
<b>Follow up and coordination domain score</b>	<b>2.66, 1.02</b>	<b>2.52, 1.09</b>	<b>2.62, 1.04</b>	<b>2.63, 1.16</b>	<b>3.34, 0.89</b>	<b>2.59, 1.05</b>
<b>PACIC total summary score</b>	<b>3.33, 0.82</b>	<b>2.95, 0.96</b>	<b>3.19, 0.95</b>	<b>2.94, 1.14</b>	<b>4.04, 0.54</b>	<b>2.84, 0.94</b>

Scale values for PACIC: Almost never = 1 (Min), Almost always = 5 (Max).

Note. During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

**Table 6.5 Patient Assessment of Chronic Illness Care (PACIC) Measure results for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.**

PACIC domain Items	Consulted a chiropractor		Consulted a massage therapist		Consulted an osteopath	
	Chiropractor (n = 25)	Medical doctor (n = 16)	Massage therapist (n = 29)	Medical doctor (n = 13)	Osteopath (n = 38)	Medical doctor (n = 22)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>						
<b>Patient activation</b>						
<i>Asked for my ideas when we made a treatment plan (n = 146)</i>	3.64, 1.15	2.69, 1.14	3.79, 1.11	3.62, 1.12	3.58, 1.06	3.32, 1.32
<i>Given choices about treatment to think about (n = 145)</i>	3.68, 1.03	3.19, 1.05	3.86, 1.19	4.15, 0.80	3.58, 1.22	3.59, 1.22
<i>Asked to talk about any problems with my medicines/treatments of their effects (n = 142)</i>	3.64, 1.15	3.19, 1.28	3.62, 1.32	4.00, 1.08	3.50, 1.36	3.73, 1.28
<b>Patient activation domain score</b>	<b>3.65, 1.01</b>	<b>3.02, 1.04</b>	<b>3.76, 1.03</b>	<b>3.92, 0.81</b>	<b>3.57, 1.01</b>	<b>3.55, 1.14</b>
<b>Delivery and practice</b>						
<i>Given a written list of things I should do to improve my health (n = 143)</i>	2.54, 1.10	2.56, 1.36	2.52, 1.12	2.69, 1.25	2.95, 1.25	2.55, 1.01
<i>Satisfied that my care was well organised (n = 146)</i>	4.36, 0.91	3.69, 0.95	4.66, 0.67	4.15, 0.90	4.39, 0.72	4.05, 0.90
<i>Shown how what I did to take care of my illness influenced by condition (n = 141)</i>	3.83, 1.09	3.13, 1.20	3.71, 1.05	3.58, 1.24	4.08, 0.98	3.18, 1.14
<b>Delivery and practice domain score</b>	<b>3.6, 0.78</b>	<b>3.13, 0.91</b>	<b>3.62, 0.61</b>	<b>3.45, 0.86</b>	<b>3.81, 0.71</b>	<b>3.26, 0.79</b>
<b>Goal setting and tailoring</b>						
<i>Asked to talk about my goals in caring for my illness (n = 143)</i>	3.24, 1.39	2.81, 1.38	3.46, 1.14	3.46, 0.97	3.45, 1.13	2.86, 1.21
<i>Helped to set specific goals to improve my eating or exercise (n = 142)</i>	3.08, 0.95	2.81, 1.47	3.07, 1.44	2.92, 0.95	3.21, 1.14	2.77, 1.19
<i>Given a copy of my treatment plan (n = 142)</i>	2.20, 1.26	2.81, 1.42	2.12, 1.14	2.58, 1.38	2.39, 1.15	2.81, 1.29
<i>Encouraged to go to a specific group or class to help me cope with my chronic illness (n = 138)</i>	2.28, 1.10	2.53, 1.46	2.67, 1.30	2.50, 1.38	2.78, 1.34	2.41, 1.30
<i>Asked questions, either directly or on a survey, about my health habits (n = 144)</i>	3.16, 1.43	3.31, 1.25	3.66, 1.26	3.42, 1.31	2.92, 1.36	2.77, 1.41

<b>Goal setting and tailoring domain score</b>	<b>2.79, 0.79</b>	<b>2.87, 1.09</b>	<b>2.99, 0.92</b>	<b>2.97, 0.92</b>	<b>2.96, 0.97</b>	<b>2.73, 1.05</b>
<b>Problem-solving and contextual counselling</b>						
<i>Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n = 144)</i>	3.76, 1.20	3.00, 1.21	4.21, 1.18	3.85, 1.41	3.89, 1.18	3.73, 1.24
<i>Helped to make a treatment plan that I could do in my daily life (n = 143)</i>	3.60, 1.15	3.00, 1.21	3.43, 1.20	3.42, 1.08	3.59, 1.14	3.14, 1.32
<i>Helped to plan ahead so I could take care of my illness even in hard times (n = 140)</i>	3.40, 1.22	3.00, 1.15	3.34, 1.20	3.58, 1.00	3.54, 1.10	3.23, 1.38
<i>Asked how my chronic illness affects my life (n = 141)</i>	3.52, 1.23	3.19, 1.28	3.93, 1.07	4.17, 0.72	3.62, 1.11	3.09, 1.31
<b>Problem-solving and contextual counselling domain score</b>	<b>3.57, 0.91</b>	<b>3.05, 1.08</b>	<b>3.74, 0.86</b>	<b>3.77, 0.76</b>	<b>3.66, 0.96</b>	<b>3.30, 1.13</b>
<b>Follow-up and coordination</b>						
<i>Contacted after a visit to see how things were going (n = 140)</i>	2.44, 1.36	2.13, 1.20	2.61, 1.31	1.92, 0.79	2.16, 1.14	2.05, 1.21
<i>Encouraged to attend programs in the community that could help me (n = 137)</i>	2.08, 1.08	2.31, 1.25	2.61, 1.26	2.42, 1.44	2.62, 1.30	2.14, 1.32
<i>Referred to a dietician, health educator, or counsellor (n = 137)</i>	1.80, 2.72	2.69, 1.70	2.00, 1.05	2.50, 1.62	2.06, 1.17	2.32, 1.39
<i>Told how my visits with other types of practitioners/doctors helped my treatment (n = 138)</i>	2.72, 1.46	2.50, 1.55	2.71, 1.21	3.33, 1.23	2.39, 1.34	2.55, 1.34
<i>Asked how my visits with other doctors/practitioners were going (n = 142)</i>	2.68, 1.49	2.56, 1.50	3.59, 1.45	3.17, 1.03	2.69, 1.39	2.76, 1.41
<b>Follow up and coordination domain score</b>	<b>2.34, 0.95</b>	<b>2.44, 1.27</b>	<b>2.67, 0.90</b>	<b>2.67, 0.84</b>	<b>2.37, 1.02</b>	<b>2.35, 1.15</b>
<b>PACIC total summary score</b>	<b>3.06, 0.72</b>	<b>2.86, 1.00</b>	<b>3.23, 0.69</b>	<b>3.27, 0.73</b>	<b>3.14, 0.80</b>	<b>2.95, 0.96</b>

Scale values for PACIC: Almost never = 1 (Min), Almost always = 5 (Max).

Note. During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

### 6.3.4 Discussion

This study is the first to provide detailed reporting of experiences of PCC specific to individuals with chronic conditions who consult with CM practitioners, across a variety of clinical professional settings. Many participants reported experiencing PCC during consultation with CM practitioners. While there was some nuanced variation between groups consulting with different CM professions, each of the five professions attracted consistently high ratings of PCC overall from patients for all four measures. This is reflective of existing literature suggesting that PCC is generally characteristic of CM consultations (7, 88).

Across all measures assessing patient perceptions of the care they received, respondents also consistently reported higher ratings for their experience of consultations with CM practitioners compared to consultations with MDs, which may be influenced by different practical approaches within conventional and complementary medicine systems. Due to its development being centred on addressing the historical burdens of acute and infectious diseases, the conventional medical system faces many challenges in moving toward a model of care provision that adequately addresses the needs of those with chronic conditions (1). In contrast, it has been suggested that CM philosophies have contributed to the development of PCC (353), which as a paradigm of clinical care is particularly well-suited to chronic illness management (83). Indeed, the philosophy of holism which underlies many CM professions appears to correlate closely in principle with PCC (89). CM practitioners also tend to provide longer consultations than MDs (7), allowing more time for patients and practitioners to explore the complex, multifactorial needs of individuals with chronic conditions. Previous studies have identified the lengthier consultations of CM services such as naturopathy and acupuncture as contributing to patients feeling heard, and to patients perceiving CM practitioners as caring and trustworthy (340, 354), which is congruous with the perceptions of CM practitioners reported by our participants. Thus, it may be that applied holistic philosophy and lengthier consultation time both contributed to our participants' reporting higher PCC in CM consultations compared to those with MDs. Clinical settings which provide holistic CM care alongside conventional medicine have demonstrated that such integration of services may be an avenue through which to enhance patient-centredness, as well as both patient and provider satisfaction (63, 66, 355).

For the majority of items across the survey, care received from naturopaths was rated most highly by respondents. While there are any number of factors that may be

contributing to this finding, a previous review of patient perceptions of care in CM proposed the importance of patient empowerment and facilitation of patient self-efficacy in some CM professions may be key (88). The other four CM professions consulted by our participants employ primarily practitioner-enacted treatments during consultation (e.g. direct application of manual therapies or acupuncture needles), demonstrated in the lower mean reported by acupuncture patients for the item *My practitioner teaches me ways to relieve symptoms myself* and higher means reported by patients of massage therapists and osteopaths for the item *My practitioner receives feedback from my body that guides treatment*. Naturopaths, however, rely largely on patient-enacted treatments (e.g. remedies or dietary/lifestyle advice that patients must self-administer outside of the consultation) – an approach requiring the naturopath to engage the patient in the treatment process, which typically involves provision of patient education and detailed discussion of the patient’s individual circumstances (356). Previous studies show such patient education by naturopaths may improve the patient’s self-efficacy and sense of empowerment, while time spent discussing the patient’s needs may result in the patient feeling heard and supported (88, 340), leading to a particularly high degree of perceived PCC during consultation with naturopaths.

While care provided by CM practitioners was typically rated more highly than care provided by MDs, patients of different CM professions differed slightly in the domains and items for which they gave lower ratings to their MDs. For example, across the PACIC measure, compared to patients of other CM professions, patients of naturopaths rated their MDs lower in the domain of *Problem solving and contextual counselling* and patients of chiropractors rated their MDs lower in *Patient activation*. This may speak to differences in patients’ unmet needs potentially prompting patients to seek care from particular CM professions – with those professions possibly being perceived as more likely to meet a specific unmet need. The individualised approach of PCC, however, is intended to facilitate the meeting of individual needs regardless of the care provider’s profession (357).

#### 6.3.4.1 Implications

Our finding that CM practitioner consultations were characteristically person-centred for our participants correlates with the existing body of literature identifying aspects of CM consultation which are aligned with PCC (7). Patients with chronic conditions have expressed a desire and need for more person-centred approaches to their care (82), while person-centred aspects of clinical care such as provider empathy, strong communication (70) and personalised consultations/treatments (350) have been

correlated with favourable health and psychosocial outcomes. The utility and importance of PCC in management of chronic conditions has been recognised in international (8) and national (2, 80) health policy and guidelines, due to its capacity to address complex presentations or underlying aspects of illness such as those seen in chronic conditions. As chronic illness increasingly contributes to the burden of disease, and as patients with chronic conditions continue to seek multiple sources of care to manage their complex needs, it should be considered that CM practitioners may represent an existing resource of person-centred clinical management to address otherwise unmet aspects of care for this patient population.

#### **6.3.4.2 Limitations**

The results of this study provide promising insights into the potential benefits of CM consultations for individuals with chronic conditions, yet certain limitations must be noted. The small sample size and convenience sampling method preclude the use of more robust statistical analyses, while a suboptimal response rate potentially indicates presence of non-response bias, limiting the capacity for generalisation of findings. However, the broad geographical spread of clinic locations enhances representativeness, while the consecutive approach to recruitment moderates risk of sampling bias.

Due to small numbers in sub-groups delineated by CM profession consulted, alongside dependency of sub-groups separated by CM vs. MD consults (i.e. patients consulting MDs were the same patients consulting CM practitioners), statistical tests of association or comparison regarding the four measures used were not possible. Future research examining such comparisons should be conducted using larger, independent samples. Additionally, participant responses rating consultations with CM practitioners and with MDs may be impacted by recall bias as the survey was administered directly following CM consultation and the time period between survey and consultations with MDs will have been more extensive (in some cases perhaps sizeable). While self-report survey research always carries a risk of response and non-response bias, the consistency of results demonstrated by this study provide compelling rationale for further attention to and research in this area.

#### **6.3.5 Conclusion**

Our findings demonstrate notably favourable and consistent patient perceptions of PCC in CM clinical settings for individuals with chronic conditions. It appears the patient experience of PCC is characteristic of CM clinical care to a greater extent than in

conventional medical settings. In light of the challenges presented to health systems by the rising rates, complexity and ongoing nature of chronic conditions, consideration should be given to the value CM professionals may contribute to addressing such challenges by providing individualised, tailored care to their patients.

## **6.4 CHAPTER SUMMARY**

The results presented in this chapter identify the extent and consistency of patient experiences of PCC appropriate to chronic condition management during consultation with CM practitioners. These results also identify nuance in the nature of care provided between different CM professions, suggesting varied strengths or attributes across those professions. Furthermore, greater perceptions of PCC are noted in CM consultations compared to those reported by patients for conventional medical consultations. While these results demonstrate an apparent provision of strongly person-centred consultation for chronic illness care by CM practitioners, they also raise questions about the role of CM practitioner services alongside conventional medical services – and within the wider context of health management – for individuals with chronic conditions. As patients with chronic conditions report different experiences of care between CM and conventional medical services, and as these services are typically provided in separate settings in Australia with coordination managed by patients, it is imperative to examine how patients are communicating with their care providers about the services and treatments they use to manage their chronic conditions.



## **7. PATIENT-PROVIDER COMMUNICATION BEHAVIOURS REGARDING TREATMENTS USED: RESULTS FROM A NATIONAL POPULATION-BASED SURVEY**

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### **7.1 RATIONALE FOR THIS ANALYSIS**

The previous chapter examined patient experiences of care provided during consultation with CM practitioners in the context of person-centred chronic illness care. Comparisons were drawn between patient perceptions of care from different CM professions, noting some variations. Comparisons were also drawn between patient perceptions of care provided by CM practitioners and by conventional medical doctors, with distinct differences observed between the two types of consultation experience. These differences in patient experience between complementary and conventional medicine settings are of particular interest considering that many patients with chronic conditions may engage in concomitant use of both services (6). Such concomitant use can carry risks when not appropriately managed and is generally not formally integrated within Australian health care settings, instead being coordinated largely by patients themselves, as discussed in section 2.3. Therefore, in keeping with the Research Aim of this thesis outlined in section 1.2, it is important to develop an understanding of how patients with chronic conditions communicate with various care providers about their concomitant use of CM and conventional medical services or treatments. Such an understanding will assist health policymakers and care providers from all settings to develop appropriate management processes and deliver optimal patient care of individuals with chronic conditions.

In response to the landscape illustrated by Chapters 4 to 6 regarding the use, motivations and experience of CM consultation by those with chronic conditions in Australia, the present chapter further develops an understanding of patient behaviours within that landscape by examining patient-provider communication during consultation. Specifically, this chapter draws upon the Phase One nationally representative sample of the CAMUHLD survey, reporting on findings from measures of patient disclosure of health care treatments to health care professionals by those with chronic conditions who consult CM practitioners. Rates of and reasons for disclosure or non-disclosure of CM use to medical doctors are assessed, alongside

rates of and reasons for disclosure or non-disclosure of conventional use to CM practitioners. These rates and reasons are compared between those who consulted with practitioners of different CM professions and between those who had consulted different types of medical doctors. Predictors of full disclosure are also explored to examine which factors might influence favourable communication behaviours.

Analyses include data from participants who had consulted with one of the clinical CM professions most accessed by individuals with chronic conditions in Australia, as described in Chapter 4. However, as outlined in section 3.2.2.4, the CAMUHLD survey collected data about disclosure to CM practitioners only from participants who had consulted with CM practitioners observed to be highly accessed in Australia in previous research, which had not observed high rates of use of osteopathy. On the basis of this previous research informing CAMUHLD survey items, data was not collected on disclosure to osteopaths and consequently is not reported in this chapter. These analyses are driven by Research Question 6 to address Research Objective 5.

While patients with chronic conditions may have contact with a wide range of conventional medical providers with whom they communicate about treatment use (e.g. doctors, pharmacists, nurses), the scope of this thesis is specific to patient experiences of clinical consultation. Subsequently, analyses presented in this chapter focus on disclosure to medical doctors (GPs and specialist doctors) who typically provide services within the context of clinical consultation, in order to best represent patient experiences of that context. This approach responds to Research Question 6 and addresses Research Objective 6.

## **7.2 PUBLICATION OF RESULTS**

The results presented within this chapter have been submitted for publication and are currently under review as follows:

Foley H, Steel A, McIntyre, E, Harnett, J, Sibbritt, D & Adams J. Disclosure of conventional and complementary medicine use to medical doctors and complementary medicine practitioners: A survey of rates and reasons amongst those with chronic conditions. PLOS One. (Under review).

A copy of the full submitted article is included below.

## **7.3 DISCLOSURE OF CONVENTIONAL AND COMPLEMENTARY MEDICINE USE TO MEDICAL DOCTORS AND COMPLEMENTARY MEDICINE PRACTITIONERS:**

## **A SURVEY OF RATES AND REASONS AMONGST THOSE WITH CHRONIC CONDITIONS**

### **7.3.1 Introduction**

The increasing prevalence of chronic conditions over recent decades is due to the culmination of many factors including advances in medical treatment of infectious diseases, an increasingly ageing population, and post-industrial changes to dietary and lifestyle habits less conducive to health maintenance (1, 2). Health systems must adapt to address the substantial medical and economic burden of chronic conditions, and to meet the different needs associated with chronic conditions for affected patients (11). Chronic conditions affect the functional capacity of individuals over a protracted course of time and often involve multiple predisposing, precipitating and perpetuating factors (29). Such complexity often leads to reduced quality of life, social and socioeconomic impacts on individuals, families and communities, and a need for continuous, ongoing provision of medical care accounting for both direct and indirect outcomes of chronic conditions (29).

Those living with chronic conditions often seek a multi-focused approach to treatment management including use of both conventional/pharmaceutical medicine and complementary medicine (CM) (5). CM is a field encompassing those health and medical practices and products that are separate from mainstream medical systems, practice and education (37). CM may include self-prescribed products and practices, or care provided by practitioners of CM professions (37), and individuals with chronic conditions use CM at higher rates than the general population (6). While concomitant CM and conventional medicine use may be customised to help address the broad and diverse needs of those living with chronic a condition(s) (66), there are also potential risks involved, such as interactions between different medicines/treatments, or use of medicines/treatments that may be contraindicated or unnecessary in the presence of certain chronic conditions (160). In order to ensure potential risks are avoided or appropriately managed, it is important for patients and care providers to communicate about the treatments being used (165).

Previous literature has examined patient disclosure of CM use to conventional medical providers (e.g. medical doctors, pharmacists, nurses) within the general population and while findings vary across studies, rates of disclosure are on average 33% (287). The reasons patients report for non-disclosure often relate to a lack of inquiry from care providers, fear of disapproval from the provider, and a lack of understanding of the

importance of disclosing CM use (287). Conversely, patients who disclose their CM use to conventional medical providers often give their reasons for disclosing as being related to provider inquiry, belief they will be supported by their provider, and/or an understanding of the importance of disclosing (287). Disclosure of conventional medicine use to CM practitioners has not yet been explored beyond a few preliminary studies which briefly report on rates of disclosure of conventional prescription medications to naturopaths (153) or CM practitioners more broadly (152). These studies have yielded mixed results, suggesting patient disclosure behaviours to CM practitioners may vary across different settings, populations or demographic groups. Despite this early work the topic of medicine disclosure to care providers has not been subject to rigorous investigation within the clinical population of those with chronic conditions. Additionally, no validated instrument has been consistently implemented to examine disclosure rates or reasons in either complementary or conventional medicine settings to date. This study aimed to describe the rates of and reasons for disclosure and non-disclosure of conventional medicine use to CM practitioners, and of CM use to medical doctors (MDs), amongst individuals with chronic conditions, using novel, validated measures.

### **7.3.2 Materials and methods**

#### *7.3.2.1 Study design and setting*

This paper reports on data collected via a cross-sectional survey conducted online between 26 July and 28 August 2017 as part of the Complementary and Alternative Medicine Use, Health Literacy and Disclosure (CAMUHLD) project. The survey was administered nationally across Australia. Analyses presented here are nested within the CAMUHLD project.

#### *7.3.2.2 Participants and recruitment*

Survey participants were adult members (aged 18 and over) of the Qualtrics research recruitment database, via which they were invited to participate. A sample broadly representative of the Australian population (regarding gender, age and state of residence) was achieved through employment of purposive convenience sampling. In line with Qualtrics operations, participants received a small financial recompense for their time as database members upon completion of the survey. Consent was provided

by participants after reading an information sheet and the survey was approximately 15 minutes in length.

An initial sample of 2,025 participants was achieved in the CAMUHLD project. Six cases were removed due to discrepancies in responses that deemed the data unreliable, resulting in a project sample of 2,019. Analyses presented here utilise data regarding disclosure behaviours provided by respondents who: a) indicated having a chronic condition, and b) had consulted with CM practitioners from one of the professions most commonly accessed by respondents with chronic conditions (massage therapy, chiropractic, acupuncture and naturopathy). The final sample for the current analyses represents 302 participants.

### 7.3.2.3 Instrument

The fifty-item CAMUHLD survey included domains of socio-demographics, health status, health service utilisation, and health communication. Items utilised from socio-demographics covered gender, age, state of residence, financial manageability, level of education, employment status, relationship status, private health insurance (PHI) coverage, and possession of a Health Care Card (provided to low-income earners and welfare recipients in Australia for financial concessions on health care and medicines). Health status items covered diagnosis of or treatment for a chronic health condition within the preceding three years (participants were presented with a list of conditions as well as an open-text option). The health service utilisation items used included consultation within the preceding twelve-months with an acupuncturist, chiropractor, massage therapist, naturopath (CM practitioners), GP or specialist doctor (MDs).

Health communication items included initial questions that asked about rates of disclosure to each type of health professional consulted (*Disclosed ALL*, *Disclosed SOME*, *Did NOT disclose*). Participants were then presented with two novel measures, which were subsequently subject to validation analyses: the Complementary Medicine Disclosure Index (CMDI; disclosure/non-disclosure of CM to conventional medical providers)(289), and the Conventional Medicine Disclosure Index (CONMED-DI; disclosure/non-disclosure of conventional medicine to CM practitioners)(288). These indices each consisted of two lists of items measuring the reasons for: a) disclosure; and b) non-disclosure of the relevant medicine type, and were assessed with a five-point Likert scale ranging from *Strongly disagree* (1) to *Strongly agree* (5). Participants were directed to the CMDI (for consultations with MDs) or CONMED-DI (for consultations with CM practitioners) in accordance with the type of health professional they reported disclosing/not disclosing to. Those who indicated they had *Disclosed ALL*

were directed to the CMDI/CONMED-DI items for disclosure, participants who indicated they *Did NOT disclose* were directed to the CMDI/CONMED-DI items for non-disclosure, while participants who indicated they had *Disclosed SOME* were directed to both lists of items for the relevant index.

#### 7.3.2.4 Data analysis

Data analysis was undertaken using Stata-14 (StataCorp LC 2015) software. Categorical variables were recoded to produce binaries as necessary for analyses including health status (presence of chronic condition: yes/no) and health service utilisation (profession consulted: yes/no). Categorical variables outlining disclosure behaviours were also recoded to a binary for backward stepwise logistic regression analyses of full disclosure (disclosed all/did not disclose all). In order to preserve data integrity, responses to disclosure questions were only included in analysis if the respondent had indicated that they had consulted with a practitioner of the health profession being disclosed to within the previous twelve months.

Frequencies and percentages were calculated for socio-demographic items and disclosure rates (disclosed ALL, disclosed SOME, or did NOT disclose), presented as sub-groups delineated by the health profession consulted. Chi-square analyses were used to test associations between respondents who did and did not consult with each of the four CM professions across socio-demographics and disclosure rates to MDs, with effect size determined by Cramer's V. Statistical significance was set at  $p < .05$  and the effect size of associations was classified as negligible (under 0.10), weak (0.10 to under 0.20), moderate (0.20 to under 0.40), relatively strong (0.40 to under 0.60), strong (0.60 to under 0.80) or very strong (0.80 to 1.00). Potential socio-demographic predictors for having fully disclosed were explored through reverse stepwise logistic regression.

Reasons for disclosure and non-disclosure were calculated as means with standard deviation to estimate the relative importance of each reason, with higher means indicating stronger agreement with the item on average. Independent t-tests were used to assess differences in reasons between respondents who did and did not consult with each of the four CM professions. Levene's test was first applied to assess equality of variance. For variables which violated the assumption of equality of variance, Welch's t-test was employed.

#### 7.3.2.5 Ethics

The project received ethical approval from the Human Research Ethics Committee at Endeavour College of Natural Health (EC00358) (#20170242).

### 7.3.3 Results

#### 7.3.3.1 Participant characteristics

Participants were predominantly female ( $n = 170$ , 56.3%), aged 18-29 years ( $n = 71$ , 32.5%), residing in the state of New South Wales ( $n = 88$ , 29.1%) and indicated that financial manageability was *difficult some of the time* ( $n = 114$ , 37.8%). Participants most commonly held trade/vocational ( $n = 105$ , 34.8%) or university ( $n = 104$ , 34.4%) qualifications, and were employed full-time ( $n = 101$ , 33.4%). Respondents were predominantly married ( $n = 142$ , 47.0%) and held PHI cover ( $n = 186$ , 61.6%), with many having PHI for CM ( $n = 144$ , 47.7%). A majority of participants indicated possession of a HCC ( $n = 177$ , 58.6%).

Table 7.1 shows that massage therapists were consulted by 61.6% ( $n = 186$ ) of respondents, chiropractors by 44.0% ( $n = 133$ ), acupuncturists by 27.5% ( $n = 83$ ) and naturopaths by 22.2% ( $n = 67$ ). Compared to those consulting the other professions, having consulted a chiropractor was moderately associated with male gender (Cramer's  $V = 0.204$ ,  $p < .001$ ), and having consulted a naturopath demonstrated a negligible association with full time employment (Cramer's  $V = 0.025$ ,  $p = .025$ ).

**Table 7.1 Socio-demographic characteristics of participants and associations with CM professional consulted.**

	Total sample n = 302 (100.0%)	Massage n = 186 (61.6%)	p- value*	Chiropractic n = 133 (44.0%)	p- value*	Acupuncture n = 83 (27.5%)	p- value*	Naturopathy n = 67 (22.2%)	p- value*
<b>Gender</b>									
Female	170 (56.3%)	114 (61.3%)	<i>.310</i>	59 (44.4%)	<i>&lt; .001</i> (0.204)	44 (53.0%)	<i>.245</i>	37 (55.2%)	<i>.538</i>
Male	132 (43.7%)	72 (38.7%)		74 (55.6%)		39 (47.0%)		30 (44.8%)	
<b>Age</b>									
18-29	71 (32.5%)	45 (24.2%)	<i>.113</i>	38 (28.6%)	<i>.480</i>	21 (25.3%)	<i>.855</i>	20 (29.9%)	<i>.109</i>
30-39	54 (17.9%)	38 (20.4%)		21 (15.8%)		13 (15.7%)		15 (22.4%)	
40-49	59 (19.5%)	41 (22.0%)		23 (17.3%)		18 (21.7%)		16 (23.9%)	
50-59	46 (15.2%)	29 (15.6%)		18 (13.5%)		14 (16.9%)		7 (10.5%)	
60 and over	72 (23.8%)	33 (17.7%)		33 (24.8%)		17 (20.5%)		9 (13.4%)	
<b>State</b>									
NSW	88 (29.1%)	52 (28.0%)	<i>.095</i>	39 (29.3%)	<i>.474</i>	22 (26.5%)	<i>.113</i>	16 (23.9%)	<i>.227</i>
VIC	76 (25.2%)	43 (23.1%)		34 (25.6%)		23 (27.7%)		16 (23.9%)	
QLD	84 (27.8%)	59 (31.7%)		30 (22.6%)		27 (32.5%)		24 (35.8%)	
SA	24 (8.0%)	16 (8.6%)		16 (12.0%)		2 (2.4%)		2 (3.0%)	
WA	21 (7.0%)	10 (5.4%)		9 (6.8%)		8 (9.6%)		7 (10.5%)	
TAS	4 (1.3%)	2 (1.1%)		1 (0.8%)		0 (0.0%)		1 (1.5%)	
ACT	5 (1.7%)	4 (2.2%)		4 (3.0%)		1 (1.2%)		1 (1.5%)	
<b>Managing financially</b>									
It is impossible	9 (3.0%)	6 (3.2%)	<i>.998</i>	4 (3.0%)	<i>.224</i>	3 (3.6%)	<i>.829</i>	3 (4.5%)	<i>.687</i>
It is difficult all of the time	56 (18.5%)	33 (17.7%)		30 (22.6%)		17 (20.5%)		15 (22.4%)	
It is difficult some of the time	114 (37.8%)	70 (37.6%)		40 (30.1%)		32 (38.6%)		24 (35.8%)	



It is not too bad	101 (33.4%)	64 (34.4%)		48 (36.1%)		24 (28.9%)		19 (28.4%)	
It is easy	22 (7.3%)	13 (7.0%)		11 (8.3%)		7 (8.4%)		6 (9.0%)	
<b>Education level</b>									
Up to year 10	42 (13.9%)	25 (13.4%)		19 (14.3%)		10 (12.1%)		9 (13.4%)	
Year 12 or equivalent	51 (16.9%)	28 (15.1%)	.989	24 (18.1%)	.687	11 (13.3%)	.847	11 (16.4%)	.365
Trade/VET	105 (34.8%)	67 (36.0%)		43 (32.3%)		30 (36.1%)		18 (26.9%)	
University degree	104 (34.4%)	66 (35.5%)		47 (35.3%)		32 (38.6%)		29 (43.3%)	
<b>Employment status</b>									
Full time work	101 (33.4%)	69 (37.1%)		50 (37.6%)		25 (30.1%)		28 (41.8%)	
Part time work	64 (21.2%)	43 (23.1%)		23 (17.3%)		15 (18.1%)		16 (23.9%)	
Casual/temporary work	21 (7.0%)	14 (7.5%)	.351	6 (4.5%)	.279	10 (12.1%)	.220	5 (7.5%)	.025 (0.167)
Looking for work	21 (7.0%)	13 (7.0%)		9 (6.8%)		8 (9.6%)		8 (11.9%)	
Not in paid workforce	95 (31.5%)	47 (25.3%)		45 (33.8%)		25 (30.1%)		10 (14.9%)	
<b>Relationship status</b>									
Never married	79 (26.2%)	50 (26.9%)		41 (30.8%)		21 (25.3%)		23 (34.3%)	
Married	142 (47.0%)	88 (47.3%)		54 (40.6%)		43 (51.8%)		25 (37.3%)	
De facto (opposite sex)	27 (8.9%)	17 (9.1%)	.706	11 (8.3%)	.446	3 (3.6%)	.315	9 (13.4%)	.171
De facto (same sex)	4 (1.3%)	4 (2.2%)		1 (0.8%)		1 (1.2%)		2 (3.0%)	
Separated/divorced/widowed	50 (16.6%)	27 (14.5%)		26 (19.6%)		15 (18.1%)		8 (11.9%)	
<b>PHI status</b>									
Has PHI	186 (61.6%)	114 (61.3%)	.983	90 (67.7%)	.067	55 (66.3%)	.301	44 (65.7%)	.426
PHI covers any CM	144 (47.7%)	91 (48.9%)	.839	72 (54.1%)	.104	46 (55.4%)	.149	35 (52.2%)	.488
<b>HCC status</b>	177 (58.6%)	102 (54.8%)	.218	82 (61.7%)	.310	55 (66.3%)	.091	42 (62.7%)	.405

Note. Some respondents consulted multiple practitioners from more than one profession.

\*Chi-square test with Cramer's V for significant results, comparing respondents who did and did not consult with this type of CM practitioner.

### 7.3.3.2 Disclosure rates and their relation to CM profession consulted

Table 7.2 presents the rates of disclosure behaviour types to CM practitioners, GPs and specialist doctors according to the CM profession consulted. Full disclosure of conventional medicine use (*Disclosed ALL* conventional medicines) to CM practitioners tended to be lower than rates of full disclosure of CM (*Disclosed ALL* CM) to MDs (GPs and specialist doctors). Overall, full disclosure rates were highest for disclosure of CM to specialist doctors. Accordingly, rates of conventional medicine non-disclosure (*Did NOT disclose* conventional medicines) to CM practitioners tended to be higher than rates of CM non-disclosure (*Did NOT disclose* CM) to GPs and specialist doctors.

Respondents who had consulted a naturopath reported the highest rates of full disclosure of conventional medicines to CM practitioners (56.9%), followed closely by those who had consulted a chiropractor (56.8%). Respondents who had consulted a massage therapist had the highest rates of non-disclosure of conventional medicines to CM practitioners (35.6%), while those who had consulted a naturopath had the lowest rates of non-disclosure (10.3%).

The highest rates of full disclosure of CM to GPs were reported by respondents who had consulted a massage therapist (70.0%), while the highest rates of disclosure of CM to specialist doctors were reported by those who had consulted a chiropractor (79.5%). Respondents who had consulted an acupuncturist reported the highest rates of non-disclosure both to GPs (12.1%) and to specialist doctors (12.0%). No statistically significant differences were seen in rates of CM disclosure to MDs between respondents who had or had not consulted with each of the four CM professions.

**Table 7.2 Rates of disclosure behaviour types to CM practitioners, GPs and specialist doctors, including differences in type of disclosure to GPs and specialist doctors between CM professions consulted.**

	CM profession consulted			
	Massage (n = 186)	Chiropractic (n = 133)	Acupuncture (n = 83)	Naturopathy (n = 67)
<b>Conventional medicine use disclosure behaviour to CM practitioner</b>				
Disclosed ALL	73 (41.2%)	67 (56.8%)	35 (46.7%)	33 (56.9%)
Disclosed SOME	41 (23.2%)	25 (21.2%)	23 (30.7%)	19 (32.8%)
Did NOT disclose	63 (35.6%)	26 (22.0%)	17 (22.7%)	6 (10.3%)
<b>CM use disclosure behaviour to GP</b>				
Disclosed ALL	128 (70.0%)	88 (68.8%)	52 (62.7%)	42 (62.7%)
Disclosed SOME	36 (19.7%)	26 (20.3%)	21 (25.3%)	19 (28.4%)
Did NOT disclose	19 (10.38%)	14 (10.9%)	10 (12.1%)	6 (9.0%)
<i>p-value*</i>	.822	.803	.142	.066
<b>CM use disclosure behaviour to a specialist doctor</b>				
Disclosed ALL	112 (74.7%)	89 (79.5%)	51 (68.0%)	48 (77.4%)
Disclosed SOME	25 (16.7%)	13 (11.6%)	15 (20.0%)	9 (14.5%)
Did NOT disclose	13 (8.7%)	10 (8.9%)	9 (12.0%)	5 (8.1%)
<i>p-value*</i>	.466	.299	.238	.807

\*Chi-square test comparing disclosure behaviour of respondents who did or did not consult with each type of CM practitioner.

### 7.3.3.3 Predictors of full disclosure

Backwards stepwise logistic regression models did not yield any predictive factors for full disclosure of conventional medicines to CM practitioners, or for full disclosure of CM to specialist doctors. However, full disclosure of CM to GPs was found to be predicted by age, financial manageability and number of chronic conditions diagnoses. Respondents aged 50-59 years (aOR 3.51,  $p = .004$ , 95% CI 1.50, 8.20) and those aged 60 and over (aOR 3.12,  $p = .002$ , 95% CI 1.52, 6.32) were found to have more than three times the odds of disclosing all CM use to their GPs. Respondents who indicated financial manageability as *difficult all of the time* had more than twice the odds of disclosing all CM to their GP (aOR 2.06,  $p = .029$ , 95% CI 1.08, 3.93). The odds of disclosing all CM to a GP increased with the number of chronic conditions, reaching statistical significance for those with four chronic conditions (aOR 2.63,  $p = .021$ , 95% CI 1.15, 5.99) and those with five or more chronic conditions (aOR 2.77,  $p = .006$ , 95% CI 1.35, 5.69).

### 7.3.3.4 Reasons for disclosure and non-disclosure of CM use to MDs

Table 7.3 reports the reasons selected by participants who completed the CMDI for disclosure of CM use to MDs ( $n = 263$ ), including the results of independent t-tests exploring differences between those who did and did not consult with each type of CM professional. These participants indicated the most agreement with the item *I wanted them to fully understand my health status* (mean = 4.44, SD = 0.73), followed by the item *I was concerned about drug interactions with the CM I was using* (mean = 4.20, SD = 0.89). The items that attracted the least agreement were *They asked me about my use of CM* (mean = 3.48, SD = 1.14) and *They have a good attitude towards CM* (mean = 3.57, SD = 0.87). Compared to those consulting other CM professions, the group of respondents who had consulted a naturopath had a significantly lower mean score for the item *They have my best interests at heart* ( $p = .005$ ), while those who had consulted a chiropractor had a significantly higher mean for the item *They asked me about my use of complementary and alternative medicine* ( $p = .017$ ).

**Table 7.3 Results of independent t-test showing differences in reasons for disclosure of CM use to medical doctors for each type of CM professional consulted.**

CMDI disclosure items:	Relative importance of reasons for each type of CM professional consulted (Mean ± SD)								
	Total sample (n = 263)	Acupuncture (n = 73)	p- value	Chiropractic (n = 114)	p- value	Massage (n = 164)	p- value	Naturopathy (n = 61)	p- value
I wanted them to fully understand my health status	4.44 ± 0.73	4.38 ± 0.74	.432	4.42 ± 0.81	.699	4.45 ± 0.69	.908	4.43 ± 0.74	.857
I was concerned about drug interactions with the complementary and alternative medicine I was using	4.20 ± 0.89	4.15 ± 0.94	.568	4.19 ± 0.93	.892	4.16 ± 0.88	.389	4.03 ± 0.87	.092
I have a good relationship with them	4.07 ± 0.89	4.01 ± 0.94	.537	4.06 ± 0.90	.911	4.10 ± 0.81	.409	3.89 ± 0.93	.066
I felt comfortable discussing complementary and alternative medicine with them	4.07 ± 0.93	4.10 ± 0.92	.767	4.04 ± 0.96	.612	4.10 ± 0.85	.536	3.87 ± 1.06	.056
They have my best interests at heart	4.06 ± 0.82	4.03 ± 0.91	.716	4.09 ± 0.83	.594	4.06 ± 0.76	.923	3.80 ± 0.85	.005
I thought they could help with my treatment decisions	3.94 ± 0.82	3.93 ± 0.82	.888	4.01 ± 0.84	.253	3.91 ± 0.77	.469	3.85 ± 0.87	.323
I knew they would be willing to discuss my complementary and alternative medicine use	3.88 ± 0.92	3.86 ± 0.95	.835	3.89 ± 0.92	.953	3.90 ± 0.85	.759	3.72 ± 1.05	.160
They understand my treatment goals	3.91 ± 0.83	3.90 ± 0.77	.919	3.94 ± 0.83	.658	3.98 ± 0.75	.135	3.89 ± 0.86	.770
I thought they might know something about complementary and alternative medicine	3.84 ± 0.91	3.89 ± 0.95	.608	3.85 ± 0.94	.916	3.82 ± 0.91	.534	3.85 ± 0.96	.935
They are open-minded	3.83 ± 0.88	3.84 ± 0.90	.905	3.90 ± 0.85	.208	3.85 ± 0.87	.596	3.66 ± 0.91	.087
I wanted their advice about complementary and alternative medicines	3.78 ± 0.88	3.86 ± 0.85	.341	3.86 ± 0.91	.197	3.77 ± 0.83	.792	3.66 ± 0.89	.211
I knew they would understand about my complementary and alternative medicine use	3.71 ± 0.98	3.78 ± 0.96	.450	3.73 ± 0.96	.763	3.71 ± 0.94	.895	3.52 ± 1.03	.096
I wanted their approval of my complementary and alternative medicine use	3.62 ± 0.99	3.60 ± 0.98	.863	3.68 ± 0.98	.425	3.62 ± 0.93	.963	3.62 ± 1.00	.977

They support my use of complementary and alternative medicines	3.60 ± 0.86	3.70 ± 0.91	.274	3.68 ± 0.97	.260	3.59 ± 0.81	.761	3.70 ± 0.88	.301
They have a good attitude towards complementary and alternative medicine	3.57 ± 0.87	3.63 ± 0.94	.519	3.67 ± 0.95	.132	3.57 ± 0.82	.981	3.44 ± 0.85	.178
They asked me about my use of complementary and alternative medicine	3.48 ± 1.14	3.51 ± 1.07	.780	3.67 ± 1.07	.017	3.53 ± 1.10	.311	3.39 ± 1.24	.522

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*Note.* Total sample includes participants who reported full disclosure (Disclosed ALL) or partial disclosure (Disclosed SOME) of CM use to a medical doctor.

*Note.* T-test analyses compare responses from individuals who did and who did not report consulting with each individual type of CM profession examined.

Table 7.4 reports responses by participants who completed CMDI items regarding reasons for non-disclosure of CM use to MDs (n = 87). Means for non-disclosure items were notably lower than those seen for disclosure items. The items attracting the most agreement were *They did not ask me about my CM use* (mean = 3.70, SD = 1.02) and *Complementary and alternative medicines are safe* (mean = 3.26, SD = 0.90). The items attracting the lowest mean scores were *It is none of their business* (mean = 2.77, SD = 0.96) and *I previously had a negative experience when I disclosed using CM* (mean = 2.80, SD = 1.11).

Amongst those who had consulted a naturopath, compared to those consulting other CM practitioners, means were significantly higher for items *They do not approve of my use of complementary and alternative medicine* ( $p = .003$ ), *I previously had a negative experience when I disclosed using complementary and alternative medicine* ( $p = .005$ ), *I did not think they would understand my choice* ( $p = .012$ ) and *I did not think they would know anything about complementary and alternative medicine* ( $p = .02$ ).

Compared to respondents consulting other CM professions, those who had consulted an acupuncturist produced a significantly higher mean score for item *I felt uncomfortable discussing it with them* ( $p = .018$ ), while for those who had consulted a massage therapist, means were significantly lower for items *I did not think they would understand my choice* ( $p = .003$ ), *It is none of their business* ( $p = 0.016$ ) and *There was not enough time in the consultation* ( $p = 0.021$ ).

**Table 7.4 Results of independent t-test showing differences in reasons for non-disclosure of CM use to medical doctors for each type of CM professional consulted**

<i>CMDI non-disclosure items:</i>									
<i>Relative importance of reasons for each type of CM professional consulted (Mean ± SD)</i>									
<b>Reasons for non-disclosure of complementary medicine use to a medical doctor</b>	<b>Total sample (n = 87)</b>	<b>Acupuncture (n = 31)</b>	<b>p-value</b>	<b>Chiropractic (n = 40)</b>	<b>p-value</b>	<b>Massage (n = 55)</b>	<b>p-value</b>	<b>Naturopathy (n = 25)</b>	<b>p-value</b>
They did not ask me about my complementary and alternative medicine use	3.70 ± 1.02	3.68 ± 1.08	.873	3.73 ± 1.04	.843	3.55 ± 1.05	.063	3.84 ± 0.94	.425
Complementary and alternative medicines are safe	3.26 ± 0.90	3.35 ± 0.88	.486	3.18 ± 0.96	.394	3.18 ± 0.86	.262	3.36 ± 0.70	.530
I was worried they wouldn't support my treatment decisions	3.22 ± 0.97	3.42 ± 0.76	.117	3.23 ± 0.80	.953	3.15 ± 1.04	.361	3.44 ± 0.82	.177
I did not think they would understand my choice	3.22 ± 1.00	3.26 ± 1.03	.786	3.25 ± 0.93	.788	2.98 ± 1.01	.003	3.64 ± 0.95	.012
I was worried they would judge me	3.15 ± 1.13	3.23 ± 1.06	.641	3.20 ± 1.04	.698	3.04 ± 1.10	.222	3.28 ± 0.98	.461
There was not enough time in the consultation	3.15 ± 0.99	3.03 ± 0.91	.417	3.30 ± 0.97	.194	2.96 ± 0.96	.021	3.24 ± 1.09	.593
I was worried they would discourage my use of complementary and alternative medicine	3.15 ± 0.99	3.13 ± 0.99	.888	3.23 ± 0.89	.516	3.00 ± 0.98	.066	3.40 ± 0.82	.137
I felt uncomfortable discussing it with them	3.14 ± 1.02	3.48 ± 0.93	.018	3.30 ± 0.91	.175	3.00 ± 1.02	.100	3.32 ± 0.95	.295
They did not need to know	3.13 ± 1.00	3.03 ± 0.84	.485	3.20 ± 1.04	.529	3.02 ± 0.99	.186	3.16 ± 0.94	.843
I did not think they would know anything about complementary and alternative medicine	3.10 ± 1.07	3.35 ± 1.11	.103	3.03 ± 1.00	.530	3.07 ± 1.00	.727	3.52 ± 1.12	.020
I was worried they would respond negatively	3.07 ± 1.00	3.13 ± 0.92	.679	3.15 ± 1.08	.488	2.93 ± 0.98	.082	3.36 ± 0.76	.084
They do not approve of my use of complementary and alternative medicine	3.00 ± 0.98	3.16 ± 0.90	.254	2.95 ± 0.93	.662	2.93 ± 0.94	.366	3.48 ± 0.77	.003
I previously had a negative experience when I disclosed using complementary and alternative medicine	2.80 ± 1.11	3.00 ± 0.97	.198	2.80 ± 1.09	.972	2.67 ± 1.04	.147	3.32 ± 0.90	.005
It is none of their business	2.77 ± 0.96	2.84 ± 1.00	.623	2.80 ± 0.99	.791	2.58 ± 0.88	.016	2.72 ± 0.79	.759

*Note.* Total sample includes participants who reported non-disclosure (Did NOT disclose) or partial disclosure (Disclosed SOME) of CM use to a medical doctor.

*Note.* T-test analyses compare responses from individuals who did and who did not report consulting with each individual type of CM profession examined.



### 7.3.3.5 Reasons for disclosure and non-disclosure of conventional medicine use to CM practitioners

Amongst participants who responded to items regarding disclosure of conventional medicines to CM practitioners (n = 216), the item attracting the highest mean indicating agreement was *I wanted them to fully understand my health status* (mean = 4.26, SD = 0.79), followed by *They have my best interests at heart* (mean = 3.95, SD = 0.90) and *They understand my treatment goals* (mean = 3.94, SD = 0.82). The item attracting the lowest mean was *I wanted their approval of my conventional medicine use* (mean = 3.22, SD = 1.03). Significantly lower means were seen for item *They are open-minded* amongst respondents who had consulted an acupuncturist ( $p = .05$ ) or a naturopath ( $p = .043$ ), as well as for item *I wanted them to fully understand my health status* amongst those who had consulted a massage therapist ( $p = .031$ ), in comparison to those consulting other CM professions. Significantly higher means were seen for item *I was concerned about drug interactions with the conventional medicine I was using* for those who had consulted a naturopath ( $p = .039$ ), and for item *I knew they would understand about my conventional medicine use* amongst those who had consulted a chiropractor ( $p = .033$ ) compared to those consulting other CM professions. See Table 7.5.

**Table 7.5 Results of independent t-test showing differences in reasons for disclosure of conventional medicine use to CM practitioners for each type of CM professional consulted.**

<i>CONMED-DI disclosure items:</i>	<i>Relative importance of reasons for each type of CM professional consulted (Mean ± SD)</i>								
<b>Reasons for disclosure of conventional medicines to CM practitioner</b>	<b>Total sample (n = 216)</b>	<b>Acupuncture (n = 67)</b>	<b>p- value</b>	<b>Chiropractic (n = 104)</b>	<b>p- value</b>	<b>Massage (n = 132)</b>	<b>p- value</b>	<b>Naturopathy (n = 61)</b>	<b>p- value</b>
I wanted them to fully understand my health status	4.26 ± 0.79	4.15 ± 0.86	.173	4.28 ± 0.78	.728	4.17 ± 0.80	.031	4.28 ± 0.69	.822
They have my best interests at heart	3.95 ± 0.90	3.84 ± 0.86	.199	3.89 ± 0.93	.353	3.94 ± 0.85	.771	3.90 ± 0.93	.596
They understand my treatment goals	3.94 ± 0.82	3.93 ± 0.77	.820	3.94 ± 0.86	.971	3.92 ± 0.75	.652	3.93 ± 0.65	.899
I was concerned about drug interactions with the conventional medicine I was using	3.87 ± 0.95	3.97 ± 0.89	.300	3.83 ± 0.98	.517	3.92 ± 0.88	.368	4.08 ± 0.86	.039
I felt comfortable discussing conventional medicines with them	3.85 ± 0.89	3.70 ± 0.92	.097	3.88 ± 0.95	.714	3.80 ± 0.88	.315	3.89 ± 0.93	.731
I have a good relationship with them	3.84 ± 0.95	3.91 ± 0.97	.483	3.93 ± 0.97	.181	3.80 ± 0.95	.445	3.87 ± 0.97	.800
They are open-minded	3.82 ± 0.92	3.64 ± 0.93	.050	3.85 ± 0.89	.734	3.80 ± 0.91	.567	3.62 ± 0.90	.043
I knew they would be willing to discuss my conventional medicine use	3.81 ± 0.86	3.78 ± 0.83	.737	3.87 ± 0.81	.325	3.72 ± 0.86	.066	3.93 ± 0.85	.169
They asked me about my use of conventional medicines	3.75 ± 0.97	3.81 ± 0.93	.538	3.76 ± 0.97	.835	3.73 ± 0.96	.842	3.87 ± 0.83	.200
I thought they might know something about conventional medicines	3.71 ± 0.91	3.82 ± 0.76	.182	3.68 ± 0.96	.690	3.71 ± 0.89	.939	3.87 ± 0.76	.074
I thought they could help with my treatment decisions	3.68 ± 0.92	3.61 ± 0.87	.496	3.68 ± 0.94	.918	3.65 ± 0.88	.627	3.70 ± 0.80	.773
They have a good attitude towards conventional medicine	3.67 ± 0.90	3.58 ± 0.91	.355	3.76 ± 0.93	.144	3.62 ± 0.84	.353	3.49 ± 0.85	.073
I knew they would understand about my conventional medicine use	3.65 ± 0.87	3.64 ± 0.81	.943	3.78 ± 0.86	.033	3.61 ± 0.87	.375	3.64 ± 0.84	.926
They support my use of conventional medicines	3.63 ± 0.88	3.61 ± 0.80	.843	3.71 ± 0.84	.188	3.58 ± 0.87	.260	3.54 ± 0.72	.301
I was concerned about side-effects of conventional medicines	3.55 ± 0.99	3.67 ± 0.94	.212	3.50 ± 1.01	.508	3.61 ± 0.98	.210	3.66 ± 1.00	.308
I wanted their advice about conventional medicines	3.49 ± 0.94	3.52 ± 0.88	.706	3.53 ± 0.93	.523	3.50 ± 0.92	.787	3.67 ± 0.93	.069
I wanted their approval of my conventional medicine use	3.22 ± 1.03	3.19 ± 1.02	.823	3.30 ± 0.97	.270	3.22 ± 1.03	.970	3.21 ± 1.03	.968

Note. Total sample includes participants who reported full disclosure (Disclosed ALL) or partial disclosure (Disclosed SOME) of conventional use to a CM practitioner.

Note. T-test analyses compare responses from individuals who did and who did not report consulting with each individual type of CM profession examined.

For responses regarding non-disclosure of conventional medicines to CM practitioners (n = 172), the highest mean recorded was for item *They did not ask me about my conventional medicine use* (mean = 3.40, SD = 0.97), followed by *I did not think it was important* (mean = 3.19, SD = 1.00). Items attracting the lowest mean were *I previously had a negative experience when I disclosed using conventional medicine* (mean = 2.71, SD = 0.96), followed by *I was worried they wouldn't support my treatment decisions* (mean = 2.80, SD = 0.93) and *I was worried they would judge me* (mean = 2.80, SD = 1.01).

Amongst respondents who consulted a naturopath, in comparison to those consulting other CM professions, significantly higher means were recorded for items *I previously had a negative experience when I disclosed using conventional medicine* ( $p = .013$ ) and *They do not approve of my use of conventional medicines* ( $p = .016$ ), while a lower mean was recorded for item *I did not think it was important* ( $p = .037$ ). For respondents who had consulted an acupuncturist, in comparison to those consulting other CM professions, a significantly lower mean was recorded for item *I forgot to mention it* ( $p = .041$ ). Compared to those who had consulted other CM professions, lower means were seen amongst respondents who had consulted a massage therapist for a number of items, namely *They do not approve of my conventional medicine use* ( $p = .015$ ), *I was worried they would discourage my use of conventional medicine* ( $p = .016$ ), *I was worried they wouldn't support my treatment decisions* ( $p = .025$ ), *I previously had a negative experience when I disclosed using conventional medicine* ( $p = .028$ ), *It is none of their business* ( $p = .041$ ), *I do not use conventional medicines regularly enough* ( $p = .048$ ), and *There was not enough time in the consultation* ( $p=0.049$ ). See Table 7.6.

**Table 7.6 Results of independent t-test showing differences in reasons for non-disclosure of conventional medicine use to CM practitioners for each type of CM professional consulted**

<b>CONMED-DI non-disclosure items:</b>									
<b>Relative importance of reasons for each type of CM professional consulted (Mean ± SD)</b>									
<b>Reasons for non-disclosure of conventional medicines to CM practitioner</b>	<b>Total sample (n = 171)</b>	<b>Acupuncture (n = 52)</b>	<b>p-value</b>	<b>Chiropractic (n = 66)</b>	<b>p-value</b>	<b>Massage (n = 126)</b>	<b>p-value</b>	<b>Naturopathy (n = 43)</b>	<b>p-value</b>
They did not ask me about my conventional medicine use	3.40 ± 0.97	3.29 ± 1.00	.330	3.41 ± 0.96	.903	3.40 ± 0.95	.985	3.23 ± 1.07	.197
I did not think it was important	3.19 ± 1.00	3.15 ± 1.04	.813	3.20 ± 1.01	.871	3.21 ± 1.01	.584	2.91 ± 0.97	.037
They did not need to know	3.10 ± 1.01	2.90 ± 0.96	.094	3.14 ± 1.02	.706	3.08 ± 1.02	.665	2.88 ± 1.16	.106
I did not think they would understand my choice	2.97 ± 0.97	2.98 ± 0.94	.929	3.08 ± 1.07	.283	2.94 ± 0.96	.443	3.14 ± 1.13	.239
There was not enough time in the consultation	2.95 ± 0.98	2.79 ± 0.87	.147	3.00 ± 1.04	.623	2.87 ± 0.93	.049	2.98 ± 0.96	.856
I was worried they would discourage my use of conventional medicine	2.93 ± 0.95	2.94 ± 0.94	.910	3.03 ± 0.94	.274	2.83 ± 0.93	.016	3.07 ± 0.86	.265
I forgot to mention it	2.92 ± 0.98	2.69 ± 1.00	.041	2.94 ± 1.02	.871	2.95 ± 0.95	.529	2.67 ± 0.81	.054
I do not use conventional medicines regularly enough	2.90 ± 0.98	2.92 ± 0.97	.884	3.02 ± 1.06	.253	2.82 ± 0.94	.048	2.84 ± 0.84	.595
I did not think they would know anything about conventional medicine	2.88 ± 0.97	2.75 ± 1.03	.237	2.91 ± 0.99	.781	2.87 ± 0.98	.822	2.86 ± 0.91	.861
I felt uncomfortable discussing it with them	2.88 ± 0.97	2.90 ± 1.00	.853	3.06 ± 0.94	.057	2.83 ± 0.94	.194	3.07 ± 1.12	.145
I was worried they would respond negatively	2.85 ± 0.92	2.75 ± 0.79	.359	2.95 ± 0.92	.231	2.79 ± 0.94	.198	3.00 ± 0.87	.212
They do not approve of my use of conventional medicines	2.84 ± 0.95	2.88 ± 1.02	.663	3.02 ± 1.03	.052	2.73 ± 0.91	.015	3.14 ± 1.10	.016
It is none of their business	2.82 ± 0.99	2.81 ± 0.99	.995	2.80 ± 1.03	.967	2.71 ± 0.94	.041	2.70 ± 1.08	.407
I was worried they wouldn't support my treatment decisions	2.80 ± 0.93	2.92 ± 0.97	.259	2.97 ± 0.93	.060	2.71 ± 0.89	.025	3.00 ± 1.00	.106
I was worried they would judge me	2.80 ± 1.01	2.79 ± 0.98	.914	2.92 ± 1.01	.207	2.78 ± 0.96	.614	3.02 ± 1.12	.096
I previously had a negative experience when I disclosed using conventional medicine	2.71 ± 0.96	2.63 ± 1.01	.514	2.82 ± 1.02	.235	2.61 ± 0.89	.028	3.02 ± 0.99	.013

Note. Total sample includes participants who reported non-disclosure (Did NOT disclose) or partial disclosure (Disclosed SOME) of conventional medicine use to a CM practitioner.

Note. T-test analyses compare responses from individuals who did and who did not report consulting with each individual type of CM profession examined.

### 7.3.4 Discussion

This study is the first to examine disclosure of both CM and conventional medicine use to health professionals by patients with chronic conditions across a range of conventional medicine and CM contexts. Our findings indicate that rates of disclosure of CM use to MDs by those with chronic conditions appear much higher than previous estimates of disclosure in the general population (287), while rates of disclosure of conventional medicine use to CM practitioners may be concerningly low. The patients with chronic conditions in our study choose to disclose primarily due to a desire to have their health status understood by their care providers, and fail to disclose primarily due to a lack of inquiry from care providers.

The finding that disclosure rates to MDs appear higher than disclosure rates to CM practitioners is noteworthy, considering some of the most highly ranked reasons for disclosing to CM practitioners suggest a respectful, communicative patient-practitioner relationship (e.g. *They have my best interests at heart* and *They understand my treatment goals*). Patient-practitioner communication in CM clinical settings is facilitated by longer consultation times, empathic, person-centred approaches by CM practitioners, and the holistic philosophies underlying CM practice (7). In contrast, patient-provider communication in conventional medical settings is reportedly limited by shorter consultation times, barriers to continuity of care, and a less person-centred experience for patients (23, 135). Yet, our results suggest disclosure may be facilitated by factors beyond consultation time or general person-centred, holistic approaches to care and communication. Robust comparisons of disclosure rates between complementary and conventional medicine settings has thus far been inhibited by a paucity of research examining disclosure of conventional medicine use to CM practitioners. Our findings are closely aligned with those of a study which briefly compared rates of disclosure between those consulting MDs and those consulting CM practitioners (152), while another study found substantially higher disclosure rates amongst those disclosing to naturopaths compared to MDs (153).

Indeed, disclosure to naturopaths was highest amongst the CM professions consulted in our study. This finding may reflect the differences in practice and treatment across different CM professions; while the massage, chiropractic and acupuncture professions most commonly use non-ingested treatments (manual therapy or acupuncture needles), naturopathic practitioners frequently prescribe orally-ingested herbs, supplements and therapeutic foods which can present a greater risk of interaction with conventional/pharmaceutical medicines (67, 161). Patients accessing naturopathic care

may be aware of this risk given those participants who consulted a naturopath in our study were more likely to report a stronger degree of concern about drug interactions as a reason for disclosing to the naturopath. Our study also found non-disclosure of conventional medicine use to naturopaths was associated with reports of negative previous experiences of disclosing and a patient belief that naturopaths do not approve of conventional medicine use. Previous studies have highlighted similar experiences and perspectives amongst patients regarding disclosure of CM use to MDs and other conventional medical providers (287). While no previous literature has examined such patient experiences or perspectives regarding disclosure to naturopaths, research has identified a diversity and complexity of views amongst CM practitioners toward conventional medicines, such as vaccines (358), and that naturopaths typically hold supportive views regarding the integration of conventional and complementary medicine generally (359). Disclosure rates in naturopathic practice might be improved by ensuring supportive communication by naturopaths to patients' regarding concomitant use of naturopathy and conventional medicine.

The finding that the lowest rates of disclosure to CM practitioners were amongst those consulting massage therapists in our sample may reflect the way patients use massage therapy and the nature of massage therapy practice. Compared to the other CM professions included in this study, massage has been suggested as more likely to be used as a non-essential/luxury practice rather than being used solely for the treatment or management of a health condition (328). When used as treatment, massage therapy is primarily accessed for musculoskeletal complaints, rather than for conditions involving additional complex physiological considerations (360) and typically involves a biomechanical focus in the scope of practice (361). Due to the aspects of perceived luxury and more targeted treatment purposes, disclosure may be seen as less necessary by patients of massage therapists, particularly as the profession does not typically involve prescription of ingested treatments that may present a risk of drug interaction. However, patient disclosure of conventional medicine use should still be encouraged by massage therapists through patient education in order to ensure a full understanding of the patient's health status and potential contraindications, such as cardiovascular conditions and associated pharmaceutical treatments that may carry risk of bruising, bleeding or blood clots (362).

While the primary reason for non-disclosure to MDs reported by our participants was not being asked by the doctor about CM, those who consulted a chiropractor reported a significantly higher mean for having disclosed due to being questioned about CM by their MD. Additionally, patients of chiropractors also reported a higher mean regarding

disclosing to their chiropractor for the item *I knew they would understand about my conventional medicine use*. This may be reflective of the status of chiropractic practice in Australia being treated as an allied health profession, which generates referrals for patients from MDs to chiropractic care and subsequently better integrated communication about concomitant use of conventional and chiropractic care (52). This may be contrasted with reasons for non-disclosure to MDs given by participants consulting with less integrated CM professions in our study - higher means were reported by naturopathy patients regarding a perception of their doctor not approving of their CM use, as well as having had a negative experience disclosing CM use previously.

#### *7.3.4.1 Implications for policy and practice*

Our study showed a failure to be asked about CM or conventional medicine use by the consulting care provider was the most prominent reason for non-disclosure to both MDs and CM practitioners, regardless of the CM profession being consulted. This finding is consistent with previous literature on CM use disclosure to MDs and other conventional medical providers (287) and identifies an opportunity for all care providers to improve patient management for those with chronic conditions through simple inquiry. Prior research has demonstrated that disclosure of CM to MDs can be improved through inclusion of a question about CM use in addition to usual clinical case-taking procedures (177), and this may be applicable to CM settings also. In view of participants reporting a desire to have their health status fully understood as a primary reason for disclosing, ensuring that patients are educated about the importance of disclosing other medication and treatment use as part of direct inquiry may also enhance patient-practitioner communication around disclosure. Aligning clinical practice with contemporary health policy relating to chronic condition management, such as recommendations for person-centred and integrated care (2, 8), may foster patient-practitioner relationships and clinical environments which encourage communication around concomitant use of multiple forms of health care.

#### *7.3.4.2 Limitations*

While our study findings provide a new depth of understanding to an issue integral to the care of patients with chronic conditions, the study is not without limitations. While the initial sample was broadly representative of the national general population, the online setting and self-report format of the survey may have led to responder and recall bias, limiting generalisability. Steps were taken to reduce these biases through

purposive elements in sampling, and by limiting questions about consultation and disclosure to the preceding 12 months. Health status regarding chronic conditions was assessed by asking participants if they had been diagnosed with or treated for a chronic condition within the previous three years. However, the duration of conditions was not ascertained and thus the experiences of participants may not accurately reflect the impact of chronicity. Additionally, as some participants had used more than one form of CM, it cannot be determined whether the CM use they had disclosed/not disclosed to their MD was the same as the CM profession they identified as having consulted and disclosed/not disclosed to. Finally, the disclosure indices limited responses regarding reasons to predetermined lists without opportunity for participants to provide open-text responses. Nevertheless, the indices were developed through rigorous examination of existing, expansive literature and the measures were subject to validation analyses (288, 289).

### **7.3.5 Conclusion**

Communication between individuals with chronic conditions and their health care providers regarding disclosure of complementary and conventional medicine use is influenced by a number of contextual factors relating to the clinical encounter, patient-provider relationship, and patient beliefs. While it is important to patients that their providers have a full understanding of their health status, opportunities to develop such understanding may not be maximised if information regarding various treatments being used by patients fails to be communicated. Disclosure may be better facilitated by patient education regarding the importance of sharing this information with care providers, direct inquiry and supportive approaches to discussion by care providers.

## **7.4 CHAPTER SUMMARY**

The findings presented in this chapter describe the communication behaviours regarding disclosure to health care providers of medicines and treatments used by patients with chronic conditions from a broad national sample. The extent of disclosure of CM use to medical doctors is assessed alongside the extent of disclosure of conventional medicine use to CM practitioners, finding higher rates of disclosure to medical doctors than to CM practitioners. While there is some variation between different professions, the primary reasons driving disclosure and non-disclosure appear



to be similar in both conventional and CM settings, noting that patient disclosure is driven by a desire to have care providers fully understand their health status, while non-disclosure is commonly a result of providers not inquiring about other treatments being used by their patients. Predictors of full disclosure are explored, finding that older age, financial difficulty and multimorbidity are associated with full disclosure of CM use to GPs.

The results in this chapter identify certain aspects of clinical consultation, the patient-provider relationship and patient beliefs as influencing such communication behaviours, and also identify how these aspects differ between different CM and conventional medical settings. These results highlight a need for closer examination of how the clinical consultation shapes patient-provider communication and subsequent management of patients' concomitant use of CM and conventional medicines in chronic illness care. Patients, providers, researchers and policymakers invested in optimising the management of chronic conditions may all benefit from deeper understanding of how clinical care can best be delivered to meet the complex needs of this patient group.

## 8. THE RELATIONSHIP BETWEEN PERSON-CENTRED CARE AND PATIENT DISCLOSURE BEHAVIOURS

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### 8.1 RATIONALE FOR THIS ANALYSIS

The results of the previous chapter presented the rates of and reasons for disclosure and non-disclosure of CM use to medical doctors and of conventional medicine use to CM practitioners by individuals with chronic conditions, taken from a large nationally-representative sample. These results found higher rates of disclosure to medical doctors than to CM practitioners, particularly to specialist doctors. The scope of various reasons reported by those with chronic conditions for disclosing or not disclosing differed across CM and conventional medical professions. This indicates nuance of patient perceptions and beliefs in different clinical settings, which often appear related to whether the profession being consulted involves prescription of ingested medicines and treatments. Despite these differences, the primary reasons which attracted the highest mean score for each disclosure index were consistent across professions. These primary reported reasons demonstrate that regardless of the precise clinical setting, patients with chronic conditions disclose to their care provider about other treatments being used due to a desire for their health status to be fully understood, and they fail to disclose this information primarily due to a lack of inquiry from the provider.

The previous chapter suggests that patient disclosure in a variety of clinical settings may be better encouraged if patients are educated about its importance – including its importance outside of the risk of interactions between ingested treatments (68, 287) – and by direct, supportive inquiry by providers about patients' use of other medicines and treatments. With CM typically being used as a complement to conventional medical services (6), leading to concomitant use and its associated risks, it is imperative that clinical practice and health policy promote optimal coordination of patient care, particularly in chronic illness care which is characteristically complex and prolonged. The apparent solutions to non-disclosure outlined in Chapter 7 draw attention to clinical communication and the patient-provider relationship more generally; they provoke consideration of how factors influencing disclosure might also relate to other aspects of patient management and responsiveness to patients' complex, ongoing needs in chronic illness care.

In response, the present chapter continues an exploration of disclosure rates and reasons during clinical consultation and extends this to examine the relationship between disclosure and PCC in the context of chronic illness care. This is undertaken by drawing from the Phase Two PECMC survey, which surveyed respondents with chronic conditions about both their disclosure behaviours and their experience of PCC in consultation with CM practitioners and medical doctors. The previous chapter reported on findings from the CAMUHLD survey, which asked participants about their disclosure to care providers over the preceding twelve months, examining how patients generally communicate about disclosure during clinical consultation. In contrast, the PECMC survey asked participants about their disclosure behaviours during their most recent consultation with each provider, focusing the timeframe for recall and allowing analyses to concentrate on specific circumstances. In addition, PECMC data assessing disclosure is linked to data assessing PCC regarding the same consultation and provider, allowing direct analysis of potential associations. This chapter responds to Research Question 6, addressing Research Objectives 5 and 6.

## **8.2 NOTES ON ANALYSES**

### **8.2.1 Participants and setting**

As outlined in section 3.3.1, the PECMC survey sample included individuals with chronic conditions who consulted with CM practitioners in clinical practices associated with three national PBRNs. The survey was provided to patients at the end of their consultation with the CM practitioner and survey items questioned participants specifically in reference to the consultation they had just attended. Items regarding consultation with medical doctors directed participants to respond in reference to their most recent consultation with a GP or specialist doctor (further details in section 3.3.2).

### **8.2.2 Variables and statistical methods**

Analyses presented in this chapter utilised data from PECMC socio-demographic items, health service utilisation items (CM and conventional medicine professions consulted), health communication items (CONMED-DI and CMDI), and measures of patient experiences of care (PACIC measure) as described in section 3.3.2. The professions consulted were treated as binary variables (did consult/did not consult). Fisher's exact test was used to identify any differences in socio-demographic and in disclosure rates between participants who did or did not consult with each CM profession.

Reasons for non-disclosure and disclosure within the CONMED-DI and CMDI were calculated as summary statistics (means and standard deviations) from the five-point Likert scale outlined in section 3.3.2 and section 3.3.3, in order to estimate the relative importance of each reason. The PACIC measure summary scores are used in the present analysis as an over-arching measure of PCC in chronic illness care. As calculations of the PACIC summary scores excluded observations with more than one missing response per domain (as described in section 3.3.3), data for some participants were not included in the ANOVA tests.

## **8.3 RESULTS**

Within the PECMC sample of those with chronic conditions ( $n = 153$ ), 93 participants (61%) completed one or both disclosure indices (CONMED-DI/CMDI). All 93 participants completed the CONMED-DI reporting on disclosure of conventional medicines to a massage therapist ( $n = 20$ ), a naturopath ( $n = 20$ ), an osteopath ( $n = 19$ ), a chiropractor ( $n = 18$ ) or an acupuncturist ( $n = 16$ ). The CMDI was completed by 83 participants who reported on disclosure of CM use to a GP ( $n = 65$ ) or a specialist doctor ( $n = 18$ ).

### **8.3.1 Participant characteristics**

Participants were predominantly female ( $n = 74$ , 79.6%), aged 65 or over ( $n = 34$ , 36.6%) and married ( $n = 49$ , 52.7%). They most commonly held vocational or trade qualifications ( $n = 40$ , 43.0%), were not in the paid workforce ( $n = 38$ , 40.9%) and reported financial manageability as not too bad ( $n = 43$ , 46.7%). PHI coverage was held by a substantial majority ( $n = 76$ , 81.7%), within which most participants held PHI coverage specifically for the CM profession consulted ( $n = 67$ , 87.0%). Less than half of participants had a HCC ( $n = 43$ , 64.2%).

Fisher's exact analyses comparing those who did or did not consult with each CM profession indicated that participants consulting an acupuncturist were more likely to be employed ( $p = 0.042$ ), while those consulting a naturopath were more likely to be aged over 65 years ( $p = 0.013$ ) and less likely to hold PHI for the profession they were consulting ( $p = 0.002$ ). Participants consulting an osteopath were less likely to be from the 45-54 years age group ( $p = 0.036$ ). Full details of participant characteristics are presented in Table 8.1.

**Table 8.1 Participant characteristics.** Socio-demographics of participants who responded to disclosure indices, by CM profession consulted.

	Full sample n = 93 (100.0%)	Acupuncture n = 16 (17.2%)†	P	Chiropractic n = 18 (19.4%)†	P	Massage n = 20 (21.5%)†	P	Naturopathy n = 20 (21.5%)†	P	Osteopathy n = 19 (20.4%)†	P
<b>Gender (n = 93)</b>											
Female	74 (79.6%)	13 (81.3%)	1.000	13 (72.2%)	.334	17 (85.0%)	.753	17 (85.0%)	.345	14 (73.7%)	.516
Male	18 (19.4%)	3 (18.8%)		5 (27.8%)		2 (10.0%)		5 (26.3%)			
Transgender‡	1 (1.1%)	0 (0.0%)		0 (0.0%)		1 (5.0%)		0 (0.0%)			
<b>Age (n = 93)</b>											
18-34	6 (6.5%)	2 (12.5%)	.297	2 (11.1%)	.727	1 (5.0%)	.359	1 (5.0%)	.013	0 (0.0%)	.036
35-44	14 (15.1%)	1 (6.3%)		2 (11.1%)		4 (20.0%)		2 (10.0%)		5 (26.3%)	
45-54	18 (19.4%)	3 (18.8%)		4 (22.2%)		6 (30.0%)		0 (0.0%)		0 (0.0%)	
55-64	21 (22.6%)	6 (37.5%)		5 (27.8%)		5 (25.0%)		5 (26.3%)			
65+	34 (36.6%)	4 (25.0%)		5 (27.8%)		4 (20.0%)		12 (60.0%)		9 (47.4%)	
<b>Relationship status (n = 93)</b>											
Never married	15 (16.1%)	2 (12.5%)	.484	1 (5.6%)	.274	6 (30.0%)	.288	3 (15.0%)	.337	3 (15.8%)	.613
Married	49 (52.7%)	10 (62.5%)		12 (66.7%)		8 (40.0%)		8 (40.0%)		11 (57.9%)	
De facto	10 (10.8%)	0 (0.0%)		3 (16.7%)		2 (10.0%)		2 (10.0%)		3 (15.8%)	
Separated/divorced/widowed	19 (20.4%)	4 (25.0%)		2 (11.1%)		4 (20.0%)		7 (35.0%)		2 (10.5%)	
<b>Education (n = 93)</b>											
Up to year 12	22 (23.7%)	4 (25.0%)	.884	5 (27.8%)	.331	2 (10.0%)	.245	5 (25.0%)	.322	6 (31.6%)	.645
VET/trade	40 (43.0%)	6 (37.5%)		5 (27.8%)		11 (55.0%)		11 (55.0%)		7 (36.8%)	
Higher education	31 (33.3%)	6 (37.5%)		8 (44.4%)		7 (35.0%)		4 (20.0%)		6 (31.6%)	
<b>Employment status (n = 93)</b>											
Full time work	23 (24.7%)	6 (37.5%)	.042	6 (33.3%)	.301	6 (30.0%)	.309	4 (20.0%)	.586	1 (5.3%)	.090
Part time work	26 (28.0%)	4 (25.0%)		2 (11.1%)		8 (40.0%)		4 (20.0%)		8 (42.1%)	
Casual/temporary work	6 (6.5%)	3 (18.8%)		1 (5.6%)		0 (0.0%)		1 (5.0%)		1 (5.3%)	
Not in paid workforce	38 (40.9%)	3 (18.8%)		9 (50.0%)		6 (30.0%)		11 (55.0%)		9 (47.4%)	
<b>Financial manageability (n = 92)</b>											
It is impossible/difficult all of the time	10 (10.9%)	1 (6.3%)	.095	2 (11.8%)	1.000	1 (5.0%)	.662	4 (20.0%)	.466	2 (10.5%)	.925
It is difficult some of the time	21 (22.8%)	7 (43.8%)		4 (23.5%)		4 (20.0%)		3 (15.0%)		3 (15.8%)	
It is not too bad	43 (46.7%)	4 (25.0%)		8 (47.1%)		12 (60.0%)		9 (45.0%)		10 (52.6%)	
It is easy	18 (19.6%)	4 (25.0%)		3 (17.7%)		3 (15.0%)		4 (20.0%)		4 (21.1%)	
<b>Health care cost subsidies</b>											
PHI cover (n = 93)	76 (81.7%)	15 (93.8%)	.288	15 (83.3%)	.574	17 (85.0%)	.476	14 (70.0%)	.116	15 (79.0%)	.476
PHI for profession consulted (n = 77)	67 (87.0%)	12 (80.0%)	.399	16 (100.0%)	.110	16 (94.1%)	.443	8 (57.1%)	.002	15 (100.0%)	.195
Health care card (n = 93)	43 (46.2%)	6 (37.5%)	.584	8 (44.4%)	1.000	6 (30.0%)	.131	13 (65.0%)	.077	10 (52.6%)	.610

†Percentage of participants who consulted this profession

‡Excluded from analysis of gender due to small cell size

### **8.3.2 Rates of disclosure of conventional medicine use to CM practitioners**

Across the total sample of participants consulting with any CM profession, the rate of full disclosure (disclosed ALL) of conventional medicines to the CM practitioner was 85.0% (n = 79), partial disclosure (disclosed SOME) was 8.6% (n = 8) and non-disclosure (disclosed NONE) was 6.5% (n = 6). The highest rate of full disclosure was to acupuncturists (100%, n = 16) and the lowest was to chiropractors (66.7%, n = 12). Fisher's exact tests found statistically significant differences in disclosure behaviours between those who did or did not consult a chiropractor, whereby the rate of full disclosure was lower and non-disclosure was higher ( $p = .035$ ). A similar pattern was seen amongst those who consulted a massage therapist ( $p = .044$ ). Full details of disclosure rates are presented in Table 8.2.

### **8.3.3 Rates of disclosure of CM use to medical doctors**

The overall rate of full disclosure to a GP was 58.5% (n = 38), partial disclosure was 23.1% (n = 15) and non-disclosure was 18.5% (n = 12). The highest rate of full disclosure to a GP was by participants who had consulted a naturopath (70.6%, n = 12) and the lowest rate of full disclosure was seen amongst those who had consulted an acupuncturist (45.5%, n = 5). Non-disclosure of CM use to a GP was highest amongst participants who had consulted a chiropractor (38.5%, n = 5). No statistically significant differences were seen between those who did or did not consult with each type of CM profession regarding rates of disclosure of CM use to a GP (see Table 8.2).

Within the full sample, the rate of full disclosure of CM use to a specialist doctor was 55.6% (n = 10), partial disclosure was 22.2% (n = 4) and non-disclosure was 22.2% (n = 4). The highest rate of full disclosure of CM use to a specialist doctor was seen amongst participants who had consulted a massage therapist (100%, n = 5) and the lowest rate of full disclosure was seen amongst those who had consulted an acupuncturist (0.0%, n = 0). The highest rate of non-disclosure of CM use to a specialist doctor was by participants who had consulted a chiropractor (66.7%, n = 2). There were no statistically significant differences found regarding rates of disclosure of CM use to a specialist doctor between those who did or did not consult with each type of CM profession (see Table 8.2)

**Table 8.2 Disclosure Rates.**

Rates of full disclosure, partial disclosure and non-disclosure of conventional medicines to CM practitioners and of CM to GPs and specialist doctors, by CM profession consulted.

		CM profession consulted										
		Any CM Profession (n = 93)	Acupuncture (n = 16)	<i>P</i> *	Chiropractic (n = 18)	<i>P</i> *	Massage (n = 20)	<i>P</i> *	Naturopathy (n = 20)	<i>P</i> *	Osteopathy (n = 19)	<i>P</i> *
<b>Disclosure of conventional medicines to CM practitioner</b>	Disclosed ALL	79 (85.0%)	16 (100.0%)		12 (66.7%)		14 (70.0%)		19 (95.0%)		18 (94.7%)	
	Disclosed SOME	8 (8.6%)	0 (0.0%)	.354	3 (16.7%)	.035	4 (20.0%)	.044	1 (5.0%)	.434	0 (0.0%)	.354
	Did NOT disclose	6 (6.5%)	0 (0.0%)		3 (16.7%)		2 (10.0%)		0 (0.0%)		1 (5.3%)	
<b>Disclosure of CM use to GP</b>	Disclosed ALL	38 (58.5%)	5 (45.5%)		7 (53.9%)		4 (57.1%)		12 (70.6%)		10 (58.8%)	
	Disclosed SOME	15 (23.1%)	4 (36.4%)	.482	1 (7.7%)	.089	2 (28.6%)	1.000	4 (23.5%)	.311	4 (23.5%)	1.000
	Did NOT disclose	12 (18.5%)	2 (18.2%)		5 (38.5%)		1 (14.3%)		1 (5.9%)		3 (17.7%)	
<b>Disclosure of CM use to Specialist</b>	Disclosed ALL	10 (55.6%)	0 (0.0%)		1 (33.3%)		5 (100.0%)		2 (40.0%)		2 (66.7%)	
	Disclosed SOME	4 (22.2%)	2 (100%)	.078	0 (0.0%)	.216	0 (0.0%)	.118	1 (20.0%)	.776	1 (33.3%)	1.000
	Did NOT disclose	4 (22.2%)	0 (0.0%)		2 (66.7%)		0 (0.0%)		2 (40.0%)		0 (0.0%)	

*Note.* Respondents who were not currently taking conventional/pharmaceutical medicines were excluded from analyses of rates of disclosure of conventional medicines to CM practitioners (as they had nothing to disclose).

\*Statistical significance of Fisher's exact test, comparing disclosure rates of participants who did and did not consult with each profession.

### 8.3.4 Reasons for non-disclosure and disclosure of conventional medicine use to a CM practitioner

The CONMED-DI reason for disclosing conventional medicine use to a CM practitioner which produced the highest mean was *They have my best interests at heart* (mean 4.68, SD 0.60), followed by *I felt comfortable discussing conventional medicines with them* (mean 4.56, SD 0.69) and *I wanted them to fully understand my health status* (mean 4.56, SD 0.69). The lowest means reported for non-disclosure in the CONMED-DI were *I wanted their approval of my conventional medicine use* (mean 2.75, SD 1.21) and *I wanted their advice about conventional medicines* (mean 3.08, SD 1.36) (see Table 8.3).

Regarding reasons for non-disclosure of conventional medicine use to a CM practitioner, the CONMED-DI item attracting the highest mean was *They did not need to know* (mean 3.57, SD 1.09), followed closely by *They did not ask me about my conventional medicine use* (mean 3.53, SD 0.99) and *I did not think it was important* (mean 3.27, SD 1.03). Reasons for non-disclosure in the CONMED-DI which produced the lowest means were *I was worried they would respond negatively* (mean 1.50, SD 0.52) and *They do not approve of my use of conventional medicines* (mean 1.50, SD 0.52) (see Table 8.3)



**Table 8.3 Disclosure and non-disclosure of conventional medicines to CM practitioners.**

Average scores of reasons for disclosure and non-disclosure of conventional medicines to CM practitioners (Conventional Medicine Disclosure Index – CONMED-DI).

<b>Reasons for disclosure of conventional medicines to CM practitioner</b>		
<b>CONMED-DI item</b>	<b>n</b>	<b>Mean ± SD</b>
They have my best interests at heart	88	4.68 ± 0.60
I felt comfortable discussing conventional medicines with them	87	4.56 ± 0.69
I wanted them to fully understand my health status	88	4.56 ± 0.71
They are open-minded	85	4.49 ± 0.72
I have a good relationship with them	86	4.47 ± 0.78
They understand my treatment goals	88	4.33 ± 0.80
I knew they would be willing to discuss my conventional medicine use	87	4.32 ± 0.84
They asked me about my use of conventional medicines	87	4.14 ± 0.95
They have a good attitude towards conventional medicine	87	4.13 ± 0.82
They support my use of conventional medicines	87	4.07 ± 0.86
I knew they would understand about my conventional medicine use	87	4.07 ± 0.86
I thought they could help with my treatment decisions	86	3.95 ± 1.11
I thought they might know something about conventional medicines	87	3.92 ± 0.98
I was concerned about drug interactions with the conventional medicine I was using	88	3.47 ± 1.39
I was concerned about side-effects of conventional medicines	88	3.14 ± 1.36
I wanted their advice about conventional medicines	87	3.08 ± 1.36
I wanted their approval of my conventional medicine use	88	2.75 ± 1.21
<b>Reasons for non-disclosure of conventional medicines to CM practitioner</b>		
<b>CONMED-DI item</b>	<b>n</b>	<b>Mean ± SD</b>
They did not need to know	14	3.57 ± 1.09
They did not ask me about my conventional medicine use	15	3.53 ± 0.99
I did not think it was important	15	3.27 ± 1.03
I forgot to mention it	13	2.31 ± 1.11
I did not think they would understand my choice	14	2.29 ± 0.91
There was not enough time in the consultation	13	2.15 ± 1.07
I did not think they would know anything about conventional medicine	14	2.14 ± 0.95
I felt uncomfortable discussing it with them	13	2.08 ± 0.95
I was worried they would judge me	14	2.00 ± 0.96
I do not use conventional medicines regularly enough	14	2.00 ± 1.24
It is none of their business	14	1.93 ± 0.73
I was worried they wouldn't support my treatment decisions	13	1.61 ± 0.51
I was worried they would discourage my use of conventional medicine	14	1.57 ± 0.65
I previously had a negative experience when I disclosed using conventional medicine	14	1.57 ± 0.65
They do not approve of my use of conventional medicines	14	1.50 ± 0.52
I was worried they would respond negatively	14	1.50 ± 0.52

### **8.3.5 Reasons for non-disclosure and disclosure of CM use to a medical doctor**

Within the CMDI, reason for disclosure of CM use to medicine doctors which attracted the highest mean was *I wanted them to fully understand my health status* (mean 4.42, SD 0.77), followed by *I have a good relationship with them* (mean 4.25, SD 0.85) and *They have my best interests at heart* (mean 4.23, SD 0.81). The lowest means reported for disclosure in the CMDI were for items *I wanted their approval of my complementary and alternative medicine use* (mean 3.03, SD 1.30), *They asked me about my use of complementary and alternative medicine* (mean 3.16, SD 1.27) and *I wanted their advice about complementary and alternative medicine* (mean 3.36, SD 1.28) (see Table 8.4).

The CMDI reason for non-disclosure of CM use to medical doctors which produced the highest mean was *They did not ask me about my complementary and alternative medicine use* (mean 4.17, SD 0.89), followed by *Complementary and alternative medicines are safe* (mean 3.65, SD 0.88) and *I did not think they would understand my choice* (mean 3.41, SD 1.08). The CMDI reason for non-disclosure which attracted the lowest mean was *It is none of their business* (mean 2.38, SD 1.02), alongside *I was worried they would judge me* (mean 2.74, SD 1.14) and *They do not approve of my use of complementary and alternative medicine* (mean 2.74, SD 1.08) (see Table 8.4).

**Table 8.4 Disclosure and non-disclosure of complementary medicine (CM) to GPs, specialists.**

Average scores of reasons for disclosure and non-disclosure of CM to medical doctors (Complementary Medicine Disclosure Index - CMDI).

<b>Reasons for disclosure of complementary medicine use to a medical doctor</b>		
<b>CMDI item</b>	<b>n</b>	<b>Mean ± SD</b>
I wanted them to fully understand my health status	69	4.42 ± 0.77
I have a good relationship with them	68	4.25 ± 0.85
They have my best interests at heart	69	4.23 ± 0.81
I felt comfortable discussing complementary and alternative medicine with them	69	4.06 ± 1.01
They are open-minded	69	3.87 ± 1.12
They understand my treatment goals	69	3.86 ± 1.03
I thought they could help with my treatment decisions	68	3.82 ± 1.01
I knew they would be willing to discuss my complementary and alternative medicine use	68	3.82 ± 1.18
They support my use of complementary and alternative medicines	69	3.72 ± 1.14
I thought they might know something about complementary and alternative medicine	69	3.70 ± 1.05
I knew they would understand about my complementary and alternative medicine use	68	3.66 ± 1.13
They have a good attitude towards complementary and alternative medicine	69	3.65 ± 1.12
I was concerned about drug interactions with the complementary and alternative medicine I was using	68	3.60 ± 1.33
I wanted their advice about complementary and alternative medicines	69	3.36 ± 1.28
They asked me about my use of complementary and alternative medicine	69	3.16 ± 1.27
I wanted their approval of my complementary and alternative medicine use	68	3.03 ± 1.30
<b>Reasons for non-disclosure of complementary medicine use to a medical doctor</b>		
<b>CMDI item</b>	<b>n</b>	<b>Mean ± SD</b>
They did not ask me about my complementary and alternative medicine use	35	4.17 ± 0.89
Complementary and alternative medicines are safe	34	3.65 ± 0.88
I did not think they would understand my choice	34	3.41 ± 1.08
They did not need to know	34	3.06 ± 0.95
I previously had a negative experience when I disclosed using complementary and alternative medicine	34	3.06 ± 1.28
I was worried they wouldn't support my treatment decisions	34	3.03 ± 1.11
I was worried they would discourage my use of complementary and alternative medicine	34	2.94 ± 1.18
I was worried they would respond negatively	34	2.94 ± 1.18
There was not enough time in the consultation	34	2.91 ± 1.16
I felt uncomfortable discussing it with them	34	2.79 ± 0.98
I did not think they would know anything about complementary and alternative medicine	34	2.76 ± 1.18
They do not approve of my use of complementary and alternative medicine	34	2.74 ± 1.08
I was worried they would judge me	34	2.74 ± 1.14
It is none of their business	34	2.38 ± 1.02

### 8.3.6 Relationship between disclosure rates and perceived person-centredness of chronic illness care

The one-way ANOVA found a statistically significant association between CONMED-DI disclosure rates and PACIC summary scores for consultation with CM practitioners. Higher PACIC means correlated with greater degrees of disclosure ( $p=0.0118$ ), indicating a relationship between person-centred chronic illness care in CM consultation and disclosure of conventional medicine use to the CM practitioner. A similar outcome was found in the ANOVA conducted between CMDI disclosure rates and PACIC summary scores for consultation with medical doctors, whereby high PACIC means correlated with a greater degree of disclosure ( $p=0.0033$ ), suggesting an association between person-centred chronic illness care in medical consultation with disclosure of CM use to the medical doctor. Full details of the ANOVA results are shown in Table 8.5.

**Table 8.5 One-way analysis of variance (ANOVA) of PACIC scores by disclosure rate.**

Difference between total mean scores of Patient Assessment of Chronic Illness Care by rates of disclosure.

<b>ANOVA of PACIC total mean scores by disclosure rate of conventional medicine use to CM practitioners.</b>				
Disclosure rate	Summary of PACIC total scores for each level of disclosure			ANOVA
	Mean	SD	N	<i>P</i>
<i>Disclosed ALL</i>	3.51	0.82	68	<i>.0118</i>
<i>Disclosed SOME</i>	3.00	0.91	7	
<i>Did NOT disclose</i>	2.48	0.32	5	
<b>ANOVA of PACIC total mean scores by disclosure rate of complementary medicine use to medical doctors.</b>				
Disclosure rate	Summary of PACIC total scores for each level of disclosure			ANOVA
	Mean	SD	N	<i>P</i>
<i>Disclosed ALL</i>	3.32	0.93	38	<i>.0033</i>
<i>Disclosed SOME</i>	2.66	1.12	18	
<i>Did NOT disclose</i>	2.46	0.66	16	

## 8.4 CHAPTER SUMMARY

The results of this chapter describe the rates of and reasons for disclosure and non-disclosure of conventional medicine use to CM practitioners by those with chronic conditions during their most recent consultation. Correspondingly, they also describe the rates of and reasons for disclosure and non-disclosure of CM use to medical doctors by those with chronic conditions who also consult CM practitioners. This chapter also identifies a correlation between stronger patient perceptions of person-centred care and higher rates of disclosure to the provider in both CM and conventional medical settings.

The results presented in this chapter build upon results from the previous chapter, complementing descriptions of general trends of disclosure from the Phase One CAMUHLD survey's national population-based sample (see Chapter 7) with descriptions of disclosure behaviours regarding recent consultations in the Phase Two PECMC survey's clinical practice-based dataset. Findings in the present chapter highlight that disclosure rates of conventional medicine use to CM practitioners is higher than disclosure rates of CM use to medical doctors. This is in contrast with findings from the previous chapter in which disclosure of CM use to medical doctors was higher than disclosure of conventional medicine use to CM practitioners. Between the two datasets, reasons for disclosure and non-disclosure were similar across both the CONMED-DI and CMDI, with a few notable exceptions such as concern about drug interactions, which was reported to hold greater relative importance to participants in the CAMUHLD sample.

This chapter bridges concepts from Chapter 6 and Chapter 7 by examining the relationship between PCC and disclosure rates. The association identified between PCC and disclosure rates sheds light on how the nature of clinical consultation might influence patient-provider communication and shape patient management for those with chronic conditions. This association provides particularly valuable insight for care providers and policymakers who work in the field of chronic illness management as it adds new information to how provision of care can be best tailored to the needs of chronic illness patients. As multiple forms of care are often employed to adequately manage the complexity of chronic conditions (5), it is essential to ensure appropriate management of the risks and benefits associated with concomitant use of multiple forms of treatment. The analyses presented in this chapter provide evidence of a relationship between PCC and patient disclosure to providers of other treatments being

used, encouraging person-centred approaches to clinical communication as a means of achieving risk management and optimal patient care.

## 9. DISCUSSION

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The results chapters of this thesis map a cohesive landscape outlining the patient characteristics, reasons for care-seeking, perceptions of care, and communication behaviours relating to consultation with CM practitioners by individuals with chronic conditions. This landscape constitutes both consistencies across patient experiences amongst those with chronic conditions who consult CM practitioners, as well as nuanced differences in such patient experiences relating to chronic condition diagnoses and the CM professions consulted. Comparisons in patient experience and communication during clinical consultation across CM and conventional medicine settings provide further context to the project findings. In keeping with the style of this thesis by compilation, the particular findings of each stage of data analysis have been discussed in the corresponding results chapters through embedded published articles. The purpose of the present chapter is to consider the intersections of each topic explored in this thesis and translate the results into broader analyses responsive to the over-arching research aim. This chapter will also devote attention to discussion of the final results chapter (Chapter 8), which is not embedded as a published article.

In alignment with the goals of health services research to inform health practice and policy, the following discussion will conceptualise the implications of this thesis to vital stakeholders involved in the clinical care of individuals with chronic conditions and the development of related policy, including patients, CM practitioners, conventional medical providers, and health policymakers. The discussion provided in this chapter will also outline the limitations of the research and recommend possible directions for future investigation building on the foundations of the thesis study findings.

### **9.1 CM PRACTITIONERS PROVIDE PCC TAILORED TO CHRONIC ILLNESS NEEDS**

The socio-demographic characteristics of those with chronic conditions who consult with CM practitioners are reflective of characteristics seen amongst those in the general population who consult CM practitioners in Australia (as outlined in Chapter 4). However, the high prevalence of chronic conditions amongst those consulting CM practitioners (as outlined in Chapter 5) suggests that having a chronic condition may itself be a characteristic associated with a higher likelihood of consulting a CM practitioner – a suggestion supported by findings from the broader CAMUHLD project

analyses (313). This high use of CM practitioner services by individuals with chronic conditions has also been noted in previous literature reviewing CM use in Australia (6). The categories of chronic conditions most strongly associated with consulting a CM practitioner in the thesis project tended to be either conditions which often benefit from manual therapeutic intervention (musculoskeletal conditions) (363) or conditions which are typically complex and challenging to treat, resulting in specific needs for patients which may not be met in the conventional medical system (mental health conditions, gastrointestinal conditions, reproductive conditions) (26, 123, 140, 324). Consulting a CM practitioner was not identified as strongly associated with reported diagnosis of those conditions which the conventional medical system currently manages through well-established public health programs that provide coordinated, integrated, accessible care, such as diabetes mellitus (364). Nonetheless, research on the experiences of individuals with diabetes in Australia has identified a substantial degree of unmet psychosocial needs and a lack of PCC perceived by this population (28), indicating that PCC from CM practitioners could potentially fill an appreciable complementary role in diabetes care.

The repeated implication across the findings of both datasets used in this project is that CM practitioner services are being sought to address otherwise unmet patient needs related to chronic condition management. This finding is of significance to health policymakers, as it draws attention to the shortcomings of the current health system in supporting those with chronic conditions, while also highlighting CM practitioner services as a potential existing remedy for the unmet needs of those patients. These findings also provide important information to conventional medicine providers who may be challenged to find suitable means by which to assist their patients in meeting complex needs associated with chronic conditions beyond the scope or structural limitations of conventional primary care. CM practitioners should also be aware of these findings to ensure they consider the full breadth of their patients' needs and their potential role within the wider scope of their patients' care.

Similar to socio-demographic trends, the CM professions most commonly consulted by those with chronic conditions in the Phase One dataset were also aligned with those most commonly consulted amongst the general population in Australia (313). However, the thesis analyses indicated a number of associations between specific categories of chronic condition and consultation with specific CM professions. While it is not immediately clear what factors are involved in these associations, such findings elicit further consideration of the implication regarding needs that are unmet by conventional medical systems for particular chronic conditions; specific CM professions may be



perceived by patients as well-suited to meeting their condition-related needs, as speculated in section 5.3.4 of Chapter Two. The interesting aspect of these condition-specific associations is that they appear within the holistic circumstances of many CM professions; holism, much like PCC, seeks to treat the individual within the context of their unique circumstances, rather than being condition-focused in its approach to care (89). Thus, condition-specific associations initially seem at odds with the nature of CM practice, yet the common observation of such associations in relevant literature (as discussed in Chapter 2.1), suggest they may be driven by patient perceptions of CM professions. While various CM professions may have unique strengths and individual CM practitioners may focus their clinical practice on condition-related special interests, it is still likely it is an holistic approach that appeals to patients (107). It may also be that the holistic approach itself provides the means to identify and address unmet needs which are indirectly yet distinctly related to specific chronic conditions.

Indeed, when the thesis investigated patients' motivations for seeking the care of CM practitioners, the reasons reported by participants were largely factors which sit adjacent to direct treatment of chronic conditions, relating to the impact of chronic conditions on individuals' lived experience of daily life. For example, improvements in wellbeing, alongside desires for preventive care, compassionate support and a greater sense of control or hope were all commonly reported reasons for seeking CM practitioner services. This is unsurprising as government reports and associated public health policy identify "*feelings of disempowerment, frustration and disengagement*" amongst patients as current challenges to effective chronic condition management (2, 34). Reasons for consultation with CM practitioners are explored in detail in Chapter 1 and Chapter 2. However, when these reasons are considered together with the results of Chapter 3 detailing patient experiences of PCC, greater context may be given to these reported motivations. A desire for improved wellbeing and preventive care (as identified in Chapters 1 and 2) is met through provision of PCC, which seeks to provide care which is "*respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions*" (80). Such care, when required, can be individualised beyond direct treatment of a condition – as the results of the PCCS and PACIC measure in Chapter 3 demonstrate – to consider wellbeing, prevention and quality of life needs. In the results of Chapter 2, participants reported seeking CM practitioner services due to a perception that CM practitioners are supportive and compassionate, while the results of Chapter 3 demonstrate these same participants reported high perceptions of provider support for their CM practitioners in the PPSS. In Chapter 2, participants reported other reasons for seeking CM

practitioner services as relating to hope about their future health and a desire for a sense of control, while the results of the Empowerment scale in Chapter 3 suggest these reasons were responded to during their consultation with the CM practitioner.

By contextualising the results of Chapter 1 and Chapter 2 regarding reasons for consultation with reference to the findings of Chapter 3 on perceived PCC, it can be asserted that many of the primary motivations behind CM practitioner service utilisation by those with chronic conditions in Australia are being satisfied via CM consultation through the delivery of PCC. Current health policy consistently underscores the importance and utility of PCC in chronic condition management with the objective to improve health, wellbeing and quality of life in this population (2). Thus, policymakers should be aware of the potential contributions of CM practitioners to this objective, and work with practitioners and researchers to identify the most efficient pathways to ensuring the resource of CM practitioner services is sufficiently and appropriately utilised.

## **9.2 CM PRACTITIONER SERVICES OFFER WHOLENESS TO CHRONIC CONDITION MANAGEMENT BY PROVIDING COMPLEMENTARY CARE**

As evidenced in this thesis, a high degree of PCC is delivered during CM consultation for individuals with chronic conditions, and this PCC appears to be well-tailored to the particular necessities of chronic illness care. Furthermore, PCC is experienced by patients to a notably stronger degree in CM consultation than during consultation with medical doctors. The differences in patient experiences of PCC between CM and conventional medicine settings shed light on the role of CM practitioners in the care of those with chronic conditions, particularly when considered alongside the *complementary* nature of CM – that CM is typically used alongside conventional medical services – as this has implications for integration of different aspects of care. Conventional medicine, within the Australian public health system, has developed to provide accessible, effective treatment of acute and infectious diseases, as well as targeted therapies for the pathology underlying some chronic conditions (11). In addition, the last decade has seen enhancements to the Australian public health system in providing care for chronic condition management (3). However, conventional health providers within the public health system continue to face challenges in providing comprehensive, multi-disciplinary and preventive care for patients with chronic conditions due to limitations regarding: the integration of various aspects of

care; the ability to tailor care to individual patient needs, availability and duration of primary care consultations; and adequate funding models (3).

It appears that CM practitioners are helping to address some of these shortfalls in comprehensiveness of care which extend to peripheral aspects of chronic illness, assisting patients with wellbeing, psychosocial support and preventive care, as well as providing complementary treatment for chronic conditions themselves. The potential for CM to address wellbeing, psychosocial support and quality of life has been discussed at length in Chapters 4 and 5. In addition, the longer consultations associated with CM practice when compared to conventional medicine consultations, alongside continuity of care provided through repeat consultations and the application of holistic CM philosophies appear suited to the provision of patient education and preventive care in chronic illness (365). Patient education and preventive care are interconnected and essential for chronic illness management, particularly given the modifiable nature of many risk factors associated with chronic conditions (18). Patient education improves health literacy, empowering individuals to self-manage and access preventive care, potentially delaying the deterioration of health associated with chronic conditions or the onset of additional conditions, complications and associated disabilities (34). For this reason, the Australian National Strategic Framework for Chronic Conditions lists its first objective as a “*Focus on prevention for a healthier Australia*” (2). If it is indeed the case that CM practitioner services address shortfalls in chronic illness care, potential benefits to patients may include more comprehensive, whole-person care that improves quality of life and self-management, and prevents unnecessary deterioration of health. Such a role for CM practitioners may also benefit other care providers and the wider health system through reduced burden of labour and cost as patient self-management increases, resulting in improved patient health and less utilisation of public health services. However, if patients are left to continue self-managing the coordination of their concomitant use of CM and conventional medicine as currently the case (5), they may be unaware of and fail to manage associated risks. Such risk management requires the expertise of health professionals, which depends upon patient disclosure of treatment use to care providers and effective patient-provider communication.

### **9.3 PCC PREDICTS PATIENT COMMUNICATION REGARDING DISCLOSURE OF TREATMENT USE TO CARE PROVIDERS**

Analysis of patient disclosure of treatment use to providers across the two samples in the thesis shows somewhat inconsistent results. Findings from the Phase One CAMUHLD sample showed notably higher rates of patient disclosure to medical doctors than CM practitioners, while those from the Phase Two PECMC sample had substantially higher rates of patient disclosure to CM practitioners than medical doctors. These findings may be impacted by the difference in timeframe for recall, with the CAMUHLD survey involving 12-month recall and the PECMC survey being administered directly after the CM consultation. The different findings may also have been due to some residual social desirability bias within the PECMC sample as participants received the survey from their CM practitioner. However, an arms-length approach to recruitment was employed to ameliorate this risk, as described in section 3.3.1.4. Despite this difference in disclosure rates, the most common reasons reported for disclosure and non-disclosure were comparable across all professions in both samples, indicating that approaches taken to improve disclosure rates could be applicable to a wide variety of clinical settings, CM and conventional alike. As identified in Chapter 7, direct provider inquiry, supportive approaches by the provider to communication, and patient education about the importance of disclosure are potential solutions to the issue of patient non-disclosure of treatment use. These potential solutions offer simple clinical care-based interventions – congruent with person-centred policy – to improve patient-provider communication regarding disclosure behaviours surrounding multiple sources of treatment.

The results of Chapter 8 identified a correlation between higher patient reports of perceived PCC and higher rates of patient disclosure of treatment use to providers in both CM and conventional medical settings. While the reasons for disclosure and non-disclosure to care providers in the CONMED-DI and CMDI outlined influential factors self-reported by patients, the association between disclosure rates and PCC identifies PCC as an external predictor of disclosure. It may be that PCC facilitates the direct, supportive communication which encourages patient disclosure of treatment use. It is also possible that some unexamined factor contributes to both PCC and disclosure-related communication behaviours, yet the facilitators of patient disclosure of treatment use identified in Chapters 7 and 8 are congruent with some aspects of PCC (80). Supportive communication approaches by providers are congruent with the PCC principle of Emotional Support, which aims to alleviate patient fear and anxiety. Patient education about the importance of disclosing various treatments being used is congruent with the PCC principle of Information, Communication and Education, which seeks to provide *“trustworthy information that is attentive, responsive, and tailored to*

*an individual's needs*" (80). Direct inquiry from providers about the patient's use of other treatments also relates to the principle of Information, Communication and Education as inquiry is an express method of ascertaining the individual's needs. As the goal of PCC is to customise care to each individual's specific needs and circumstances, communication about other treatments being used by the patient may be an essential part of discerning the specific needs and circumstances of the patient.

The importance of disclosure for management of risks associated with concomitant use has been explored in detail in Chapter 2.3 and Chapter 7. However, the value of facilitating open, supportive communication between patients and providers is not limited to this particular type of risk management. If the patient-provider relationship is developed to foster honest, frank discussions within which patients feel comfortable to disclose sensitive information, providers are then more able to identify risks and opportunities for enhanced patient care regarding a variety of other issues. This includes issues which patients may not know to be important, or which may even be perceived by patients as stigmatising. Previous literature has examined this need for direct, supportive communication pertaining to the disclosure of factors such as sexual orientation (366), trauma (367), HIV+ status (368) and domestic violence (369) in order to ensure optimal and appropriate care is provided to patients experiencing such circumstances. These findings are significant to health care providers and policymakers as they demonstrate a clear and implementable pathway to improving the management of patients with chronic conditions through clinical consultation that may not only offset risks associated with poor coordination of CM and conventional health care, but also have other wide-reaching benefits. Asking patients about what other treatments they use, educating patients about the importance of sharing such information, and doing so in a compassionate, non-judgmental manner that creates a supportive environment may encourage development of communication that could extend to other important aspects of patient management and subsequently enhance treatment outcomes. The correlation of PCC with disclosure behaviours is also significant to patients themselves, as it implies that discussing treatment use with providers could result in more comprehensive care and better outcomes.

#### **9.4 COORDINATION AND INTEGRATION OF CM PRACTITIONER SERVICES RESPONDS TO PUBLIC HEALTH POLICY**

While the importance of disclosure is clear, improving rates of patient disclosure of concomitant use to both CM practitioners and medical doctors is only one of a number

of possible steps towards optimising chronic illness care. Coordination and integration of care are essential for effective management of chronic conditions, as outlined in international health policy and recommended for Member States of the WHO, which includes Australia (4). Australian Government reports have identified one of the challenges faced by the public health system in managing chronic conditions as being *“a fragmented system, with providers and services working in isolation from each other rather than as a team”* (34). In response, the National Strategic Framework for Chronic Conditions notes the need for improved coordination of care and lists *“Collaboration and partnerships”* as a defining principle (2). The Framework was developed with the vision that *“all Australians live healthier lives through effective prevention and management of chronic conditions”*. While the Framework refers to partners as including *“the public and private health sectors, including all health care providers and private health insurers”*, it does not specifically reference CM, overlooking – as this thesis indicates – opportunities for collaboration and partnership with CM practitioners who provide dynamic, person-centred chronic illness care. Other principles within the Framework include *“Evidence-based”* and *“Person-centred approaches”*, as well as *“Access”*. Both evidence-based medicine and PCC include within their paradigms a role for patient preferences, needs and values, while PCC also acknowledges accessibility as an essential facet to optimal care provision. The research conducted for this thesis, alongside the body of existing literature discussed in section 2.1, strongly support that patient preferences, needs and values in the context of chronic condition management often include the use of CM. Consequently, pathways to improved accessibility of CM services should be considered for this clinical population by care providers and health policymakers.

The development of a health system that provides more accessible and flexible integrated care inclusive of CM practitioner services is likely to offer some benefit to patients with chronic conditions, although further research is required to determine how this might be effectively achieved. To preserve the full value provided by the CM consultation to those with chronic conditions, models of integrative health care which involve parallel care provision by a multidisciplinary team of CM and conventional medical providers who collaborate respectfully to provide personalised, holistic care may be the most powerful approach (61). This would allow all care providers involved to focus on optimising care within their own expertise and scope of practice, and has been shown to be a preferred model for many care providers and patients (61). Acknowledgement of the value that CM practitioner services can provide to individuals with chronic conditions alongside streamlined processes for referral between CM

practitioners and conventional medical providers that foster collaborative approaches to patient care could be of great utility in achieving the aims of the Framework. Such processes of referral have been increasing to some degree with chiropractic, osteopathic and acupuncture services, facilitated by the legitimisation of these professions through statutory regulation (52, 53). Some other professions commonly consulted by those with chronic conditions, such as naturopathy, face greater challenges in progressing toward integration – this may be related to a lack of statutory regulation and subsequent difficulties in being perceived as legitimate sources of care by conventional medical providers and policymakers (359, 370). Strengthening the processes of collaborative, integrated care for a broader scope of suitable CM professions could reduce the burden currently carried by individual patients to coordinate their own care, as well as enhancing accessibility of services by simplifying navigation of health systems that are often confusing for patients (5). Further research is required to determine which CM professions are most suitable for integration and collaboration with conventional medical professionals in the context of chronic condition management. This thesis provides a valuable foundation from which to begin such a line of inquiry.

## **9.5 SUMMARY OF SIGNIFICANCE TO STAKEHOLDERS**

### **9.5.1 Patients**

The findings of this thesis are of significance to all key stakeholders in chronic condition management in Australia, including patients, care providers, and policymakers whose work affects the functioning of Australian health systems. The significance to patients with chronic conditions lies in the identification of characteristics of the CM consultation which are well suited to meeting these patients' needs, providing evidence that CM practitioner services may be a valuable resource to investigate if not already being utilised. This thesis also highlights the importance patients place on open communication with care providers in both CM and conventional medicine settings regarding various treatments being used to facilitate receipt of optimal care. In addition, this thesis recommends improvements to coordination of care (in line with national (2) and international (4) health policies for chronic condition management), which could alleviate the current pressure on patients to navigate between the various elements of a disconnected health care team.

### **9.5.2 Care providers**

CM practitioners will find significance in the results presented in this thesis regarding the need to reflect on the role they play in chronic illness care for their patients. While it may be validating for CM practitioners to note the positive experience their patients report regarding PCC, these results also encourage CM practitioners to explore the degree to which they consciously employ patient education and empowerment as part of preventive care with chronically ill patients. Additionally, with mind to some of the reasons participants in this research have given for failing to disclose conventional medicine use to their CM practitioners, CM practitioners should consider giving more attention to educating their patients on the risks associated with CM use itself and the concomitant use of CM with conventional/pharmaceutical medicines.

The results presented in this thesis illuminate the behaviours and motivations of patients with chronic conditions regarding CM consultations and this is of significance to conventional medical providers who provide care to these patients. This information is informative as well as instructive, especially for primary care providers who may be seeking greater knowledge on what is and what is not valuable to the wider care of their patients, by demonstrating the nature of care contributed by CM practitioners from the most commonly consulted CM professions in Australia. Conventional medical providers may also find significance in the results regarding disclosure of CM use and be prompted to include direct, supportive inquiry on the topic in routine consultations.

Conventional medical providers and CM practitioners alike should consider encouraging their patients to discuss the treatments they prescribe with other health care providers they visit and explain the importance of managing concomitant treatment use in the complex circumstances of chronic conditions. Beyond this patient-provider communication, this thesis suggests care providers from both CM and conventional medicine settings would benefit their patients and streamline their patient care by engaging in collaborative communication and partnerships with each other. Such collaboration is not only encouraged for the sake of effective care in Australian health policy (2), but also aligned with the principles of PCC and evidence-based medicine in terms of being respectful and considerate of patient preferences, needs and values (80).

### **9.5.3 Policymakers and health systems**

Finally, this thesis presents findings of significance to policymakers and the health systems they seek to influence. Foremost is the apparent value CM practitioners can contribute to reducing the burden on health systems created by increasing rates of chronic condition diagnoses and multimorbidity through person-centred and preventive



care that aligns with national and international policy. The National Strategic Framework for Chronic Conditions holds the objective of providing “*efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life*” and describes the success of this objective as measurable when “*Australians with chronic conditions receive coordinated, person-centred and appropriate care*” (2). The findings of this thesis offer insight to policymakers regarding the integral role of CM practitioners in providing PCC and possibly supporting quality of life for many Australians with chronic conditions, highlighting the potential utility of CM practitioner services in achieving the objectives of the Framework. Given this evidence, the onus then falls within the purview and responsibility of the Australian government to further explore the contributions and value of CM practitioners in caring for this patient group and, where appropriate, to develop infrastructure and processes for patients and providers to more effectively coordinate such care. Further to this, the findings of this thesis highlight the need for CM practitioner services to be included in the development of policy and health care environments conducive to appropriate integration of care and collaborative partnerships between care providers.

## **9.6 LIMITATIONS**

While this thesis provides valuable and novel insight into the importance of the role played by CM practitioners for individuals with chronic conditions in Australia, the findings must be considered within the context of certain limitations. Firstly, the temporal nature of cross-sectional studies limits the ability to extrapolate findings to conclusions regarding causation. While the correlations and associations identified in our analyses may be speculated upon as to causative factors for the sake of informing future research, it is important to interpret the findings with mind to the limits of correlation and not to draw conclusions about which factors have caused the phenomena identified in the results. Care has been taken in the presentation of results and associated discussions throughout this thesis to ensure associations are framed appropriately and any speculative points of exploration are explicitly defined as such in order not to mislead the reader. In addition, while this thesis explored aspects of care such as PCC and disclosure communications and consultation-related outcomes, it was not within the scope of this thesis to examine clinical or health outcomes. It has been demonstrated that CM practitioners are attending to PCC factors of care, and existing literature demonstrates correlations between PCC and health outcomes (84-87). However, further research is required to determine whether the PCC identified in

this thesis as characteristic of CM consultation translates to treatment-related outcomes impacting chronic conditions or the lives of patients.

There are potential sampling biases present in the datasets used in this thesis. The Phase One CAMUHLD survey recruited participants through an online research company database, which can create difficulties in assessing the representativeness of a sample and in calculating a true response rate. This is due to a number of factors associated with online research, such as the potential that database membership may appeal to people with certain unknown characteristics, or that certain groups within the target population may not be internet users (371). However, attempts were made to ameliorate this limitation with a stratified sampling method, applying quotas for participants from each demographic representing the national population (as outlined in section 3.2.1). The benefits of online recruitment also allowed achievement of a sizeable sample, strengthening the representativeness of the sample and validity of statistical analyses. Some members of research company databases may also be users who participate in many surveys and are thus vulnerable to survey fatigue (372). This can affect the validity of responses, particularly to items which appear later in the survey, such as the CMDI and CONMED-DI disclosure indices did in the CAMUHLD survey. However, the alignment of responses regarding reasons for disclosure and non-disclosure seen across both the Phase One and Phase Two datasets would suggest that survey fatigue did not impact responses to the CMDI or CONMED-DI in the CAMUHLD survey. Limitations introduced by the employment of an online survey method may have been offset to some degree by the Phase Two PECMC survey using a face-to-face recruitment method.

Potential sampling issues in the Phase Two PECMC survey include those related to random error, as the convenience sampling method and sample size did not allow for assessment of the sample representativeness of the target population. Attempts were made to reduce the risk of such error by directing the recruiting CM practitioners to invite consecutive patients and by selecting CM practitioners on the basis of their clinic location to ensure a wide geographical spread. For each profession, an attempt was made to include at least one practitioner from each of the larger Australian states and at least one practitioner from any of the smaller states. While it was not possible to achieve this for every CM profession, a balance was successfully achieved across the professions collectively. Additionally, the response rate for the PECMC survey was lower than usual acceptability thresholds for survey research (373) and was likely affected by the extra step requiring participants to mail the survey back to the research team. Nonetheless, this extra step was essential to avoid social desirability bias and

perceived coercion from the CM practitioner by allowing respondents to self-administer the survey away from the clinical environment. This approach resulted in a smaller sample size than was desired yet allowed validity and integrity of the data to be prioritised. Both the Phase One and Phase Two datasets may have been affected by self-selection bias whereby individuals with particular unknown traits may have been less likely to participate, as participation was voluntary for both phases.

In seeking to define the role of CM practitioner services for those with chronic conditions, it was necessary to draw comparisons with the care experienced in conventional medicine consultations. For PCC measures, this was done through the interdependent PCCS, PPSS and Empowerment scale measures, which are designed for CM settings but have not been validated in conventional medicine settings. Thus, there may be some limitation to the validity of comparisons made using these measures between patient experiences of care in consultation with CM practitioners and medical doctors. However, this limitation was offset by the use of the PACIC measure, which was designed for conventional primary care settings and has been validated in both conventional and CM environments, as outlined in section 3.3.2.3. The consistency of results across all measures pertaining to PCC adds further weight to the validity of the associated findings.

## **9.7 FUTURE DIRECTIONS IN RESEARCH**

The findings presented in this thesis provide new information to the growing field of health services research in CM and novel perspectives to chronic illness care in Australia. In doing so, this thesis also identifies related areas of importance where research is lacking. These deficits require research examining both clinical factors and service utilisation factors regarding the role of CM practitioner services in chronic illness care.

### **9.7.1 PCC in CM for quality of life outcomes**

While this thesis focuses on the CM consultation experience, there is a need for research examining outcomes beyond the consultation itself. Studies exploring whether the PCC received during CM consultation translates to quality of life outcomes in chronic conditions would provide further evidence regarding the function and utility of PCC. This would assist policymakers and health system managers in determining how care should be structured to most effectively and efficiently meet the needs of chronic illness patients beyond direct treatment of pathology. It would also assist CM

practitioners in tailoring their care to patients with complex quality of life needs, and patients themselves would benefit from identification of the services which might best suit their individual quality of life needs.

### **9.7.2 Patient education and preventive care in CM clinical practice**

Studies examining the application of patient education in CM clinical practice could help determine the capacity of CM practitioners to contribute to building self-efficacy and health literacy in those with chronic conditions. Such studies should explore the extent of patient education occurring in CM clinical practice for individuals with chronic conditions and whether it translates to enhanced health literacy, improved self-management practices and/or a greater sense of patient empowerment. Research in this area could also assess whether patient education and preventive care as provided by CM practitioners results in reduced risk factors or improved risk management for health factors related to chronic conditions. Particular value would be seen in applying such research to patient populations with chronic conditions currently known to be contributing substantial burden to public health systems, such as those recognised by the Australian Government as National Health Priority Areas (cancer, asthma, arthritis and other musculoskeletal diseases, cardiovascular diseases, mental health and diabetes) (6).

### **9.7.3 PCC in CM for clinical and health outcomes**

Pragmatic studies assessing the combined aspects of PCC and therapeutic treatments on clinical and health outcomes in chronic conditions would assist in identifying the extent of the therapeutic value of CM practitioner services for this patient population. Assessment of the impact of the consultation combined with the treatments and interventions used by CM practitioners should be conducted in naturalistic observational settings to assess the true effects of CM practice on disease processes, clinical markers and symptom management. Research of this nature could also investigate associations between specific chronic condition diagnoses and the utilisation of specific CM professions as a means of exploring potential condition-related benefits resulting from consultation with particular types of CM practitioners.

### **9.7.4 Integrative health care research**

This thesis has suggested potential benefits to patient care through the integration of CM practitioner services with conventional medical services to enhance patient accessibility to the care required for optimal management of chronic conditions. There is a pressing need for research to examine this type of integrative health care from a

multitude of perspectives. An exploration of risks and risk management associated with concomitant use of multiple forms of treatment is required for both direct and indirect risks, through both experimental and observational research. Identification of the types of CM practitioner services suitable for integration with conventional chronic illness care should focus on which professions are best positioned to address unmet needs and fill existing gaps in care. Studies assessing the potential benefits of integrative care should examine both clinical/health outcomes and outcomes regarding patient experience through a person-centred lens.

There is also a need for health services research examining the infrastructure of integrative care to identify the most effective and efficient processes for navigating the complexities of chronic conditions. This should include exploration of processes regarding collaboration and communication between providers to address the current limitations inherent to patients' self-coordination of care. In addition, research assessing the economic aspects of integrative care is essential to ensure any associated financial cost to patients or public health systems is acceptable and does not outweigh potential benefits. These types of research would be valuable for informing policy development and health care processes with the ultimate goal of providing optimised care well-tailored to the needs of the growing population of individuals with chronic conditions in Australia and around the world.

### **9.7.5 Influence of gender dynamics on patient-practitioner communication and patient experience of PCC**

The analyses presented in this thesis considered patient gender as a potentially influential factor in patient behaviours and experiences, drawing comparisons, identifying associations, and examining patient gender as a potential predictor for outcomes of interest. However, an examination of gender dynamics between patients and providers was beyond the scope of this thesis as the gender of health care providers was not recorded during data collection. Existing literature suggests the dynamics created by the interaction between the patient's gender and provider's gender may influence factors such as clinical communication, consultation length, power dynamics and the agenda that patients bring to the consultation (374). It is therefore reasonable to assert that these gender dynamics may play a role in outcomes of patient disclosure and perceptions of PCC. The impact and importance of gender dynamics in CM is of particular interest due to the field being represented predominantly by female practitioners (375). This is an area of research worthy of focused attention and detailed analysis in future studies.

## 10. CONCLUSION

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This thesis presents an examination of the experience of patients with chronic conditions regarding consultation with CM practitioners. The examination is guided by a focus upon PCC and explores patient-provider communication regarding the variety of treatments used by patients. The project also draws comparisons between CM and conventional medical settings to better understand the role of the CM consultation within the wider context of chronic illness care. The study was conducted through a health services research framework, consequently producing several findings directly relevant to contemporary health care practice and policy regarding provision of health care for individuals with chronic conditions.

Firstly, this study identified that consultation with CM practitioners is prevalent amongst those with chronic conditions and that such consultation may itself be associated with chronic condition status. Following from this finding, and to address Research Objective 1, the characteristics of those with chronic conditions who consult CM practitioners are described. Most notable among the identified characteristics are socio-demographic factors relating to social determinants of health. Those with chronic conditions who consult CM practitioners are also likely to report multimorbidity, having complex conditions which are difficult to treat as well as compounding impacts of their health status on daily life function.

In response to Research Objective 2, correlations are noted between the type of CM profession consulted and socio-demographic factors, as well as the category of chronic condition diagnosis reported by participants. It appears that the consultations with different CM professions may relate to differences in social and economic circumstances. While some nuance is observed between those consulting with different CM professions, motivations for seeking these consultations are fairly consistent, predominantly relating to a desire for improved wellbeing and compassionate support from providers, alongside direct treatment of chronic conditions. Use of CM practitioner services typically involves continuity of care and occurs alongside utilisation of conventional medical services.

Patient perceptions of PCC for those with chronic conditions are consistently high in CM consultations and appear to be characteristic of CM clinical approaches. While this is true of all the CM professions included in this project, the experience of PCC is notably higher for those consulting naturopaths. These findings respond directly to

Research Objective 3. Patient reports of PCC are typically higher in CM consultations when compared to consultations in conventional medical settings for chronic illness care (Research Objective 4).

The communication behaviours of those with chronic conditions surrounding disclosure of conventional medicine use to CM practitioners (Research Objective 5) and disclosure of CM use to conventional medical providers (Research Objective 6) are complex. The different rates of disclosure reported by the two samples used in this thesis preclude conclusions being drawn regarding the extent of disclosure. However, reasons for disclosing and not disclosing appear to be consistent. Patients with chronic conditions disclose their use of other treatments to both CM practitioners and medical doctors primarily because they want their health status to be fully understood by their provider, and they fail to disclose primarily due to their provider not asking them about other treatments being used. In addition, higher rates of disclosure in both CM and conventional medical settings are correlated with stronger patient perceptions of PCC.

The significance of the findings of this thesis relate directly to patient care for those with chronic conditions and to associated public health policy by emphasising the potential for CM practitioner services to address unmet needs in chronic illness care. This thesis demonstrates that individuals with chronic conditions in Australia not only seek and value consultation with CM practitioners – they also experience PCC in CM consultation that reflects the need for PCC outlined in public health policy as integral to effective management of chronic conditions. This thesis also indicates the potential utility of PCC in improving patient-provider communication and coordination of care between CM and conventional medical settings.

This thesis provides a foundation for promising future directions in related research investigation. The nuance in patient behaviours and experiences dependent on factors such as the type of chronic condition diagnosis or CM profession consulted opens interesting lines of inquiry around how care can be best tailored to specific patient populations. Identification of the characteristic PCC in CM consultation encourages examination of the under-utilised potential of CM practitioner services in chronic illness care. This thesis provides compelling insight into the need for Australian health care provision and public health policy to better align with the needs and desires of individuals with chronic conditions to access, coordinate and integrate CM practitioner services within the wider scope of their care.

## 11. APPENDICES

### APPENDIX 2.1 PUBLISHED MANUSCRIPT ASSOCIATED WITH REVIEW REPORTED IN CHAPTER 2, SECTION 2.3

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# SCIENTIFIC REPORTS

## OPEN Disclosure of complementary medicine use to medical providers: a systematic review and meta-analysis

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H. Foley<sup>1</sup>, A. Steel<sup>1</sup>, H. Cramer<sup>1,2</sup>, J. Wardle<sup>1</sup> & J. Adams<sup>1</sup>

Concomitant complementary medicine (CM) and conventional medicine use is frequent and carries potential risks. Yet, CM users frequently neglect to disclose CM use to medical providers. Our systematic review examines rates of and reasons for CM use disclosure to medical providers. Observational studies published 2003–2016 were searched (AMED, CINAHL, MEDLINE, PsycINFO). Eighty-six papers reporting disclosure rates and/or reasons for disclosure/non-disclosure of CM use to medical providers were reviewed. Fourteen were selected for meta-analysis of disclosure rates of biologically-based CM. Overall disclosure rates varied (7–80%). Meta-analysis revealed a 33% disclosure rate (95%CI: 24% to 43%) for biologically-based CM. Reasons for non-disclosure included lack of inquiry from medical providers, fear of provider disapproval, perception of disclosure as unimportant, belief providers lacked CM knowledge, lacking time, and belief CM was safe. Reasons for disclosure included inquiry from medical providers, belief providers would support CM use, belief disclosure was important for safety, and belief providers would give advice about CM. Disclosure appears to be influenced by the nature of patient-provider communication. However, inconsistent definitions of CM and lack of a standard measure for disclosure created substantial heterogeneity between studies. Disclosure of CM use to medical providers must be encouraged for safe, effective patient care.

Health care seeking invariably involves choices regarding the use of what can often be many competing health care services, treatments and providers from both within and beyond the public health care system. This level of individual choice in health seeking is increasingly recognised with person-centred care being given predilection as a favourable model of care provision in public health<sup>1,2</sup>, situating individuals as active participants at the centre of their health management. Patient autonomy and preference are important features of person-centred care<sup>2</sup> to be considered by medical providers alongside safety and treatment outcomes in their patient management.

Amidst this context, complementary medicine (CM) - a broad, varied field of health care practices and products customarily excluded from conventional medical practice and dominant health care systems<sup>3</sup> - is often the focus of relatively hidden patient health seeking yet is making its presence felt in primary care, chronic disease management and other areas<sup>4</sup>. Despite appreciable gaps in evidence of effectiveness<sup>5</sup>, CM use remains prevalent amongst the general population<sup>6</sup>. While there is controversy amongst medical providers around the role and value of CM<sup>7</sup>, the vast majority of CM use is concurrent to conventional medicine<sup>8</sup> with CM users visiting a GP more frequently than non-CM users<sup>9</sup>.

Serious adverse effects and harm from CM appear relatively rare but substantial associated direct and indirect risks remain<sup>10,11</sup>, particularly regarding ingestive biologically-based CM (such as herbal medicines or supplements)<sup>12–14</sup>, which may be obtained from unreliable sources, self-prescribed or consumed without professional supervision<sup>11,15</sup>. Exacerbating such risks is an absence of both awareness of concurrent CM and conventional medicine use, and of procedures ensuring appropriate oversight of concurrent use<sup>11</sup>. Furthermore, patients often approach CM as inherently safe and may not perceive a need to communicate their CM use to medical providers<sup>16,17</sup>. Addressing the risks associated with concurrent use is the responsibility of both patients and their medical providers<sup>18</sup>, and arguably essential for general practitioners in their capacity as primary care gatekeepers<sup>19</sup>.

A previous review of the literature pertaining to CM use disclosure to medical providers published in 2004 identified twelve papers published between 1997–2002 reporting a CM disclosure rate of 23–90% alongside key factors - patient concern about possible negative response from their medical provider, patient perception that

<sup>1</sup>Faculty of Health, University of Technology Sydney, Ultimo, Australia. <sup>2</sup>Department of Internal and Integrative Medicine, Kliniken Essen-Mitte, Faculty of Medicine, University of Duisburg-Essen, Essen, Germany. Correspondence and requests for materials should be addressed to H.F. (email: [ho.pe.m.foley@student.uts.edu.au](mailto:ho.pe.m.foley@student.uts.edu.au))



the medical provider was not sufficiently knowledgeable in CM and therefore unable to contribute useful information, and the absence of medical provider inquiry about the patient's CM use – fuelling non-disclosure<sup>30</sup>. Disclosure has been increasingly identified as a central challenge facing patient management amidst concurrent use over the last 13 years<sup>21,22</sup> but no systematic review or meta-analysis has been conducted on this topic over this recent period.

In direct response, this paper provides an update to the previous review, assessing research findings regarding CM use disclosure to medical providers since 2003. Our review employs a qualitative synthesis to explore disclosure rates, patient attitudes to disclosure, reasons for disclosing and not disclosing, and the role of patient-provider communication in disclosure. In addition, to gain further insight into the extent of this important health services issue across settings, we undertook a meta-analysis of disclosure rates among patients using ingestive biologically-based CM.

## Methods

A review protocol was developed in accordance with the PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist<sup>31</sup> and MOOSE (Meta-analysis of Observational Studies in Epidemiology) guidelines (see Supplementary Methods S1)<sup>32</sup>. We developed the protocol for the systematic review before initiating the literature search. The protocol was not registered on a systematic review protocol database. The strategy for the meta-analysis was developed after all articles had been selected for the systematic review based upon the trend we observed in the rates of disclosure among individuals using biologically-based CM products. Prior to initiating the meta-analysis the protocol was modified to define the statistical methods we would employ for the quantitative synthesis. The final manuscript was prepared in accordance with AMSTAR guidelines<sup>33</sup> where appropriate with respect to the observational nature of the review aim.

**Review aim.** This review aims to describe the prevalence and characteristics of disclosure of CM use to medical providers.

**Search strategy.** The search strategy was informed by the review published by Robinson & McGrail<sup>20</sup>. A search was conducted on 13–14 February 2017 on the EBSCOhost platform of the following databases: AMED, CINAHL, MEDLINE, and PsycINFO. Three search strings were combined to identify studies which assessed the use of CM, patient-provider communication, and conventional medicine clinical settings. CM search terms were chosen on the basis of CM modalities identified as common in use among the general population in recent literature<sup>34</sup>. Truncation symbols were applied where appropriate to capture related terms. The full search string was as follows: S1 (*complementary medicine OR complementary therap\* OR alternative medicine OR alternative therap\* OR natural medicine OR natural therap\* OR acupunctur\* OR aromatherap\* OR ayurved\* OR chiropract\* OR herbal\* OR phytotherap\* OR homeopath\* OR hypnosis OR hypnotherap\* OR massage OR naturopath\* OR nutrition\* OR diet therap\* OR vitamin therap\* OR supplement OR osteopath\* OR reflexology\* OR traditional Chinese medicine OR yoga*) AND S2 (*disclos\* OR communicat\* OR patient use OR reasons for use OR discuss\**) AND S3 (*medical practi\* OR general practi\* OR health care provider OR primary care provider OR physician*). The full search strategy is outlined in Table 1.

In order to provide an update on the review by Robinson & McGrail<sup>20</sup>, a date range of January 2003 to December 2016 was set. The reference and bibliographic lists of all studies included in the review were searched to minimise the likelihood of missed citations. In addition, any systematic reviews identified during the literature search which presented data on topics related to the primary research aim were also searched manually. The authors contributed their own content expertise in clinical practice, health services research and primary care to ensure important known articles were not overlooked.

**Selection criteria.** Our review included cross-sectional data from observational studies as this research design was deemed the most appropriate for determining prevalence of health behaviours, determinants and outcomes<sup>35</sup>. All observational study designs constituting original, peer-reviewed research were considered for the qualitative synthesis if they reported on rates of, or reasons for, disclosure/non-disclosure of CM use to conventional medicine providers by a broad range of members from the general population. CM use was defined as the use of any practice or product falling outside of those considered part of conventional medicine<sup>36</sup>, whether administered as self-treatment or by a CM practitioner. We excluded experimental study designs, which may have impacted on natural communication patterns between patients and providers, alongside studies assessing specific populations which could not reasonably be considered to represent a broad range of individuals (e.g. disease-specific populations). Studies were not excluded on the basis of language.

During selection of studies for meta-analysis, additional criteria were applied with respect to homogeneity, in order to ensure the central estimate of disclosure frequency would provide external validity. This additional criteria required that participants were adults, the study reported a true and well-defined rate of disclosure occurring within the previous twelve months, and involved participants who used biologically-based CM (herbs/plant-based medicines, vitamins, minerals and other oral supplements). Of those papers reporting studies sharing a common data source (e.g. if multiple papers reported on data from the same survey study), we included only one of those publications in order not to artificially inflate our sample size. In such cases, the risk of bias was evaluated for all such publications and only included that publication deemed to have the lowest risk of bias.

**Study selection.** Citations were exported into EndNote X8 (Clarivate Analytics 2017) reference management software for assessment. Following removal of duplicates, the initial citations were screened against inclusion/exclusion criteria by title and abstract. Review and commentary articles were set aside for a manual search of their included studies. Remaining citations were screened by full-text perusal and those found to adhere to all selection criteria were selected for review. The reference lists of the selected studies were manually searched for

Protocol title	Disclosure of complementary medicine use to medical providers: An update and systematic review	
Date	Jan 2003–Dec 2016	
Database Platform	Search String	Expanders
AMED EESCOhost	S1 (complementary medicine OR complementary therap* OR alternative medicine OR alternative therap* OR natural medicine OR natural therap* OR acupuncture* OR aromatherap* OR ayurved* OR chiropract* OR herbal* OR phytotherap* OR homeopath* OR hypnosis OR hypnotherap* OR massage OR naturopath* OR nutrition* OR diet therap* OR vitamin therapy OR supplement OR osteopath* OR reflexology* OR traditional Chinese medicine OR yoga) AND S2 (disclos* OR communi-c* OR patient use OR reasons for use OR discusg*) AND S3 (medical practi* OR general practic* OR health care provider OR primary care provider OR physician)	Apply related words, Apply equivalent subjects.
CINAHL EESCOhost		
MEDLINE with full text EESCOhost		
PsycINFO EESCOhost		

**Table 1.** Search strategy.

additional articles. Full review of all eligible citations was conducted by the lead author (HF). A selected sample of eligible studies (10%) were reviewed at each stage of screening by a second reviewer (AS), as were any studies under question, and discrepancies were addressed through discussion until consensus was reached. The justification for excluding articles following screening the full text was recorded.

**Data extraction and risk of bias assessment.** Papers selected for review were re-read thoroughly with data extracted into pre-prepared tables outlining study characteristics, outcomes of interest (disclosure/non-disclosure rates and reasons) and parameters of those outcomes (CM type disclosed, how disclosure was defined). Further to this, papers were read in full-text once more to identify other notable findings relating to disclosure, which were categorised and tabulated heuristically. The template for data extraction was drafted during the pre-review protocol development phase with agreement from all authors. Data extraction was conducted by one reviewer (HF) with a selected sample (10% alongside any data under question) checked by another reviewer (AS). Any discrepancies were addressed through discussion until consensus was reached.

The resulting tables were examined to identify studies meeting the criteria for meta-analysis. These identified studies were subjected to risk of bias assessment using Hoy *et al.*'s tool for prevalence studies, which assesses ten items across four domains (sample selection, non-response bias, measurement bias, analysis bias) alongside a summary score<sup>29</sup>. Studies identified as high risk of bias were excluded from the final selection for meta-analysis. Risk of bias was considered high if four or more items were not adequately addressed, if the first three items indicated an unacceptable level of sampling bias, or if item ten was not adequately addressed as this item affected calculation of disclosure rates.

**Data synthesis and statistical analysis.** Due to the expected heterogeneity of each study's parameters of disclosure, no average disclosure rate was calculated for the full review; instead a meta-analysis was conducted on those studies demonstrating sufficient homogeneity in study design and a low risk of bias. The principal summary measure used for meta-analysis was disclosure rate of CM use to medical providers. Meta-analysis was conducted using events (number of disclosers) and subset of sample size (number of CM users) to determine event rates of disclosure. Where studies reported disclosure rates only as percentages, events were calculated using figures for the number of participants who responded to the disclosure question. Where these figures were unavailable, the study was considered to fail to address item 10 on the risk of bias assessment tool and was excluded from meta-analysis.

Statistical heterogeneity between studies was explored using  $I^2$  and chi-square statistics.  $I^2$  values greater than 25%, greater than 50%, and greater than 75% indicate moderate, substantial, and considerable heterogeneity, respectively<sup>30</sup>. Due to the relatively low power of this test, a  $P$  value of 0.10 or less from the chi-square test was regarded to indicate significant heterogeneity<sup>30</sup>. Analysis was completed using Comprehensive Meta-Analysis V3 software (Biostat Inc. 2017).

## Results

From an initial 5,071 non-duplicate citations, eighty-six studies were selected for review. The reasons for exclusion at full-text screening are provided in Table 2.

**Risk of bias assessment.** Twenty studies met the initial inclusion criteria for meta-analysis and were subjected to assessment of reporting quality and risk of bias using Hoy *et al.*'s tool for prevalence studies<sup>29</sup>. Collectively, studies performed poorly across most domains relating to external validity, either due to poor methodological conduct or inadequate reporting on methods relating to target population (item 1), random selection (item 3) and response bias (item 4). However, sampling frame representation was well conducted and reported (item 2). Domains relating to internal validity were addressed well, with the exception of instrument validity (item 7).

Of the twenty studies, four were found to exhibit a high risk of bias due to poorly defined parameters for disclosure rate definition or analysis<sup>31–34</sup> and were consequently excluded from meta-analysis. The remaining sixty-six studies which did not meet the initial inclusion criteria for meta-analysis represented a heterogeneous range of study designs in which disclosure was not reported as a primary outcome, but as a secondary outcome or qualitative finding, and thus the resulting data underwent narrative synthesis without risk of bias appraisal. Table 3 displays full details of risk of bias assessment.

First Author	Year	Title	Reason for Exclusion
Anbari <sup>100</sup>	2015	Evaluation of Trends in the Use of Complementary and Alternative Medicine in Health Centers in Khorramabad (West of Iran)	Did not report on disclosure of CM use
Avog <sup>104</sup>	2008	The effects of health status on the utilization of complementary and alternative medicine	Did not report on disclosure of CM use
Ben-Arye <sup>101</sup>	2014	Asking patients the right questions about herbal and dietary supplements: Cross cultural perspectives	Experimental study, used intervention to deliberately increase disclosure rates
Desai <sup>105</sup>	2015	Health care use amongst online buyers of medications and vitamins	Did not report on disclosure of CM use
Emmert <sup>106</sup>	2012	Consumers' experiences and values in conventional and alternative medicine paradigms: a problem detection study (PDS)	Did not report on disclosure of CM use
Featherstone <sup>107</sup>	2003	Characteristics associated with reported CAM use in patients attending six GPs practices in the Tayside and Grampian regions of Scotland: a survey	Did not report on disclosure of CM use
Harnack <sup>108</sup>	2003	Results of a population-based survey of adults' attitudes and beliefs about herbal products	Did not report on disclosure of CM use
Hunt <sup>109</sup>	2010	Complementary and alternative medicine use in England: results from a national survey	Did not report on disclosure of CM use
Zhang <sup>102</sup>	2008	Complementary and alternative medicine use among primary care patients in west Texas	Did not report on disclosure of CM use

**Table 2.** Studies excluded at full text appraisal with reasons for exclusion.

**Study characteristics.** Of the eighty-six studies reviewed, seventy-nine provided quantitative data<sup>31–35,36–110</sup>, three qualitative data<sup>111–113</sup>, and four mixed-method data<sup>34,114–116</sup> relevant to CM disclosure rates and/or reasons for disclosure/non-disclosure (selection process summarised in Fig. 1). Nine studies were excluded following review of the full text. A vast majority of the selected studies ( $n = 83$ ) used a cross-sectional survey design<sup>31,32,34–130,114–116</sup>, two employed a multistage qualitative approach<sup>111,112</sup>, and one an ethnographic interview design<sup>113</sup>. While the final selection of research spanned twenty countries, just under half of the studies ( $n = 40$ ) were conducted in the United States (US)<sup>31–35,37,40,41,43–54,56,57,60,76,79,80,87–91,94,100,101,105,107,108,112–114</sup>. Settings were diverse with data collection occurring primarily in general practice or hospital clinics<sup>34–38,41,42,55,58,61–64,66,68,69,74,76–79,81,82,86,87,92,97,98,101,103,106,107,109,111,112,114–116</sup>, face-to-face in participants' households<sup>35,39,46–50,52–54,67,70,72,84,85,88–91,93,94,100,102,104</sup>, or by telephone and/or mail<sup>21,40,45,51,56,57,59,65,73,75,95,96,108,110</sup>. Less common settings included CM clinics<sup>34,42,68</sup>, retail outlets<sup>60,71,99,105</sup>, community meal sites<sup>44,113</sup>, seminars<sup>78,80</sup>, and online platforms<sup>32,83</sup>.

While some samples consisted entirely of CM users<sup>45,50,51,54,83,89,98</sup>, most involved a subset of CM users within a larger sample. Full samples ranged from 35 to 34,525 with an average of 4,144. Amongst those studies reporting figures for the subset of CM users, samples ranged from 28 to 16,784 with an average of 1,268 and a total of 101,417. Participants were predominantly adults with a small number of studies focussed on older adults<sup>44,57,65,94,95,105,108,113,114</sup>, children<sup>65,96,97,98,73,97,100,106,115,116</sup>, adolescents<sup>41,97</sup>, or all age groups<sup>61,99,112</sup>. More than half of the studies included users of various types of CM ( $n = 45$ )<sup>31,33,34,38,41–43,50,51,54,57–59,61–62,65,66,68,72,73,75,76,80–82,85,88,89,90,97,102–113,115,116</sup>, while others were limited to users of specific types of CM such as herbs and/or supplements<sup>32–34,37,44–47,52,53,55,56,60,64,67,69–71,74,77–79,83,85,87,92–95,98–101,108,114</sup>, yoga<sup>40,51</sup>, tai chi<sup>69,90</sup>, mind-body medicine<sup>40</sup>, practitioner-provided CM<sup>79</sup>, or local traditional medicine<sup>84</sup>.

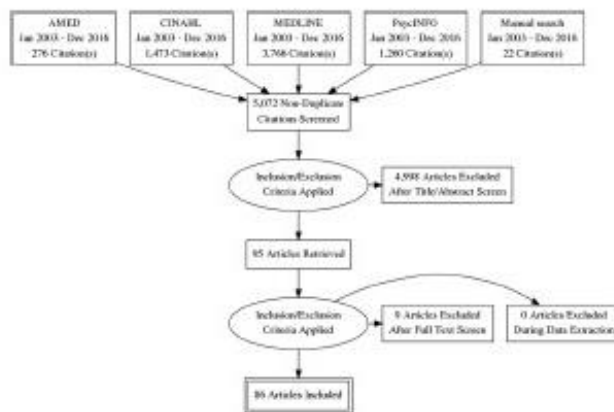
Almost half of the selected studies ( $n = 40$ ) used a convenience sampling method<sup>32,34–37,41–44,55,58,60–64,66,68,69,74,76–82,86,87,92,97,101,103,106,107,109,111,114–116</sup>. However, twenty-two studies used a nationally representative sample<sup>31,39,40,46–54,59,73,85,89–91,94,96,100,110</sup>, while others applied some method of probability randomisation<sup>38,56,65,75,84,88,99</sup>, stratification<sup>73,85,87,97,99,100</sup>, weighting<sup>71,104,113</sup>, or purposiveness<sup>93,98,102,105,112</sup> during sampling. Table 4 provides full details of the study characteristics identified from the reviewed literature.

Following risk of bias assessment, sixteen studies were considered suitable for meta-analysis of CM disclosure rates. Two were excluded from analysis<sup>46,52</sup> on the basis that they used data from an earlier version of the same national survey as reported in another included manuscript<sup>84</sup>. Studies selected for meta-analysis represented a wide geographical spread including North America<sup>35,54,87</sup>, Central America<sup>88</sup>, Continental Europe<sup>80,77,82</sup>, the United Kingdom<sup>79</sup>, the Middle East<sup>36,57,85</sup>, West Africa<sup>84</sup>, and Asia<sup>62,83</sup>. Sample sizes included in the meta-analysis ranged from 35 to 7,493 with an average of 840 and a total of 11,754 CM users. Papers excluded due to a high risk of reporting bias represented an additional 3,222 CM users.

**Prevalence and parameters of disclosure.** Rates of disclosure varied substantially across studies, ranging from 7%<sup>114</sup> to 80%<sup>40</sup>. Studies including biologically-based CM fell within a range of 7%<sup>114</sup> to 77%<sup>44</sup>, while the highest rate of disclosure (80%) was reported by researchers assessing the use of mind-body medicine exclusively<sup>40</sup>. Parameters used for defining and measuring disclosure also varied, with the most common parameters outlined as participant disclosure of their use of CM within the last twelve months to a medical provider ( $n = 30$ )<sup>31–33,36,38,40,45–50,52,54,57,62,65,67,68,70,71,73,81,82,84,86,87,89,95,100,115,116</sup>. Others studies examined participants' disclosure to a medical provider of their current CM use<sup>35,74,77–79,80,98,109,111</sup>, use within the last month<sup>34,53,69,86</sup>, use within the last 24 months<sup>50,51</sup>, had always/usually/sometimes/never disclosed<sup>39,59,60,66,72,110</sup>, had ever discussed their CM use with a conventional provider<sup>37,45,64,75,76</sup>, had partially or fully disclosed their CM use<sup>46,114</sup>, had disclosed when asked<sup>41</sup>, had discussed before use<sup>92</sup>, reported rates of disclosure per episode of use<sup>89</sup>, or how the patient felt about disclosing<sup>80,112</sup>. A number of papers did not explicitly define their parameters for measuring disclosure<sup>42,44,55,58,61,62,96,97,103,104,96,97,99,101–108,113</sup>.

Paper	External Validity				Internal Validity						Summary
	Item 1 Population	Item 2 Sampling frame	Item 3 Sample selection	Item 4 Non-response bias	Item 5 Method of data collection	Item 6 Case definition	Item 7 Instrument validity	Item 8 Mode of data collection	Item 9 Prevalence period	Item 10 Parameter of interest	
Djuv 2013 <sup>71</sup>	N	Y	N	N	Y	Y	N	Y	Y	Y	Moderate
Fath 2015 <sup>72</sup>	Y	Y	Y	Y	Y	Y	Y	N	Y	N	High
Gyast 2015 <sup>74</sup>	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Low
Herron 2003 <sup>75</sup>	N	Y	N	N	Y	Y	N	Y	Y	Y	Moderate
Hori 2008 <sup>76</sup>	N	Y	N	Y	Y	Y	N	Y	Y	Y	Low
Hsu 2016 <sup>77</sup>	N	Y	N	N	Y	Y	N	Y	Y	Y	Moderate
Jou 2016 <sup>78</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Low
Kennedy 2005 <sup>46</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Low
Wu 2011 <sup>72</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Low
McCrea 2011 <sup>72</sup>	N	N	N	N	Y	N	N	Y	Y	Y	High
Mileva-Pecheva 2011 <sup>78</sup>	N	Y	Y	N	Y	Y	N	Y	Y	Y	Moderate
Naja 2015 <sup>79</sup>	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Moderate
Nur 2010 <sup>80</sup>	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Low
Rivera 2007 <sup>81</sup>	N	Y	Y	N	Y	Y	N	Y	Y	N	High
Shamer 2014 <sup>82</sup>	N	Y	N	Y	Y	N	Y	Y	Y	Y	Moderate
Tan 2004 <sup>83</sup>	N	N	Y	N	Y	Y	N	Y	Y	Y	Moderate
Turn 2015 <sup>84</sup>	N	Y	N	N	Y	Y	N	Y	Y	N	High
Thomas 2004 <sup>85</sup>	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Low
Torres-Zeno 2016 <sup>86</sup>	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Low
Vitale 2014 <sup>87</sup>	N	Y	N	N	Y	Y	N	Y	Y	Y	Moderate

**Table 3.** Risk of bias assessment for meta-analysis selection (selected papers in bold). N = criterion not adequately met; Y = criterion adequately met.



**Figure 1.** Literature search and study selection flow chart. Prisma flowchart outlining process of literature search and selection of articles for review.

The outcomes of the meta-analysis of the rate of disclosure of CM use by individuals using biologically-based CM is presented in Fig. 2. The measure of central tendency provided an overall disclosure rate of 33% (95% CI 24.1% to 42.8%,  $I^2 = 98.6\%$ ). Between the fourteen included studies, the lowest reported disclosure rate was 12% and the highest was 59%. Heterogeneity was assessed across the fourteen samples (Q-value 904.955,  $p < 0.001$ ,  $I^2 = 98.563$ ). Although homogeneity was affected by the substantially larger sample size in Jou *et al.*'s 2016 study<sup>78</sup>, the paper was not excluded as it used a strong, internationally recognised dataset with very low risk of bias. The employment of a random effects model accounted for the impact of this study on homogeneity and its inclusion was not found to impact significantly on the measure of consistency within this model.

**Reasons for non-disclosure and disclosure.** Twenty-five studies reported participant reasons for non-disclosure<sup>36,37,42,54–57,59,67,76–79,83–85,90,92,98,103,107,110–113</sup>, and four reported reasons for disclosure of CM use to medical providers<sup>56,111–113</sup>. The most commonly cited reasons patients gave for non-disclosure were fear of the provider's disapproval<sup>36,42,54–56,67,76–79,83–85,90,92,103,107,110–113</sup>, followed by the provider not asking<sup>37,42,54–57,59,67,76–79,83,84,90,98,110–113</sup>, the patient perceiving disclosure as unimportant<sup>42,54–57,58,67,76,79,84,86,90,92,98,106,107,110</sup>, belief the physician would not have relevant knowledge of CM<sup>36,42,54,56,67,76–79,107,113</sup>, lack of time during consultation or forgetting<sup>36,42,54,56,67,76,79,92,105</sup>, belief that CM was safe and would not interfere with conventional treatment<sup>42,76,83,85,111</sup>, the patient not using CM regularly or at the time of consulting with the conventional provider<sup>54,79,83,85</sup>, and previous experiences of a negative response from conventional providers<sup>54,84,96,112</sup>. The most commonly cited reason for disclosure was that the provider asked about CM use<sup>36,111,112</sup>, followed by the patient expecting the provider to be supportive of their CM use<sup>112,113</sup>, believing disclosure was important for safety<sup>36,113</sup>, belief the provider would have relevant knowledge or advice about CM<sup>56</sup>, and belief that disclosing CM use may help other patients with the same condition<sup>56</sup>. Full details of reasons are shown in Table 5.

When participants were asked whether they thought disclosure was important, more than 67% agreed it was<sup>36,62,66,80,110</sup>. This percentage was highest (93%) among participants who were surveyed in CM clinics<sup>66</sup>, which was consistent with other studies reporting higher disclosure rates among users of practitioner-provided CM compared with self-administered CM<sup>36,51,81,89</sup>. Conversely, one study found lower disclosure rates among those using practitioner-provided CM, specifically where participants were consulting a CM practitioner and a medical provider for the same condition<sup>66</sup>.

**Impact of provider response on decisions to disclose.** In a qualitative analysis, Shelley *et al.* found patients' perceptions of how their medical provider might respond to their CM use was an important factor in the decision of whether or not to disclose<sup>12</sup>. A perception of the medical provider as accepting and non-judgemental encouraged disclosure while fear of a negative response from their medical provider led to non-disclosure<sup>12</sup>. One paper reported 59% of participants wanted to discuss CM with their medical provider (despite only 49% having done so), and 37% of non-disclosers wished it were easier to have such discussions<sup>25</sup>. In another study, the percentage of participants who wanted to discuss CM with their provider represented a substantial majority at 82% (despite only 60% having done so)<sup>61</sup>.

When the actual response of the provider to disclosure of CM use was explored by researchers, negative or discouraging responses were reported by a minority of respondents representing less than 20% of disclosers<sup>65,71,77,85,106</sup>, or were not reported at all<sup>111</sup>. However, in five papers positive or encouraging responses to disclosure of CM use by a medical doctor were reported by a substantial proportion of respondents representing 32–91% of disclosers<sup>65,69,77,79,85,106</sup>. Neutral responses from medical providers were also common, reported by 8–32% of disclosers in three studies<sup>77,85,111</sup>.

## Discussion

This review and meta-analysis provides a detailed overview and update of CM use disclosure to medical providers. Regarding the update to the 2004 paper<sup>28</sup> afforded by this review, a substantially larger volume of literature reporting on CM disclosure was identified in our search, suggesting an increase in researcher interest in this aspect of patient-provider communication. Our analysis reveals little discernible improvement to disclosure rates over the last thirteen years. Consistent with the findings of the previous review, we found reports of disclosure vary widely. However, our additional meta-analysis on selected papers shows approximately two in three CM users do not disclose their CM use to medical providers. In view of the potential risks associated with unmanaged concomitant use of conventional and complementary medicine<sup>11,14</sup>, the value of increasing this rate of disclosure is accentuated.

Furthermore, our narrative review identified three distinct yet interrelated findings relating to patient-practitioner communication. Firstly, disclosure of CM use to medical providers is influenced by the nature of providers' communication style; secondly, perceived provider knowledge of CM use is a barrier to discussions of CM use in clinical consultation; and thirdly, such discussions and subsequent disclosure of CM use may be facilitated by direct inquiry about CM use by providers. We consider this in the context of contemporary person-centred health care models.

Communication style was a repeated factor affecting disclosure rates in this review; disclosure of CM use was found to be encouraged by patient perceptions of acceptance and non-judgement from medical providers<sup>12</sup>, and inhibited by patient fears or previous experiences of discouraging responses from providers<sup>36,42,54–56,67,76–79,83–85,90,92,103,107,110–113</sup>. In practice, negative responses from medical providers appear to represent a deviation from the more commonly positive or neutral responses noted by participants of the reviewed studies as well as others<sup>117,118</sup>. However, such fears and subsequent non-disclosure of CM use could potentially be addressed by medical providers through communication with patients about CM in a direct, supportive, non-judgemental manner to build trust and communicative success<sup>119</sup>.

The reviewed literature shows patient perceptions of medical providers as lacking relevant knowledge about CM is a notable reason for non-disclosure. While examination of provider attitudes was not within the scope of this review, three reviewed papers included an assessment of medical providers' attitudes toward discussing CM and identified lack of CM knowledge as a cause of providers' reluctance to initiate such discussions<sup>76,111,112</sup>. Providers' own perceived lack of CM knowledge as an obstacle to patient-provider CM communication also reflects other research examining provider perspectives on CM<sup>120,121</sup>. While the inclusion of CM in medical school curricula does occur in some countries (e.g. the US<sup>122</sup>, Canada<sup>123</sup>, UK<sup>124</sup>, Germany<sup>125</sup>, and Switzerland<sup>126</sup>), and is of interest to medical students<sup>125,128</sup>, this level of CM learning appears insufficient to equip medical providers with the confidence to address patient CM queries<sup>120,121</sup>. Furthermore, the depth and scope of CM knowledge to be realistically encouraged amongst medical providers has been contested<sup>124,125</sup> and may be best facilitated on a

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source	
Herron <sup>38</sup>	2003	Cross-sectional survey	5 teaching physician offices	United States	Adult patients of rural physician clinics	176 (110)	49%	Various CM	Not reported.	
Najm <sup>39</sup>	2003	Cross-sectional survey	Senior centres and shopping malls	United States	Community-dwelling older adults in ethnically diverse neighbourhoods, age $\geq 65$	525 (251)	38%	Various CM	Archstone Foundation and Irvine Health Foundation.	
Stevenson <sup>41</sup>	2003	Semi-structured interview	20 general practice clinics and homes of clinic patients	England	Patients of participating clinics, age $\geq 16$	35 (28)	NR	Various CM	UK Department of Health, Sir Slegman Warburg's voluntary settlement.	
Carter <sup>42</sup>	2004	Cross-sectional survey	Self-administered, recruited by magazine and website	Britain	British adults aged $\geq 50$	271 (NR)	33%	Herbs and nutrients	No funding received.	
Gleeson <sup>43</sup>	2004	Cross-sectional survey	25 primary care clinics	Israel	Patients of HMO clinics	723 (261)	55%	Various CM	Not reported.	
Kuo <sup>47</sup>	2004	Cross-sectional survey	6 Primary care clinics, via SPUR-Nel PBRN	United States	Adult patients visiting clinics for routine, non-acute care, age $\geq 18$	322 (116)	31–67%	Herbs	Agency for Healthcare Research and Quality, Bureau of Health Professions.	
Rolnick <sup>48</sup>	2004	Cross-sectional survey	Emergency department of teaching hospital	United States	Adult patients who were medically stable, age $\geq 18$	174 (82)	69%	Various CM	Mercy Foundation	
Tan <sup>49</sup>	2004	Cross-sectional survey	2 University hospitals, internal & surgery polyclinics	Turkey	Adult patients age $\geq 18$ , residents of Eastern Turkey	714 (499)	15%	Various CM	Not reported.	
Thomas <sup>46</sup>	2004	Cross-sectional survey	Omni-bus survey, conducted in households	England, Scotland, Wales	Adults living in UK, age $\geq 15$	1,794 (179)	37%	Practitioner-provided CM	UK Department of Health.	
Wolko <sup>45</sup>	2004	Cross-sectional survey	Telephone, random digit dialling	United States	English-speaking adult residents	2,055 (397)	80% <sup>2</sup>	Mind-body therapies	National Institutes of Health.	
Braun <sup>41</sup>	2005	Cross-sectional survey	Urban adolescent ambulatory clinic	United States	Adolescents attending ambulatory clinic, age 12–18	401 (273)	14%	Various CM	National Institutes of Health, Maternal and Child Health Bureau.	
Basse <sup>45</sup>	2005	Cross-sectional survey	Naturopathic college clinic	Canada	Patients of clinic, age $\geq 18$	174 (161)	59%	Natural products	Canadian Institutes of Health.	
Kim <sup>45</sup>	2005	Cross-sectional survey	4 Emergency departments, 2 teaching, 2 community	United States	Emergency department patients age $\geq 18$ , not in acute/ emotional distress	539 (199)	36%	Various CM	Not reported.	
Lim <sup>45</sup>	2005	Cross-sectional survey	Homes of participants	Singapore	Adult citizens and permanent residents, age $\geq 18$	468 (356)	26%	Various CM	Not reported.	
Shahrokh <sup>44</sup>	2005	Cross-sectional survey	Congregate meal sites in 4 counties	United States	Community-dwelling older adults	69 (35)	77%	Herbs and nutrients	Not reported.	
Wheaton <sup>45</sup>	2005	Cross-sectional survey	Computer Assisted Telephone Interview	United States	American adults and their children who used herbs in past 12 months	2,982 (2,982)	34%	Medicinal herbs	Not reported.	
Bruno <sup>48</sup>	2005	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	General population older adults, $\geq 65$	5,860 (NR)	43%	Herbs	Not reported.	
Kennedy <sup>46</sup>	2005	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	General population adults, age $\geq 18$	30,412 (5,787)	33%	Herbs & supplements	No funding received.	
Kennedy <sup>47</sup>	2008	Secondary analysis of data from Kennedy 2005 (above), describes characteristics of disclosers by ethnic sub-group						18–37%		

Continued

First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Birdee <sup>48</sup>	2008	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	Civilian adults, sub-population: yoga users	31,044 (1,593)	25%	Yoga	National Institutes of Health.
Birdee <sup>48</sup>	2009	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	Civilian adults, sub-population: tai chi, qigong users	31,044 (429)	25%	Tai chi & Qigong	National Institutes of Health.
Chao <sup>49</sup>	2008	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	General population adults, age ≥ 18	10,759 (10,759)	39%	Various CM	National Institutes of Health
		Cross-sectional survey	2001 HCQS data set			2,003 (2,003)	66%		
Fath <sup>51</sup>	2013	Cross-sectional survey	2001 HCQS data set	United States	General population adults, age ≥ 18	1,995 (1,995)	71%	Various CM	Not reported.
Wu <sup>52</sup>	2011	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	General population adults, age ≥ 18	30,427 (5,787)	33%	Herbs & supplements	Not reported.
			2007 NHIS All Med Suppl.			22,657 (3,982)	46%		
Gardner <sup>108</sup>	2007	Cross-sectional survey	2002 NHIS All Med Suppl.	United States	General population adults, age ≥ 18	31,044 (5,787)	34%	Herbs	National Institutes of Health
Laditka <sup>53</sup>	2012	Cross-sectional survey	2007 NHIS All Med Suppl.	United States	General population adults, age ≥ 18	22,783 (16,784)	62%	Cognitive health supplements	No funding received.
Shim <sup>46</sup>	2014	Cross-sectional survey	2007 NHIS All Med Suppl.	United States	General population adults, age ≥ 18	7,347 (7,347)	46%	Various CM	Not reported.
Jou <sup>54</sup>	2016	Cross-sectional survey	2012 NHIS All Med Suppl.	United States	General population adults ≥ 18 using both CM & primary care physician	7,495 (7,493)	59%	Various CM	University of Minnesota.
Cincotta <sup>55</sup>	2006	Cross-sectional survey	University Hospital of Wales	Wales	Infants, children and adolescents (or their parent/carer) of any age attending hospital	500 (206)	34%	Various CM	Not reported.
			Royal Children's Hospital	Australia		503 (258)	37%		
MacLennan <sup>56</sup>	2006	Cross-sectional survey	Health Omnibus Survey of South Australian households	Australia	South Australian residents, age ≥ 15	3,015 (1,574)	47%	Various CM	Not reported.
Saw <sup>57</sup>	2006	Cross-sectional survey	Penang Hospital	Malaysia	Adult patients from cardiology, neurology, infectious and nephrology wards, age ≥ 18	250 (106)	9%	Herbal medicine	Not reported.
Shah <sup>58</sup>	2006	Cross-sectional survey	Mail via market research co.	United States	Adult Ohio residents age ≥ 18	210 (100)	11–46%	Herbal	Not reported.
Shiv <sup>59</sup>	2006	Cross-sectional survey	Telephone interview-administered questionnaire	United States	General population adults with over-representation of minorities, age ≥ 18	6,305 (NR)	55–72%	Various CM	National Institutes of Health, National Cancer Institute
Chung <sup>62</sup>	2007	Cross-sectional survey	By mail, random selection by driver's license date of birth	United States	Community-dwelling older adults, age ≥ 65	445 (278)	53%	Various CM	Center for Gerontological Nursing, University of California, University of Minnesota, College of St. Catherine, Minnesota Gerontological Society.
Clemen <sup>60</sup>	2007	Cross-sectional survey	16 randomly selected primary health care facilities	Trinidad	Patients aged ≥ 16 who used herbal remedies	265 (265)	23%	Herbal remedies	Not reported.

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First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Jean <sup>98</sup>	2007	Cross-sectional survey	University-affiliated hospital	French Canada	Children (parents of) attending the hospital as outpatients	114 (61)	47%	Various CM	No funding received.
Rivera <sup>99</sup>	2007	Cross-sectional survey	Households in border cities of El Paso & Ciudad Juarez	United States & Mexico	Residents of border cities, adults.	1,001 (661)	33% (USA) 14% (Mexico)	Herbal products	Paso del Norte Health Foundation.
Xue <sup>96</sup>	2007	Cross-sectional survey	Computer Assisted Telephone Interview, random digit dialling	Australia	Australian adults, age ≥ 18	1,067 (735)	45%*	Various CM	RMIT University, Sydney Institute of Traditional Chinese Medicine, Chiropractor Association of Australia, Australian Acupuncture and Chinese Medicine Association, Australian Research Centre for Complementary and Alternative Medicine.
Zhang <sup>100</sup>	2007	Cross-sectional survey	Computer-assisted telephone interview	Australia	Australian general population adults age ≥ 18, sub-population: older adults age ≥ 65	178 (NR)	60%	Various CM	Not reported.
Alltrak <sup>97</sup>	2008	Cross-sectional survey	Primary health care clinic in Abu Dhabi	United Arab Emirates	United Arab Emirates nationals (citizens) attending clinic for general health care	330 (250)	32%	Herbal medicine	Not reported.
Archer <sup>95</sup>	2008	Cross-sectional survey, pilot study	Urban herb store	United States	Store customers, age ≥ 18	35 (32)	37%	Herbs & supplements	Not reported.
Aydin <sup>99</sup>	2008	Cross-sectional survey, pilot study	Participant households and offices	Turkey	General population adults ≥ 18, representative of local population	873 (484)	26%	Herbal medicine	Not reported.
Cizmajic <sup>97</sup>	2008	Cross-sectional survey	14 primary care practices	Croatia	Patients in primary healthcare, all ages	941 (301)	60%	Various CM	Not reported.
Hori <sup>100</sup>	2008	Cross-sectional survey	General outpatient clinics of Shobetsu Daini Hospital	Japan	Adult outpatients of non-specialist clinics, age ≥ 18	496 (246)	42%	Various CM	Not reported.
Low <sup>99</sup>	2008	Cross-sectional survey	Paediatric clinics and hospitals	Ireland	Children (parents of) attending as outpatients and inpatients	185 (105)	40%	Various CM	Not reported.
Ozluok <sup>98</sup>	2008	Cross-sectional survey	Paediatric outpatient clinics of 3 hospitals	Turkey	Children (parents of) attending paediatric outpatient clinics	600 (339)	51%	Various CM	Not reported.
Robinson <sup>98</sup>	2008	Cross-sectional survey	North West London multi-ethnic hospital	England	Children (parents of) attending general and sub-specialist outpatient clinics	243 (69)	46%	Various CM	No funding received.
Shaked <sup>96</sup>	2008	Cross-sectional survey	Aberdeen Royal Infirmary	Scotland	Patients admitted to general, cardiothoracic and vascular surgery wards, age ≥ 16	430 (196)	40%	Herbal and non-herbal	Not reported.
Levine <sup>95</sup>	2009	Cross-sectional survey	Telephone, randomly selected	Canada	Community dwelling older adult Ontarians, age ≥ 60	1,206 (616)	75%*	Natural health products	Samuel McLaughlin Foundation, Toronto.

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First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Shelley <sup>112</sup>	2009	Multistage qualitative	Low-income serving primary care clinics and community, via RIOS Net PBRN	United States	Patients of participating clinics and members of predominantly Hispanic and Native American communities, all ages	93 (NR)	NR	Various CM	National Center for Complementary and Alternative Medicine
Delgado <sup>98</sup>	2010	Cross-sectional survey	18 pharmacies	Jamaica	Adults and parents/careers or children who were using prescription medicines	365 (288)	18%*	Herbs	International Foundation for Science, University of the West Indies, SuperPlus Food Stores
Mc Kenna <sup>98</sup>	2010	Cross-sectional survey	Urban general practice	Ireland	Adult patients attending urban GP ≥ 18	328 (89)	34%	Various CM	RCSI
Nur <sup>97</sup>	2010	Cross-sectional survey	Households and workplaces	Turkey	Adult Swis residents, age ≥ 18	3,876 (1,518)	38%	Herbs	Not reported.
Shorof <sup>99</sup>	2010	Cross-sectional survey	4 metropolitan hospitals in Adelaide	Australia	Hospitalised adults, age ≥ 18	353 (319)	38–48%	Herbs and other CM	Not reported
Araz <sup>116</sup>	2011	Cross-sectional survey	Outpatient university clinic	Turkey	Children (parents of) and parents, age ≥ 17	268 (193)	32%	Various CM	Not reported.
Ben-Arye <sup>98</sup>	2011	Cross-sectional survey	Conventional & CM clinics	Israel	Children (parents of) and parents, insured	599 (NR)	19%, 61% <sup>†</sup>	Various CM	No funding received.
McCrea <sup>91</sup>	2011	Cross-sectional survey	State university, online	United States	College students of introductory psychology course	305 (89)	25%	Herbs	Not reported.
Mileva-Pecheva <sup>98</sup>	2011	Cross-sectional survey	General practice clinics	Macedonia	Adult outpatients of GP clinics, age ≥ 18	256 (105)	57%	Vitamin & mineral food supplements	Not reported.
Picking <sup>98</sup>	2011	Cross-sectional survey	Households in 3 districts	Jamaica	Adults from urban and rural districts	372 (270)	19%	Herbal medicine	Commonwealth Scholarship Commission, University of the West Indies, Environmental Foundation of Jamaica, Forest Conservation Fund, International Foundation for Science (Sweden).
Alaeddine <sup>91</sup>	2012	Cross-sectional survey	Shopping malls	Lebanon	Adults, age 18–65	480 (293)	55%*	Herbal medicine	Faculty of Medicine, Saint Joseph University
Elotemy <sup>92</sup>	2012	Cross-sectional survey	Households within Riyadh region (city and surrounds)	Saudi Arabia	Residents of Riyadh region, age ≥ 18	518 (438)	51%	Various CM	No funding received.
Kim <sup>98</sup>	2012	Cross-sectional survey	Telephone, list-assisted random-digit dialling	Korea	Children (parents or caregivers of), non-institutionalised, age ≥ 18	2,077 (1,365)	29%	Various CM	Ministry for Health, Welfare & Family Affairs, Korea.
Samuels <sup>94</sup>	2012	Cross-sectional survey	Department of Internal medicine	Israel	Hospitalised internal medicine patients, not under sedation	280 (43)	74%	Non-vitamin, non-mineral supplements	Mirsky Foundation
Thomson <sup>97</sup>	2012	Cross-sectional survey	2010 QSS (Queensland social survey) data, telephone	Australia	Adults living in Queensland, Australia	1,261 (778)	60%	Various CM	School of Nursing, Midwifery & Health, University of Stirling
Zhang <sup>98</sup>	2012	Cross-sectional survey	Ambulatory family medicine clinics in 2 cities	United States	Adult patients of participating clinics, age ≥ 18	468 (452)	55%	Various CM	Texas Tech University Health Sciences Center.

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First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Arcury <sup>13</sup>	2013	Ethnographic interview	Senior meal & housing sites	United States	Community-dwelling older adults, age ≥ 65	62 (39)	59%	Various CM	National Center for CAM
Djav <sup>14</sup>	2013	Cross-sectional survey	General practice office	Norway	Patients visiting the GP office, age ≥ 18	381 (164)	18%	Herbs	Liaison Committee between Central Norway RHA and NTNU
Loren <sup>15</sup>	2013	Cross-sectional survey	4 Primary Care Research Network GP practices	England	Children (carers of) attending GP, age ≥ 16	394 (179)	25%	Various CM	King's Fund
Chang <sup>16</sup>	2014	Cross-sectional survey	2007 telephone survey	Taiwan	General population adults, age ≥ 18	1,260 (NR)	45%	Various CM	Department of Health, Executive Yan, ROC
		Cross-sectional survey	2011 telephone survey			2,266 (NR)	52%		
Chiba <sup>17</sup>	2014	Cross-sectional survey	Healthfood seminars, pharmacies, hospitals	Japan	In-patients, ambulatory patients & healthy subjects, age < 20 to > 80	2,732 (874)	28–30%	Dietary supplements or food	Health and Labour Sciences Research Grants
Chin-Lee <sup>18</sup>	2014	Cross-sectional survey	Community medical practice and community pharmacy	United States	Patients seeking primary health care services, age 18–89	164 (49)	41%	Probiotics	Not reported
Jang <sup>14</sup>	2014	Cross-sectional survey and audio analysis	Academically-affiliated physician offices	United States	Older adult primary care patients, ≥ 50, with new, worsening or uncontrolled problem	256 (142)	7–42%	Dietary supplements	University of California at L.A. National Institute on Aging
Nguyen <sup>19</sup>	2014	Cross-sectional survey	Remote area medical events in 2 counties	United States	Patients seeking free medical care at remote area medical events, age ≥ 18	192 (94)	44%	Various CM	Not reported
Shamer <sup>20</sup>	2014	Cross-sectional survey	3 Rural family medicine clinics	Japan	Adults who visit rural Japanese family medicine clinics, age ≥ 20	519 (415)	23%	Various CM	Shizuoka Prefectural Government
Vitale <sup>21</sup>	2014	Cross-sectional survey	Primary health centre	Croatia	Adult patients visiting primary health centre for any reason, age ≥ 18	228 (187)	34%	Various CM	Not reported
Chiba <sup>17</sup>	2015	Cross-sectional survey	Online via market research company	Japan	In-patients, ambulatory patients, non-patients, using both CM & medication, age < 20 to > 60	2,109 (2,109)	26%	Dietary supplements	Health and Labour Sciences Research Grants
Faith <sup>11</sup>	2015	Cross-sectional survey	National Cancer Institute's HINTS 3 (telephone, mail)	United States	General population adults, age ≥ 18	7,674 (1,729)	52%	Various CM	Not reported
Gardner <sup>22</sup>	2015	Cross-sectional survey	Boston Medical Centre	United States	Adults age ≥ 18	558 (333)	18%*	Supplements and herbs	National Center for CAM
Gyasi <sup>24</sup>	2015	Cross-sectional survey	Households within two settlements of Ashanti	Ghana	Adult community members, age ≥ 18	324 (279)	12%	Traditional CM of Ghana	Council for the Development of Social Science Research in Africa, Institute for Research in Africa and French Embassy in Ghana Grant Programme
Naja <sup>25</sup>	2015	Cross-sectional survey	Face to face in households	Lebanon	Lebanese adults	1,500 (448)	28%	Biologically-based CM	Lebanese National Council for Scientific Research

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First author	Year	Study design	Setting	Country	Population	Sample (CM users)	Disclosure rate	CM type used	Funding source
Turn <sup>14</sup>	2015	Cross-sectional survey and audio analysis	Primary care, integrative and CM clinics	United States	Adult outpatients of participating clinics, age $\geq 18$	603 (477)	34–49%	Dietary supplements	National Center for CAM, Office of Dietary Supplements.
Ben-Arye <sup>6b</sup>	2016	Cross-sectional survey	In-patients, academic clinic	Israel	Adult inpatients, age $\geq 18$	927 (458)	70%	Herbs & supplements	No funding received.
Cramer <sup>11</sup>	2016	Cross-sectional survey	2012 NHIS All Med Suppl.	United States	Civilian adult sub-population: yoga users	34,525 (4,422)	34%	Yoga	German Assn of Yoga Teachers.
Hsu <sup>6c</sup>	2016	Cross-sectional survey	Public health centre	United States	Adult patients of Chinatown public health centre, age $\geq 18$	50 (35)	31%	Chinese herbal	Not reported.
Lauche <sup>6d</sup>	2016	Cross-sectional survey	2012 NHIS All Med Suppl.	United States	Civilian adult sub-population: tai chi, qigong users	34,525 (NR)	42%	Tai chi & Qigong	Not reported.
Torres-Zeno <sup>6e</sup>	2016	Cross-sectional survey	Household interviews	Puerto Rico	Adults in Bayamon municipality, age $\geq 18$	203 (187)	36%	Various CM	Not reported.

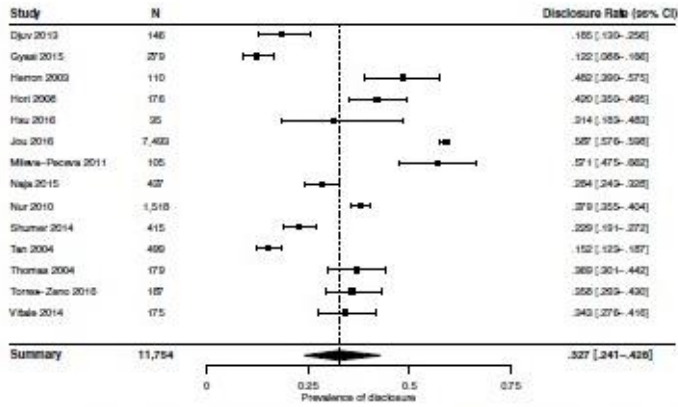
**Table 4.** Study characteristics and details of disclosure. CM = complementary medicine; NR = Not reported; Disclosure rate = % of CM users. <sup>a</sup>Studies conducted different analyses on sub-populations from the same 2002 NHIS data source. <sup>b</sup>Studies use same 2001 HCQS data, with slightly different sample size and results due to how data was handled. <sup>c</sup>Studies use same 2007 NHIS data, with slightly different sample size and results due to how data was handled. <sup>d</sup>Rate is % of CM users who also saw a physician. <sup>e</sup>Rate is % of CM users who were also taking conventional medications. <sup>f</sup>Disclosure of CM to physician by patients from conventional clinics (19.4%) vs CM (61.2%) clinics.

case by case basis taking into account the circumstances of both provider and patient involved. Ideally, regardless of the level of CM knowledge held, the medical provider should strive to facilitate overall coordination and continuity of care for patients covering all treatments and providers, including those of CM.

Our analyses suggest there may be a vital role for medical providers in facilitating patient preference by enquiring with patients about CM in order to help improve disclosure rates. Other studies show discussions in conventional medical settings about CM use are more commonly patient rather than provider initiated<sup>118,129</sup>, a pattern reflected in the findings of some papers in this review<sup>35,68,76</sup>. This pattern suggests provider initiation of such discussions may be an avenue for improving disclosure rates, which may be achieved by means such as standard inclusion of CM use inquiry in case-taking education for medical students, as is currently the case in Switzerland<sup>130</sup>. Indeed, examination of the impact on disclosure rates of specific questions related to dietary supplements found medical providers' questioning more than doubled the rate of supplement use disclosure<sup>131</sup>. This communicative success may be facilitated through employment of person-centred approaches to clinical care, which encompass patient involvement in shared decision-making, provider empathy and recognition of patients' values<sup>119</sup>, encouraging a shared responsibility for communication and subsequent discussion of CM use.

While this review provides insight which could be integral to improving patient care during concomitant use of CM and conventional medicine, it also reveals the complexities of patient-practitioner communication in contemporary clinical settings. Further research into the nature of prevailing communication patterns, including differences in disclosure behaviours between populations of different demographics, is needed. As research into disclosure becomes more nuanced and data collection more consistent (e.g. through development and use of standardised instruments), future research could examine changes in patterns of and influences on disclosure. Additionally, research exploring the relationship between communication and treatment outcomes is warranted to provide a richer, deeper understanding of the impact of patient care dynamics. Such understanding could arguably provide the scaffolding for robust, effective, efficient public health policy and practice guidelines.

**Limitations of this review.** The findings from our review need to be considered within the context of certain limitations. The varied nature and lack of a consistent international definition of CM lend a high degree of heterogeneity to the collection of studies appraised<sup>132</sup>. Likewise, while the wide variation in disclosure rates is likely to be partially due to confounding factors relating to differences among target populations (e.g. age, gender), settings (e.g. hospital, community clinics), geographical location (e.g. country/region), and sample sizes, the absence of a standard, validated tool for measuring disclosure also impacts the analysis and reporting on disclosure rates. The heterogeneity produced by these limitations reduced the number of papers suitable for meta-analysis and prevented a more robust, fixed-model meta-analysis on this topic, as well as prohibiting meta-analyses of CM categories other than biologically-based CM due to insufficient data. Additionally, identifying a comprehensive selection of studies to review was difficult due to disclosure frequently being reported as a secondary outcome and thus not being mentioned in the paper's title, abstract or keywords. However, these limitations have been minimised where possible by following systematic review best practice, and while remaining mindful of the limitations of our review, the importance of the findings presented here for contemporary healthcare practice and provision should not be underestimated.



**Figure 2.** Meta-analysis results: disclosure rates for biologically-based complementary medicine. Results of meta-analysis assessing rates of disclosure of biologically-based complementary medicine use to medical providers.

	No. of studies	Studies reporting reason	Studies reporting as main reason*
<b>Reasons for non-disclosure</b>			
Patient was afraid of physician's response or thought physician will disapprove	20	16(80%)	13(65%)
Physician didn't ask or wasn't interested	19	17(89%)	16(84%)
Patient didn't think it was important or necessary	18	12(67%)	16(89%)
Didn't think physician had relevant knowledge/wasn't their business to know	10	8(80%)	8(80%)
No time/physician too busy/didn't think about it/forgot	9	8(89%)	4(44%)
Thought CM was safe/wouldn't interfere with treatment	4	3(75%)	3(75%)
Was not using CM at the time/not using CM regularly/not attending a physician at the time	4	3(75%)	3(75%)
Previous negative response or bad experience with disclosing	4	3(75%)	0(0%)
Patient had enough knowledge about CM	1	1(100%)	0(0%)
Wanted to compare advice between conventional and CM practitioners	1	1(100%)	0(0%)
Desire to protect cultural knowledge about CM	1	1(100%)	0(0%)
Concerns physician will see patient's CM use as detracting from their income	1	1(100%)	0(0%)
<b>Reasons for disclosure</b>			
Physician asked	3	3(100%)	0(0%)
Patient believed physician would be supportive	2	2(100%)	0(0%)
Patient believed it was important for safety reasons	2	2(100%)	2(100%)
Patient believed physician would have relevant knowledge or advice about CM	1	1(100%)	0(0%)
To help someone else with the same condition	1	1(100%)	0(0%)

**Table 5.** Reasons for non-disclosure and disclosure. \*Studies in which the corresponding reason was the reason most commonly reported by participants.

**Conclusion**

The rate of disclosure regarding CM use to medical providers remains low and it appears that disclosure is still a major challenge facing health care providers. This review, alongside previous research, suggests that patient decision-making regarding disclosure and non-disclosure of CM use to a medical provider is impacted by the nature of patient-provider communication during consultation and perceptions of provider knowledge of CM. The initiation of conversations about CM with patients and provision of consultations characterised by person-centred, collaborative communication by medical providers may contribute towards increased disclosure rates and mitigate against the potential direct and indirect risks of un-coordinated concurrent CM and

conventional medical care. This is a topic which should be treated with gravity; it is central to wider patient management and care in contemporary clinical settings, particularly for primary care providers acting as gatekeeper in their patients' care.

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### Author Contributions

H.F. and A.S. conceived of the design and methodology for this review. H.F. developed the review protocol and searched the literature with input and support from A.S. H.F., A.S. and H.C. analysed the results, and interpreted the results in conjunction with J.W. and J.A. H.F. developed the initial draft of the manuscript and all authors contributed to writing, critically editing, revising, and approving the final manuscript. All authors have read and approved the final manuscript. H.F. is guarantor, held full access to all data, and takes responsibility for the integrity of the data and the accuracy of the data analysis.

### Additional Information

**Supplementary information** accompanies this paper at <https://doi.org/10.1038/s41598-018-38279-8>.

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## APPENDIX 3.1 THE COMPLEMENTARY AND ALTERNATIVE MEDICINE USE, HEALTH LITERACY AND DISCLOSURE (CAMUHLD) PROJECT SURVEY

13/11/2017

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### Default Question Block

Information about this research

#### WHO IS DOING THE RESEARCH?

My name is Dr Erica McIntyre and I am a research associate from the School of Psychology at Charles Sturt University. My colleagues are Dr Amie Steel, a postdoctoral research fellow from the Australian Research Centre in Complementary and Integrative Medicine (ARCCIM) at UTS and Associate Director-Research at Endeavour College of Natural Health, and Dr Joanna Harnett, Associate Lecturer from the Faculty of Pharmacy at the University of Sydney.

#### WHAT IS THIS RESEARCH ABOUT?

This research is to find out about the patterns of complementary use in the Australian population. It is also designed to explore the understanding and communication of complementary medicine use in Australia.

#### IF I SAY YES, WHAT WILL IT INVOLVE?

We will ask you to complete an online questionnaire that may take up to 15 minutes to complete. Your completion of this survey will be taken as your consent to participate.

#### ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there is some inconvenience. This survey will take up to 15 minutes to complete.

#### WHY HAVE I BEEN ASKED?

You are a member of the Australian general population.

#### DO I HAVE TO SAY YES?

No. Your participation is completely voluntary.

#### WHAT WILL HAPPEN IF I SAY NO?

Nothing. We will not contact you about this research again.

#### IF I SAY YES, CAN I CHANGE MY MIND LATER?

You can change your mind at any time and you do not have to say why. We won't contact you about this research again.

#### WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I or my colleagues can help you with, please feel free to contact me at emcintyre@csu.edu.au.

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772, and quote this number (20170242)

I agree to participate in the research project Complementary medicine use, literacy and disclosure in the Australian population (#20170242) being conducted by Dr Erica McIntyre (emcintyre@csu.edu.au).

I understand that the purpose of this study is to explore the patterns of complementary medicine use in the Australian general population as well as the understanding and communication of complementary medicine use in Australia.

I understand that I have been asked to participate in this research because my behaviours and perspectives as a member of the Australian population is valuable, and that my participation in this research will involve completing an online survey lasting approximately 15 minutes.

I am aware that I can contact Dr Erica McIntyre if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason.

I agree that I have had an opportunity to have all of my questions answered fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

Do you agree with all of the above and consent to participate in this research project?

- Yes  
 No

#### Section 1: About You

What is your gender? Please select the response that best applies to you.

<https://au1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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- Female
- Male
- Unspecified

What is your age range?

- 18-29
- 30-39
- 40-49
- 50-59
- 60 and over

What is your residential postcode?

Postcode

How do you manage financially at the moment? (Mark one only)

- It is impossible
- It is difficult all of the time
- It is difficult some of the time
- It is not too bad
- It is easy

What is the highest qualification you have completed?

- No formal qualifications
- Year 10 or equivalent
- Year 12 or equivalent
- Trade/apprenticeship
- Certificate/diploma
- University degree
- Higher university degree (e.g. Masters, PhD)

Do you currently have private health insurance?

- Yes
- No

Do you currently have a Health Care Card?

- Yes
- No

What best describes your current employment status? (Mark one only)

- Full time work (35 or more hours per week)
- Part time work (less than 35 hours per week)
- Casual/temp work (irregular hours)
- Looking for work
- Not in the paid workforce

What is your present marital status?

- Never married
- Married
- De facto (opposite sex)
- De facto (same sex)
- Separated
- Divorced
- Widowed

If you currently have private health insurance for ancillary services, please indicate which services are covered:

- I do not have private health insurance for ancillary services

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- Yoga/pilates/meditation
- Physiotherapy
- Psychology services
- Chiropractic
- Osteopathy
- Acupuncture
- Chinese medicine/herbs
- Homeopathy
- Naturopathy
- Western herbal medicine
- Remedial massage/massage therapy
- Nutrition/dietetics
- Not sure

**Section 2**

Section 2: About your health and wellbeing

The following questions ask you how satisfied you feel, on a scale from zero to 10. Zero means you feel no satisfaction at all and 10 means you feel completely satisfied.

	1	2	3	4	5	6	7	8	9	10
Thinking about your own life and personal circumstances, how satisfied are you with your life as whole?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your standard of living?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with what you are achieving in life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your personal relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with how safe you feel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with feeling part of your community?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your future security?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your spirituality and religion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In general would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

For how long (if at all) has your health limited you in each of the following activities?

	Limited for more than 3 months	Limited for less than 3 months	Not limited at all
The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking uphill or climbing a few flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Limited for more than 3 months	Limited for less than 3 months	Not limited at all
Bending, lifting, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating, dressing, bathing, or using the toilet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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How much bodily pain have you had during the past 4 weeks:

- 1 - None
- 2 - Very mild
- 3 - Mild
- 4 - Moderate
- 5 - Severe
- 6 - Very severe

Does your health keep you from working at a job, doing work around the house, or going to school?

- 1 - YES, for more than 3 months
- 2 - YES, for 3 months or less
- 3 - NO

Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?

- 1 - YES, for more than 3 months
- 2 - YES, for 3 months or less
- 3 - NO

For each of the following questions, please mark the circle for the one answer that comes closest to the way you have been feeling during the **past month**.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
How much of the time, during the past month, has your health limited your social activities (like visiting with friends or close relatives)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much of the time, during the past month, have you been a very nervous person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the past month, how much of the time have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much of the time, during the past month, have you felt downhearted and blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the past month, how much of the time have you been a happy person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please select the answer that describes whether the following statements is true or false for you.

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I am somewhat ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been feeling bad lately	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the last 3 years, have you been diagnosed or treated for: (Mark all that apply)

- Type 1 diabetes
- Non-insulin dependent Type 2 diabetes
- Insulin dependent Type 2 diabetes
- Cancer - benign
- Cancer - malignant
- Heart disease
- Hypertension (high blood pressure)
- Dyslipidaemia (high cholesterol and/or triglycerides)
- Osteoarthritis
- Other musculoskeletal disorder
- Asthma

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- Bronchitis
- Other respiratory disorder
- Endometriosis
- Polycystic ovarian syndrome
- Other female reproductive disorder
- Benign prostatic hyperplasia
- Other male reproductive disorder
- Irritable bowel syndrome
- Inflammatory bowel disease
- Celiac disease
- Gastro-oesophageal- reflux disease (GERD)
- Chronic constipation
- Other gastrointestinal/digestive disorder
- Mood disorder (e.g. depression)
- Anxiety disorder
- Sleep disorder
- Substance use disorder
- Schizophrenia or other psychotic disorder
- Other mental health disorder
- Other health condition - please specify
- None of the above

In the last year, have you visited a doctor concerned about your health?

- Yes
- No
- Unsure

What was the outcome of your visit with your medical doctor? (select all that apply)

- I was provided an adequate explanation of my health complaint
- I was provided a formal diagnosis of my health condition
- I was prescribed an acceptable treatment plan to manage my health complaint
- I am still bothered by the same health concern
- I am bothered by a new health concern
- Other - please specify:

**Section 3**

Section 3: About your use of health services

What was the frequency of your visits to the following health professionals in the **previous 12 months**? Please select the responses that best apply to you.

	Number of visits
A family doctor or another General practitioner (GP)	<input type="text"/>
A specialist doctor	<input type="text"/>
A hospital doctor (in outpatients or casualty)	<input type="text"/>
A pharmacist	<input type="text"/>
A counsellor or other mental health worker	<input type="text"/>
A community nurse	<input type="text"/>
A physiotherapist	<input type="text"/>

Section 3: About your use of health services (continued)

What was the frequency of your visits to the following health professionals in the **previous 12 months**? Please select the responses that best apply to you.

	Number of visits
A chiropractor	<input type="text"/>
An osteopath	<input type="text"/>
A massage therapist	<input type="text"/>

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	Number of visits
An acupuncturist	<input type="text"/>
A naturopath	<input type="text"/>
A Western herbalist	<input type="text"/>
A traditional Chinese medicine practitioner	<input type="text"/>
A homeopath	<input type="text"/>
An aromatherapist	<input type="text"/>
A yoga teacher	<input type="text"/>
Other (please specify) <input type="text"/>	<input type="text"/>

What was the reason and cost for visiting a **family doctor or another General Practitioner (GP)** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per GP visit (\$)** - Consultation fees only

What was the reason and cost for visiting a **specialist doctor** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Specialist doctor visit (\$)** - Consultation fees only

What was the reason and cost for visiting a **hospital doctor (in outpatients or casualty)** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Hospital doctor visit (\$)** - Consultation fees only

What was the reason and cost for visiting a **pharmacist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing

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Other (please specify)

What was the reason and cost for visiting a **counsellor or other mental health worker** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Counsellor or other mental health worker visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **community nurse** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Community nurse visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **physiotherapist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Physiotherapist visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **chiropractor** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Chiropractor visit** (\$) - [Consultation fees only](#)

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What was the reason and cost for visiting an **osteopath** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Osteopath visit** (\$) - Consultation fees only

What was the reason and cost for visiting a **massage therapist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Massage therapist visit** (\$) - Consultation fees only

What was the reason and cost for visiting an **acupuncturist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Acupuncturist visit** (\$) - Consultation fees only

What was the reason and cost for visiting a **naturopath** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Naturopath visit** (\$) - Consultation fees only

What was the reason and cost for visiting a **Western herbalist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month



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- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Western herbalist visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **traditional Chinese medicine practitioner** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per traditional Chinese medicine practitioner visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **homeopath** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Homeopath visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting an **aromatherapist** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Aromatherapist visit** (\$) - [Consultation fees only](#)

What was the reason and cost for visiting a **yoga teacher** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing

Other (please specify)

Estimated out-of-pocket expenses **per Yoga visit (\$)** - Consultation fees only

What was the reason and cost for visiting an **Other (specified) service** in the **previous 12 months**? Please select the responses that best apply to you.

- For an acute illness/condition, one that lasted less than one month
- To treat a long-term health condition (one that lasted more than 1 month) or its symptoms
- To improve wellbeing
- Other (please specify)

Estimated out-of-pocket expenses **per Other (specified) service visit (\$)** - Consultation fees only

If you used any of the following treatments in the **previous 12 months**, who prescribed them to you and how much did you spend on them? Please select the responses that best apply to you.

	Source of prescription							Expenses Estimated out-of-pocket expenses per visit (\$) <i>Write amount below - enter 0 if none spent</i>
	Did not use	A family doctor or general practitioner (GP)	A specialist doctor	A pharmacist	A pharmacy or health food store assistant	A complementary or alternative health practitioner	Self-prescribed	
Prescription-only pharmaceuticals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Over-the-counter pharmaceuticals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Western or Chinese herbal medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Vitamin/mineral supplements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Yoga, Tai Chi or Qigong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Aromatherapy oils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Homeopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Flower essences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Relaxation techniques/meditation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>
Other (please specify if used)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px;" type="text"/>

Do you take prescription medicine daily?

- Yes
- No

What condition is the medicine taken to treat?

Section 4

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Section 4: Knowledge about complementary and alternative medicine

Complementary and alternative medicines are treatments not normally considered part of mainstream healthcare, such as herbal medicine, nutritional supplements and homeopathy.

Below is a list of statements about **herbal products**. Please indicate the degree to which you agree or disagree with each statement.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The federal government sets standards for the quality of herbal products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal products come in a variety of forms, for example, liquid, lotion, pills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal products are readily available in a variety of stores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is enough information on the herbal product label to make a well-informed choice about using it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal products sold in Australia may be made in foreign countries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It does not matter how often an herbal product is taken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There is no need to inform a health care provider about taking herbal products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal products do not have side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The law requires that the label on the herbal product contain information about what the product is supposed to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a famous person recommends a herbal product, it must work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The AUST R and AUST L numbers mean that there has been quality control in the manufacture of the herbal product	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The words "organic" and "natural" mean the same thing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
If a herbal product is helpful for a friend or family member it will help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal products can prevent most health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The way herbal products work in the body is often not known	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to know the correct amount of a herbal product to be used	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is plenty of good information about the quality of herbal products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Many herbal products can be purchased over the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There are few research studies showing that herbal products work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is little research about the safety of herbal products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to keep track of what happens after starting to take a herbal product	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following statements may appear similar to those previously answered, but they measure different things. Please read the following question carefully before answering.

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Below is a list of statements about **vitamin supplements**. Please indicate the degree to which you agree or disagree with each statement.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The federal government sets the standards for the quality of vitamin supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin supplements come in a variety of forms, for example, liquid, powder, pills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin supplements are readily available in a variety of stores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is enough information on the vitamin supplement label to make a well-informed choice about using it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin supplement sold in Australia may be made in foreign countries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It does not matter how often a vitamin supplement is taken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no need to inform a health care provider about taking vitamin supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Vitamin supplements do not have side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The law requires that the label on the vitamin supplement contain information about what the product is supposed to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a famous person recommends a vitamin supplement, it must work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The AUST R and AUST L numbers mean that there has been quality control in the manufacture of the herbal product	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a vitamin supplement is helpful for a friend or family member it will help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin supplements can prevent most health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The way vitamin supplements work in the body is often not known	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
It is important to know the correct amount of a vitamin supplement to be used	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is plenty of good information about the quality of vitamin supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Many vitamin supplements can be purchased over the internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are few research studies showing that vitamin supplements work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is little research about the safety of vitamin supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to keep track of what happens after starting to take a vitamin supplement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following statements may appear similar to those previously answered, but they measure different things. Please read the following question carefully before answering.

Below is a list of statements about **complementary and alternative medicine practitioners**. Please indicate the degree to which you agree or disagree with each statement.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The federal government sets the standards for the practice requirements of all complementary and alternative medicine practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is enough information available about complementary and alternative medicine practitioners to make a well-informed choice about consulting with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
complementary and alternative medicine practitioners practicing in Australia may be trained in foreign countries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatments received from a complementary or alternative medicine practitioner do not have risks of side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The law requires that complementary and alternative medicine practitioners provide accurate information about what their treatments are supposed to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a particular type of complementary or alternative medicine practitioner is helpful for a friend or family member they will help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
complementary and alternative medicine practitioners can treat most health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no need to inform a complementary or alternative medicine practitioner about the medicines I take	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There are channels I can use to report any concerns I have about the practices of a complementary or alternative medicine practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are few research studies showing that complementary and alternative medicine treatments work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is little research about the safety of complementary and alternative medicine practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't understand the differences between the various types of complementary and alternative practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 5

Section 5: Accessing and sharing information about complementary and alternative medicine.

*Complementary and alternative medicines are treatments not normally considered part of mainstream healthcare, such as herbal medicine, nutritional supplements and homeopathy.*

The following question relates to the disclosure of information about your use of health treatments to health professionals providing your health care in the previous 12 months.

Please select the response that best reflects your experience with the following health professionals...

	I told them about ALL complementary and alternative medicines I was using	I only told them about SOME of my complementary and alternative medicine use	I DID NOT tell them about my complementary and alternative medicine use	I did not visit this type of health professional
A specialist doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A hospital doctor (in outpatients or casualty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A pharmacist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Section 5: Accessing and sharing information about complementary and alternative medicine.

*Complementary and alternative medicines are treatments not normally considered part of mainstream healthcare, such as herbal medicine, nutritional supplements and homeopathy.*

The following question relates to the disclosure of information about your use of health treatments to health professionals providing your health care in the **previous 12 months**.

Please select the response that best reflects your experience with the following health professionals...

	I told them about ALL complementary and alternative medicines I was using	I only told them about SOME of my complementary and alternative medicine use	I DID NOT tell them about my complementary and alternative medicine use	I did not visit this type of health professional
A family doctor or general practitioner (GP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions relate to your interactions with a medical doctor in the **last 12 months**. Please indicate your level of agreement with the following statements (1 = Strongly Agree to 5 = Strongly Disagree)

I **did not disclose** my complementary and alternative medicine use to my medical doctor because...

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
They did not ask me about my complementary and alternative medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think it was important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary and alternative medicines are safe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forgot to mention it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I was worried they would discourage my use of complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not approve of my use of complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not use complementary and alternative medicine regularly enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed using complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I <b>disclosed</b> my complementary and alternative medicine use to my medical doctor because...					
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I was concerned about drug interactions with the complementary and alternative medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing complementary and alternative medicine with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I knew they would be willing to discuss my alternative medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my complementary and alternative medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my complementary and alternative medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards complementary and alternative medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
They support my use of complementary and alternative medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about complementary and alternative medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions relate to the disclosure of information about your use of conventional medicines to complementary and alternative medicine practitioners providing you health care.

*Conventional medicines are treatments that are considered part of mainstream healthcare, such as pharmaceutical drugs.*

Please select the response that best reflects your experience with the following health professionals in the **previous 12 months...**

	I told them about ALL conventional medicines I was using	I only told them about SOME of my conventional medicine use	I DID NOT tell them about my conventional medicine use	I did not visit this type of health professional
Massage therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Acupuncturist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Naturopath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Western herbalist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Traditional Chinese medicine practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Homeopath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chiropractor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions relate to your interactions with complementary and alternative health practitioners (e.g. naturopath, herbalist, homeopath) in the **last 12 months**. Please indicate your level of agreement with the following statements (1 = Strongly Agree to 5 = Strongly Disagree)

I **did not disclose** my conventional medicine use to my complementary and alternative health practitioner because...

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	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
They did not ask me about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think it was important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forgot to mention it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would try to discourage my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
They do not approve of my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not use conventional medicines regularly enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed using conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I **disclosed** my conventional medicine use to my complementary and alternative health practitioner because...

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about interactions with the conventional medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing conventional medicines with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I knew they would be willing to discuss my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree



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	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
They support my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about side-effects of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank You!

Thank you for taking our survey. Your response is very important to us.

Powered by Qualtrics

## APPENDIX 3.2 PHASE TWO SURVEY: PATIENT EXPERIENCES OF THE COMPLEMENTARY MEDICINE CONSULTATION (PECMC)

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

### Patient Experiences of the Complementary Medicine Consultation: >Profession<

This research is to find out about the experience patients have during consultation with their complementary medicine practitioners. This will help us to understand the role complementary medicine practitioners are playing for their patients in order to help meet the needs of consumers of health and medical services.

This survey should take 15-25mins to complete. Your input is valuable and much appreciated. *Thank you!*

#### INSTRUCTIONS

- Please read each question carefully. Please answer every question to the best of your knowledge. If you are unsure about how to answer a question, mark the option which most closely describes your response.
- Mark the boxes ☒ and circles ⊗ with a cross or tick to indicate your answer.
- Boxes ☐ may allow more than one answer while circles ○ allow only one.
- If you make a mistake, simply scribble it out and mark the correct answer.

#### By completing the survey, you agree to the following:

I have read the participant information sheet, or someone has read it to me in a language that I understand. I understand the purposes, process and risks of the research described. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I have not completed this survey previously. I freely agree to participate in the research survey described and understand that I am free to withdraw at any time without affecting the health care I receive.

I Agree

## SECTION 1: About You

### Q1. What is your age?

- 18-24       25-34       35-44       45-54  
 55-64       65-74       75 and over

### Q2. What is your gender?

- Female       Male       Transgender       Other

### Q3. What is your residential postcode?

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### Q4. What is your relationship status?

- Never married       Married       De facto  
 Separated       Divorced       Widowed

### Q5. What is the highest qualification you have completed?

- No formal qualification       Year 10 or equivalent  
 Year 12 or equivalent       Trade or apprenticeship  
 Certificate or diploma       University degree (e.g. Bachelor)  
 Higher university degree (e.g. Masters, PhD)

### Q6. What best describes your employment status?

- Full time work (35 hours or more per week)       Part time work (less than 35 hours per week)  
 Casual or temporary work (irregular hours)       Currently looking for work  
 Not currently in the paid workforce, nor looking

### Q7. How do you manage financially at the moment?

- It is impossible       It is difficult all the time  
 It is difficult some of the time       It is not too bad  
 It is easy

### Q8. Do you currently have private health insurance?

- No       Yes

#### Q8a. If Yes, which of the following ancillary services does your private health insurance cover?

- Yoga or pilates       Physiotherapy  
 Psychology services       Chiropractic  
 Osteopathy       Acupuncture  
 Chinese herbalism       Homeopathy  
 Naturopathy       Western herbalism  
 Massage therapy       Nutrition or dietetics  
 Myotherapy or musculoskeletal therapy  
 My private health insurance doesn't cover ancillary services  
 I do not know/can not remember

### Q9. Do you currently have a Health Care Card?

- No       Yes

## SECTION 2: About Your Health

**Q10.** From the following list, please select *all* conditions you currently have, that have been *diagnosed by a doctor or other health professional* and approximately how long it's been since you were diagnosed.

Condition	Time since diagnosis (specify years/months)
Arthritis	<input type="checkbox"/> ____ Yrs / Mths
Asthma	<input type="checkbox"/> ____ Yrs / Mths
Cancer or post-cancer treatment complications	<input type="checkbox"/> ____ Yrs / Mths
COPD (chronic obstructive pulmonary disease)	<input type="checkbox"/> ____ Yrs / Mths
Diabetes (type 1)	<input type="checkbox"/> ____ Yrs / Mths
Diabetes (type 2)	<input type="checkbox"/> ____ Yrs / Mths
Heart disease/cardiovascular disease	<input type="checkbox"/> ____ Yrs / Mths
Hypertension/high blood pressure	<input type="checkbox"/> ____ Yrs / Mths
Musculoskeletal condition	<input type="checkbox"/> ____ Yrs / Mths
Chronic pain	<input type="checkbox"/> ____ Yrs / Mths
Depression	<input type="checkbox"/> ____ Yrs / Mths
Anxiety	<input type="checkbox"/> ____ Yrs / Mths
Other mental health condition	<input type="checkbox"/> ____ Yrs / Mths
Insomnia or other sleep disorder	<input type="checkbox"/> ____ Yrs / Mths
Obesity	<input type="checkbox"/> ____ Yrs / Mths
Alzheimer's disease or dementia	<input type="checkbox"/> ____ Yrs / Mths
Congenital condition (e.g. cystic fibrosis)	<input type="checkbox"/> ____ Yrs / Mths
Chronic kidney disease	<input type="checkbox"/> ____ Yrs / Mths

**Q10 CONTINUED.** From the following list, please select *all* conditions you currently have, that have been *diagnosed by a doctor or other health professional* and approximately how long it's been since you were diagnosed.

Condition	Time since diagnosis (specify years/months)
Endometriosis	<input type="checkbox"/> ____ Yrs / Mths
PCOS (polycystic ovarian syndrome)	<input type="checkbox"/> ____ Yrs / Mths
Other female reproductive disorder	<input type="checkbox"/> ____ Yrs / Mths
Prostatic hyperplasia	<input type="checkbox"/> ____ Yrs / Mths
Other male reproductive disorder	<input type="checkbox"/> ____ Yrs / Mths
Inflammatory bowel disease (Crohn's disease or ulcerative colitis)	<input type="checkbox"/> ____ Yrs / Mths
IBS (irritable bowel syndrome)	<input type="checkbox"/> ____ Yrs / Mths
Fibromyalgia or CFS/ME (chronic fatigue syndrome/myalgic encephalomyelitis)	<input type="checkbox"/> ____ Yrs / Mths
Other autoimmune disease (not listed above)	<input type="checkbox"/> ____ Yrs / Mths
Other chronic condition/s (not listed above)	
Please specify: _____	<input type="checkbox"/> ____ Yrs / Mths
_____	<input type="checkbox"/> ____ Yrs / Mths
None of the above	<input type="radio"/> ____ Yrs / Mths

**If you selected one of the conditions in the list, please continue to the next question over the page.**

**If you answered "None of the above" and have not been diagnosed with any chronic health conditions, we do not need you to answer any further questions and you have completed the survey. Thank you for your time.**

### SECTION 3A: Your Experiences of Complementary Medicine

The following questions relate specifically to your experience with the *health professional you are visiting today*.

**Q11. At the conclusion of your visit today, how many times will you have visited this practitioner?**

- 1 - This was my first visit
  2 times
  3 times
  4 times
  5 or more times

**Q12. How much do you agree or disagree with the following statements about your reasons for consulting the health professional you are visiting today?**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Doesn't apply
To seek treatment for an acute illness lasting less than 1 month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To seek treatment for a long-term illness lasting more than 1 month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was dissatisfied with my conventional medical treatment and wanted to try something different	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To reduce side-effects of my current medical treatments/medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To enhance the effectiveness of my current medical treatments/medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To improve general wellbeing and prevent future health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was seeking holistic/natural treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This type of health care suits my personal belief system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe this type of health care is safe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This type of health care gives me hope about my future health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This type of health care gives me a sense of control about my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This health care professional is supportive and compassionate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q13. When thinking about your consultation today, how much do you agree or disagree with the following statements?</b>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I feel seen and heard as a unique individual by my practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner has a full picture of me as an individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner is really interested in finding and addressing my health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The root causes of my problems are identified by my practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The root causes of my problems are being treated by my practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The treatment is individualised for me at each session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner receives feedback from my body that guides treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner asks me for feedback from my body that guides treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know what to expect during treatment sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner teaches me ways to relieve symptoms myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q14. When thinking about your consultation today, how much do you agree or disagree with the following statements?</b>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My practitioner cares about me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel cared for during treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner accepts me as I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I receive personal attention during treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can talk openly with my practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner gives me hope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I trust my practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q15. When thinking about what has happened for you as a result of today's consultation, how would you describe the following?:</b>			
	No	Yes, a little	Yes, a lot
Do you feel more in control of your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you know what to do to take care of your health problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you believe that your health problem will improve?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you advocate more for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have techniques you can use when your symptoms get worse?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q16 Still thinking about the health care professional you've seen today, think about the health care you've received for your chronic condition/s over the past 6 months (if you've been seeing this practitioner for less than 6 months, think about the care you've received since you started seeing them).</b>					
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>	Almost Never	Generally Not	Sometimes	Most of the Time	Almost Always
Asked for my ideas when we made a treatment plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given choices about treatment to think about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked to talk about any problems with my medicines/treatments or their effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given a written list of things I should do to improve my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Satisfied that my care was well organised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown how what I did to take care of my illness influenced my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked to talk about my goals in caring for my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to set specific goals to improve my eating or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given a copy of my treatment plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to go to a specific group or class to help me cope with my chronic illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked questions, either directly or on a survey, about my health habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sure that my practitioner thought about my values and my traditions when they recommended treatments to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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<b>(Q16 Continued) Over the past 6 months, when receiving medical care for my chronic condition, I was:</b>	Almost Never	Generally Not	Sometimes	Most of the Time	Almost Always
Helped to make a treatment plan that I could do in my daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to plan ahead so I could take care of my illness even in hard times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my chronic illness affects my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contacted after a visit to see how things were going	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to attend programs in the community that could help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred to a dietitian, health educator, or counsellor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Told how my visits with other types of practitioners, like doctors or specialists, helped my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my visits with other doctors/practitioners were going	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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**SECTION 3B: Sharing Information About Your Medicines With Your Complementary Medicine Practitioner**

The following questions relate to the disclosure of information about your use of health services to health professionals providing your care.

Please select the response that best reflects your experience in the previous 12 months with ***the health care professional you consulted with today***. If you have been visiting this health care professional for less than 12 months, please think about your experience since you started consulting with them.

**Q17. Did you tell your practitioner about the *conventional medicines* you are using? (Conventional medicines are treatments that are considered part of mainstream health care, such as pharmaceutical drugs).**

- I am not currently taking any conventional medicines  
**GO TO QUESTION 20 (SKIP QUESTIONS 18 & 19)**
- I told them about ALL conventional medicines I am using  
**GO TO QUESTION 19 (SKIP QUESTION 18)**
- I only told them about SOME of my conventional medicine use  
**CONTINUE TO BOTH QUESTIONS 18 & 19**
- I DID NOT tell them about my conventional medicine use  
**GO TO QUESTION 18 AND SKIP QUESTION 19**



The following questions relate to your interactions with *the healthcare professional you consulted with today*, over the last 12 months, or since you started consulting with them.

Please indicate your level of agreement with the following statements.

Q18. I DID NOT disclose my conventional medicine use to my complementary medicine practitioner because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
They did not ask me about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think it was important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forgot to mention it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would try to discourage my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not approve of my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not use conventional medicines regularly enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions relate to your interactions with *the healthcare professional you consulted with today*, over the last 12 months, or since you started consulting with them.

Please indicate your level of agreement with the following statements.

Q19. I DISCLOSED my conventional medicine use to my complementary medicine practitioner because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about drug interactions with the conventional medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing conventional medicine with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would be willing to discuss my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my conventional medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They support my use of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about side-effects of conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about conventional medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q20. Are you currently receiving care for your chronic health condition/s from any other practitioner/s? (select all that apply)**

- Yes, from a GP (general practitioner)  
**CONTINUE ON TO QUESTION 21**
- Yes, from a specialist doctor  
**CONTINUE ON TO QUESTION 21**
- Yes, from another type of health professional (please specify):
- \_\_\_\_\_  
**WE HAVE NO FURTHER QUESTIONS FOR YOU.**  
**Thank you for taking the time to participate in this research.**
- No, I am not currently receiving care from any other practitioners.  
**WE HAVE NO FURTHER QUESTIONS FOR YOU.**  
**Thank you for taking the time to participate in this research.**

If you answered any of the 'Yes' options to the above question,  
please continue with the rest of the survey.

If you answered 'No' to the above question, you have completed the survey  
- please return it using the reply-paid envelope as soon as possible.

#### SECTION 4A: Your Experiences of Care in Conventional Medicine

**Q21. If you receive care from both a GP and a specialist doctor, please indicate which is the person most involved in your care:**

- My **GP** is most involved in providing my health care
- My **Specialist doctor** is most involved in providing my health care
- I do not receive care from both a GP and a specialist doctor  
(I only receive care from one of these professionals, as specified in the previous question)

The following questions relate to the care you receive from your usual GP or Specialist doctor. If you consult with both a GP and a specialist doctor, please answer the questions for the one who is most involved in your care.

<b>Q22. When thinking about your most recent consultation with your usual GP/Specialist doctor, how much do you agree or disagree with the following statements:</b>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I feel seen and heard as a unique individual by my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor has a full picture of me as an individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor is really interested in finding and addressing my health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The root causes of my problems are identified by my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The root causes of my problems are being treated by my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The treatment is individualised for me at each session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor receives feedback from my body that guides treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor asks me for feedback from my body that guides treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know what to expect during treatment sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My practitioner teaches me ways to relieve symptoms myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q23. When thinking about your most recent consultation with your usual GP/Specialist doctor, how much do you agree or disagree with the following statements?:</b>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My doctor cares about me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel cared for during treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor accepts me as I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I receive personal attention during treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can talk openly with my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor gives me hope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I trust my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>Q24. When thinking about what has happened for you as a result of your most recent consultation with your usual GP/Specialist doctor, how would you describe the following?:</b>			
	No	Yes, a little	Yes, a lot
Do you feel more in control of your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you know what to do to take care of your health problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you believe that your health problem will improve?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you advocate more for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have techniques you can use when your symptoms get worse?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q25. Think about the health care you've received from your usual GP/Specialist doctor for your chronic condition/s over the past 6 months (if it's been more than 6 months since you've seen your doctor or nurse, think about your most recent trip).**

<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>	Almost Never	Generally Not	Sometimes	Most of the Time	Almost Always
Asked for my ideas when we made a treatment plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given choices about treatment to think about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked to talk about any problems with my medicines or their effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given a written list of things I should do to improve my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Satisfied that my care was well organised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown how what I did to take care of my illness influenced my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked to talk about my goals in caring for my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to set specific goals to improve my eating or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given a copy of my treatment plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to go to a specific group or class to help me cope with my chronic illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked questions, either directly or on a survey, about my health habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sure that my doctor thought about my values and my traditions when they recommended treatments to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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**(Q25. Continued) Over the past 6 months, when receiving medical care for my chronic condition, I was:**

	Almost Never	Generally Not	Sometimes	Most of the Time	Almost Always
Helped to make a treatment plan that I could do in my daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to plan ahead so I could take care of my illness even in hard times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my chronic illness affects my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contacted after a visit to see how things were going	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to attend programs in the community that could help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred to a dietitian, health educator, or counsellor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Told how my visits with other types of doctors, like the eye doctor or surgeon, helped my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my visits with other doctors were going	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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**SECTION 4B: Sharing Information About Your Complementary Medicines With Your Doctor**

The following questions relate to the disclosure of information about your use of health services to the **usual GP/Specialist doctor providing your health care**.

Please select the response that best reflects your experience in the previous 12 months with **your usual GP/Specialist doctor**. If you have been visiting this health care professional for less than 12 months, please think about your experience since you started consulting with them.

**Q26. Did you tell your GP/Specialist doctor about the *complementary medicines* you are using?**

**(Complementary medicines are treatments/health care not normally considered part of mainstream health care, such as herbal medicine, nutritional supplements, acupuncture or massage).**

- I told them about ALL complementary medicines I was using  
**GO TO QUESTION 28 (SKIP QUESTION 27)**
- I only told them about SOME of my complementary medicine use  
**CONTINUE TO BOTH QUESTIONS 27 & 28**
- I DID NOT tell them about my complementary medicine use  
**GO TO QUESTION 27 (AND SKIP QUESTION 28)**

The following questions relate to your interactions with your usual GP/ Specialist doctor, over the last 12 months, or since you started consulting with them.

Please indicate your level of agreement with the following statements.

Q27. I DID NOT disclose my complementary medicine use to my GP/Specialist doctor because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
They did not ask me about my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would understand my choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would judge me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary medicines are safe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They did not need to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was not enough time in the consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uncomfortable discussing it with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they wouldn't support my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not think they would know anything about complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is none of their business	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would try to discourage my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not approve of my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried they would respond negatively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I previously had a negative experience when I disclosed conventional medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions relate to your interactions with *your usual GP/Specialist doctor*, over the last 12 months, or since you started consulting with them.

Please indicate your level of agreement with the following statements.

Q28. I DISCLOSED my complementary medicine use to my GP/Specialist doctor because...	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I wanted them to fully understand my health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about drug interactions with the complementary medicine I was using	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they might know something about complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They asked me about my use of complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a good relationship with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt comfortable discussing complementary medicine with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would be willing to discuss my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their approval of my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew they would understand about my complementary medicine use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have a good attitude towards complementary medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They are open-minded	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought they could help with my treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They support my use of complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They understand my treatment goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They have my best interests at heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted their advice about complementary medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Q29. How much time has passed since your consultation with the practitioner who gave you this survey?**

- I filled in this survey within 24 hours of my consultation
- My consultation was more than 24 hours ago, but within the last 3 days
- My consultation was more than 3 days ago, but within the last week
- My consultation was more than a week ago, but within the last fortnight
- My consultation was more than 2 weeks ago

You have now completed the survey -  
**please return it using the reply-paid envelope provided  
 as soon as possible.**

You may tear off the next page to keep in order to enter the  
 prize draw if you wish.



**THANK YOU!**

for taking the time to complete this survey.  
 Your contribution to our research is greatly appreciated.

**You now have the opportunity to win a \$100 gift voucher  
 to be spent online at fishpond.com.au**

To enter the draw, simply go to the website link below  
 or scan the QR code with your phone and enter your details

<https://www.surveygizmo.com/s3/4614432/Voucher-Draw-Survey>



*The details you provide will not be linked to your survey responses or used for  
 any purpose other than selecting the winner of the draw.  
 No third party will have access to these details. After the winner is notified  
 and the voucher is delivered, your details will be deleted.*

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

## Patient Experiences of the Complementary Medicine Consultation

This research is a project of the Australian Research Centre in Complementary and Integrative Medicine (ARCCIM), University of Technology Sydney (UTS).

**Investigator:** Hope Foley, PhD Candidate, primary contact for this study  
[hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au)

**Supervisors:** Distinguished Professor Jon Adams, Director  
[jon.adams@uts.edu.au](mailto:jon.adams@uts.edu.au)  
Doctor Amie Steel, Postdoctoral Research Fellow  
[amie.steel@uts.edu.au](mailto:amie.steel@uts.edu.au)

**Location:** Clinics of complementary medicine practitioners within the Australian community, the Practitioner Research and Collaboration Initiative (PRACI), the Osteopathy Research and Innovation Network (ORION), and the Australian Chiropractic Research Network (ACORN).

**Ethics approval:** This project has been approved by the Human Research Ethics Committee (HREC) of the University of Technology Sydney (UTS) (ETH18-2769). If you would like to talk to someone who is not connected with the research, you may contact the UTS HREC on [research.ethics@uts.edu.au](mailto:research.ethics@uts.edu.au) or (02) 9541 2478.

## APPENDIX 3.3 PHASE TWO PRACTITIONER INVITATION, INFORMATION SHEET, EXPRESSION OF INTEREST AND CONSENT FORM

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

### Patient Experiences of the Complementary Medicine Consultation

**Dear Practitioner,**

You are invited to take part in a research study exploring patient experiences of consulting with complementary medicine practitioners.

There is currently little data relating to the clinical care provided to Australians by complementary medicine (CM) practitioners, limiting the visibility and understanding of the role such practitioners play in the wider field of Australian health care provision.

This project seeks to generate data about the nature of care provided in CM clinical practice within the Australian community to help address this lack of visibility and understanding. We would like to ask you to assist us in gathering this data by asking your patients to complete a short survey.

For further information and instructions on how to participate, please see the attached Practitioner Information Sheet, which includes a link where you can submit your expression of interest.

**Thank you!**

**Your time is appreciated.**

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

## Patient Experiences of the Complementary Medicine Consultation - Practitioner Information Sheet and Invitation to Participate

<b>Principal Investigator:</b>	Hope Foley, PhD Candidate ARCCIM, Faculty of Health, UTS <a href="mailto:hope.m.foley@student.uts.edu.au">hope.m.foley@student.uts.edu.au</a>
<b>Supervisors:</b>	Distinguished Prof Jon Adams, Director ARCCIM, Faculty of Health, UTS <a href="mailto:jon.adams@uts.edu.au">jon.adams@uts.edu.au</a>  Dr Amie Steel, Postdoctoral Research Fellow ARCCIM, Faculty of Health, UTS <a href="mailto:amie.steel@uts.edu.au">amie.steel@uts.edu.au</a>
<b>Location:</b>	Clinics of complementary medicine practitioners within the Australian community, accessed via the Practitioner Research and Collaboration Initiative (PRACI), Osteopathy Research and Innovation Network (ORION), and Australian Chiropractic Research Network (ACORN).
<b>Ethics approval:</b>	This project has been approved by the Human Research Ethics Committee (HREC) of the University of Technology Sydney (UTS) (ETH18-2769). If you would like to talk to someone who is not connected with the research, you may contact the UTS HREC on <a href="mailto:research.ethics@uts.edu.au">research.ethics@uts.edu.au</a> or (02) 9514 2478.

## INFORMATION ABOUT THIS RESEARCH

### INTRODUCTION

There is currently little data relating to the clinical care provided to Australians by complementary medicine (CM) practitioners, limiting the visibility and understanding of the role such practitioners play in the wider field of Australian health care provision.

This project seeks to generate data about the nature of care provided in CM clinical practice within the Australian community to help address this lack of visibility and understanding. We would like to ask you to assist us in gathering this data by asking your patients to complete a short survey.

### PROJECT OVERVIEW

Clinical consultation is an important aspect of health care delivery that impacts on treatment outcomes and other factors affecting patient health and wellbeing. This is particularly true in relation to rising rates of chronic conditions, which require ongoing, individualised care for treatment to be effective and sustainable. This research intends to examine how the care received by individuals who consult with CM practitioners in Australia is being experienced, and how this care may be addressing the needs of such individuals with and

without chronic conditions. This will help us to understand the role complementary medicine practitioners are playing for their patients in order to help meet the needs of consumers of health and medical services, and to contribute data to the scientific evidence base for complementary medicine disciplines.

#### **WHAT DOES PARTICIPATION IN THIS RESEARCH INVOLVE?**

Participation will involve recruiting patient participants. You will be required to inform your patients of the study and invite them to complete a short survey of multiple-choice questions, which will be provided on paper. We will ask you to invite 15 consecutive patients to participate. The survey will be anonymous – your patients will not be asked to provide their name or any other identifying information, and patients will complete the survey at home, so you will not be aware of who has or has not participated. Patients will seal their completed survey in a reply-paid envelope (provided by us) to return to the research team.

#### **WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART?**

We cannot guarantee that you will experience any benefits from this research, however, possible benefits may include:

- Contributing to the scientific knowledge base for CM.
- Providing evidence to support your profession.
- Collecting data that may benefit future patients/consumers of health care.
- Gaining experience of research methods and processes.

#### **IS THERE ANY RISK OR INCONVENIENCE?**

There are no notable risks. The process of inviting patients to participate will involve a short (approx. 5mins) conversation, which may be a slight inconvenience to yourself or your patients. The survey is anonymous and will not have any consequence for your practice or your working relationship with your patients.

#### **WHY HAVE I BEEN ASKED TO PARTICIPATE?**

You are invited to take part in this research because you are a complementary medicine practitioner operating within the Australian community, and because you have indicated an interest in participating in research by joining the PRACI/ORION/ACORN practitioner-based research network.

#### **DO I HAVE TO SAY YES?**

No. Participation in this research is voluntary. If you don't wish to take part, you don't have to.

#### **WHAT WILL HAPPEN IF I SAY NO TO PARTICIPATING?**

Nothing. You will not be contacted about this research again. You may be contacted about future research projects due to your membership with PRACI/ORION/ACORN. Your relationship with these PBRNs, with the research team at UTS, and with your patients will not be affected.

#### **IF I SAY YES, CAN I WITHDRAW LATER?**

You can change your mind at any time and you don't have to say why. You will be thanked for your time and you will not be contacted about the research again. If you choose to withdraw, please notify a member of the research team before doing so.

#### **WHAT WILL HAPPEN TO INFORMATION ABOUT ME?**

It is anticipated that results of this research will be published and/or presented in a variety of forums (e.g. PhD thesis, journals, conferences). In any publication and/or presentation, information will be presented in such a way that you cannot be identified. Any information obtained for the purpose of this research that can identify you or your business will be treated as confidential and securely stored. It will not be disclosed to any third party without your permission, unless required by law.

#### WHO IS DOING THE RESEARCH?

My name is Hope Foley and I am a PhD candidate from the Australian Research Centre in Complementary and Integrative Medicine (ARCCIM) at the University of Technology Sydney (UTS). The results of this research will help me in completing a Doctorate of Philosophy in Public Health. My supervisors are Distinguished Prof Jon Adams, Director of ARCCIM, and Dr Amie Steel, Postdoctoral Research Fellow at ARCCIM.

#### WHAT IF I HAVE QUESTIONS OR CONCERNS?

If you have concerns about the research that you think I or my supervisors can help you with, please feel free to contact me on [hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au)

#### WHAT IF I HAVE A COMPLAINT?

If you would like to talk to someone who is not connected with the research, you may contact the UTS Human Research Ethics Committee (HREC) on [research.ethics@uts.edu.au](mailto:research.ethics@uts.edu.au) or (02) 9514 2478 and quote this number: ETH18-2769.

IF YOU ARE INTERESTED IN ASSISTING WITH THIS RESEARCH, PLEASE CONTACT THE RESEARCH TEAM AT: <https://www.surveymzmo.com/s3/4609286/EOI-form-Patient-Experiences-of-CM-Study>

#### FLOWCHART OVERVIEW OF THE RESEARCH PROCESS

Practitioner receives invitation and information about research. If interested, informs research team via online EOI form, provides consent and receives survey materials.

Practitioner invites 15 consecutive patients to the research, using the provided script, and allowing time for questions. Practitioner provides these patients with a survey materials pack to take home.

Patients decide whether or not to consent and complete the survey at home. If the patient chooses to consent and participate, the survey is completed. The survey is then sealed in the reply-paid envelope provided and dropped in to a post-box.

Research team receives completed surveys by post. These surveys contain no data which could identify the participating patients or practitioners.

## EOI - Patient Experiences of the Complementary Medicine Consultation

Response ID: [REDACTED]

**1. Practitioner Expression of Interest and Consent Form**

1. Please provide your full name:

[REDACTED]

2. Please select your primary profession (if you have more than one qualification, please select the one which best describes your clinical practice):

[REDACTED]

3. Approximately how many patients do you consult with per week, on average?

[REDACTED]

4. Please provide an email address at which you can be readily contacted:

[REDACTED]

5. Please provide a phone number:

[REDACTED]

6. Please provide the postcode of your primary clinic location:

[REDACTED]

7. Please provide a mailing address to which we can send hardcopy survey materials:

[REDACTED]

8. What is your preferred contact method?

[REDACTED]

9. By ticking the box below and submitting this form, I acknowledge that I have read the [practitioner information sheet](#), or someone has read it to me in a language that I understand. I understand the purposes, process and risks of the research described. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I freely agree to participate in the research described by assisting with the recruitment of my patients, and understand that I am free to withdraw at any time without affecting any relationship I have with PRAC/ORION/ACORN or members of the research team conducting this project at UTS:ARCCIM.

I consent to participate in the research described above.

## APPENDIX 3.4 PHASE TWO PECMC SURVEY PATIENT INFORMATION SHEET

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

### Patient Experiences of the Complementary Medicine Consultation - Participant Information Sheet and Consent

<b>Principal Investigator:</b>	Hope Foley, PhD Candidate ARCCIM, Faculty of Health, UTS <a href="mailto:hope.m.foley@student.uts.edu.au">hope.m.foley@student.uts.edu.au</a>
<b>Supervisors:</b>	Distinguished Prof Jon Adams, Director ARCCIM, Faculty of Health, UTS <a href="mailto:jon.adams@uts.edu.au">jon.adams@uts.edu.au</a>  Dr Amie Steel, Postdoctoral Research Fellow ARCCIM, Faculty of Health, UTS <a href="mailto:amie.steel@uts.edu.au">amie.steel@uts.edu.au</a>
<b>Location:</b>	Clinics of complementary medicine practitioners within the Australian community, accessed via the Practitioner Research and Collaboration Initiative (PRACI), Osteopathy Research and Innovation Network (ORION), and Australian Chiropractic Research Network (ACORN).
<b>Ethics approval:</b>	This project has been approved by the Human Research Ethics Committee (HREC) of the University of Technology Sydney (UTS) (ETH18-2769). If you would like to talk to someone who is not connected with the research, you may contact the UTS HREC on <a href="mailto:research.ethics@uts.edu.au">research.ethics@uts.edu.au</a> or (02) 9514 2478.

### INFORMATION ABOUT THIS RESEARCH

This participant information sheet/consent form tells you about the research being conducted. It explains the processes involved in taking part so you can decide if you want to participate. Please read this sheet carefully. Ask questions if there is anything you don't understand or would like to know more about.

#### WHO IS DOING THE RESEARCH?

My name is Hope Foley and I am a PhD candidate from the Australian Research Centre in Complementary and Integrative Medicine (ARCCIM) at University of Technology Sydney (UTS). The results of this research will help me in completing a Doctorate of Philosophy in Public Health. My supervisors are Distinguished Prof Jon Adams, Director of ARCCIM, and Dr Amie Steel, Postdoctoral Research Fellow at ARCCIM.

#### WHAT IS THIS RESEARCH ABOUT?

This research is to find out about the perceptions patients have regarding the care they receive during consultation with their complementary medicine practitioners. This will help us to understand the role complementary medicine practitioners are playing for their patients in order to help meet the needs of consumers of health and medical services. The results will be published in my PhD thesis and may also be shared via scientific journal articles or presented at conferences.



**IF I SAY YES, WHAT WILL IT INVOLVE?**

You will be asked to complete a short survey of multiple-choice questions, which will be provided to you on paper. This survey will be anonymous.

**IS THERE ANY RISK OR INCONVENIENCE?**

There are no notable risks and you will not be asked to provide any personal identifying information. However, as the survey asks questions about experiences of healthcare services, you may experience some emotional discomfort if you have had distressing experiences during health care consultation. If you do experience discomfort or distress and would like some help, please let your practitioner know, or contact your GP or other health professional. Alternatively, for immediate emotional support, please call Lifeline on 13 11 14. The survey will take approximately 15-25 minutes to complete, which may be a slight inconvenience. As a thank you for your time, you will be given the opportunity to enter a draw to win a \$100 gift voucher at the completion of the survey, to be used at Amazon.com.au.

**WHY HAVE I BEEN ASKED TO PARTICIPATE?**

You are invited to take part in this research because you have consulted with a complementary medicine practitioner and we are interested in learning about the experience you've had.

**DO I HAVE TO SAY YES?**

No. Participation in this research is voluntary. If you don't wish to take part, you don't have to.

**WHAT WILL HAPPEN IF I SAY NO?**

Nothing. You will not be contacted about the research again. Your consultation will proceed as usual and there will be no impact on your relationship with your practitioner, with the researchers, or UTS:ARCCIM.

**IF I SAY YES, CAN I CHANGE MY MIND LATER?**

You can change your mind at any time and you don't have to say why. You will be thanked for your time and you will not be contacted about the research again.

**WHAT IF I HAVE QUESTIONS OR CONCERNS?**

If you have concerns about the research that you think I or my supervisors can help you with, please feel free to contact me on [hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au)

**WHAT IF I HAVE A COMPLAINT?**

If you would like to talk to someone who is not connected with the research, you may contact the UTS Human Research Ethics Committee (HREC) on [research.ethics@uts.edu.au](mailto:research.ethics@uts.edu.au) or (02) 9514 2478 and quote this number: ETH18-2769.

**DECLARATION OF CONSENT TO PARTICIPATE**

By completing the survey, you agree to the following:

I have read the participant information sheet, or someone has read it to me in a language that I understand. I understand the purposes, process and risks of the research described. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I have not completed this survey previously. I freely agree to participate in the research survey described and understand that I am free to withdraw at any time without affecting the health care I receive.

## APPENDIX 3.5 PRACTITIONER RECRUITMENT GUIDE AND SCRIPT

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

### Patient Experiences of the Complementary Medicine Consultation - Recruitment Process Overview & Ethical Considerations

Dear Practitioner,

Thank you for your interest in participating in this study's recruitment. Below are some important points to guide you in the process of recruitment.

It is essential that these points are applied in order to ensure the study is conducted in accordance with ethical requirements, and to ensure integrity of data via consistency of data collection procedures.

- 1.**
  - **Invite the patient to participate at the end of the consultation.**  
This will ensure the consultation process and experience is not disturbed or altered by the study. It also supports data integrity by keeping the recruitment process consistent and ensuring patients are reporting on their most recent consultation.
- 2.**
  - **Does the patient meet the inclusion criteria?**  
Invite only patients who are adults (aged 18+), who understand English well enough to complete the questionnaire, who are capable of freely consenting to participation, and have not already participated.
- 3.**
  - **Invite consecutive patients to reduce risk of selection bias.**  
Results of the study could be flawed if our own (conscious or unconscious) perspectives lead us to invite certain patients and not others. By inviting consecutive patients, we remove the potential impact of this. At times it may not be possible to invite a patient due to unforeseen circumstances, however, it is important to attempt not to skip anyone.
- 4.**
  - **It is important that practitioners are not aware of who has and has not participated.**  
Ensure your patient takes the survey home with them, and don't ask your patient about their survey. It's fine if your patient freely offers this information without prompting, but the survey must allow for anonymity.

#### Recruitment Process Overview:

Practitioner receives invitation and information about research from PRACI/ORION/ACORN administrators.  
If interested, informs research team via online EOI form, provides consent and receives survey materials - 15 packs, each containing Patient Information Sheet, hardcopy survey, and reply-paid envelope.

Practitioner invites 15 consecutive patients to the research, using the provided script, and allowing time for questions.  
Practitioner provides each of these 15 patients with a survey materials pack to take home.

Patients decide whether or not to consent and complete the survey at home. If the patient chooses to consent and participate, the survey is completed within 24 hours (or the relevant survey question is marked to indicate that more than 24 hours has passed). The survey is then sealed in the reply-paid envelope provided and dropped in to a post-box as soon as possible, at the participant's convenience.

Research team receives completed surveys by post. These surveys contain no data which could identify the participating patients or practitioners. The number of surveys returned is compared against the number of surveys given out in order to calculate a response rate.

If you have any queries or concerns about the above information, please contact Hope Foley, from our research team on [redacted] or [hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au)

Your participation is valuable to us.

We are very happy to answer any questions you have and to provide any further support you might require in order to participate in the study.

# UTS:ARCCIM

CRITICAL METHODS, TRANSLATIONAL RESEARCH

## Patient Experiences of the Complementary Medicine Consultation - Practitioner Guidelines for Patient Recruitment Procedures

Dear Practitioner,

Please follow the script provided below at the conclusion of your consultation with adult patients (aged over 18 years) who you believe have an adequate understanding of English to complete a questionnaire, and who are capable of giving informed consent.

Please follow this script for consecutive individual patients who meet the above criteria until 15 patients have been invited to participate. Please provide these patients with the envelope containing the Patient Information Sheet and Survey, and allow the patients to ask questions if they wish. Each patient may complete the survey only once – if the patient has already completed the survey, do not include them as one of the 15 consecutive invitees.

Thank you for your valuable assistance with this research.

### PRACTITIONER SCRIPT

I would like to inform you that you are eligible to participate in a research study I'm recruiting for. This would involve completing a questionnaire on paper, which could take 15-25 minutes. The questionnaire asks questions about your experiences of consulting with myself and other health care practitioners.

Completing the questionnaire is voluntary, and the information you provide is anonymous. Participating in this survey will have no effect on your care or relationship with me here. I will not see or know the answers you provide on the questionnaire, which you will seal in an envelope and send back to the researchers who are conducting this project. The researchers will not know who you are. The findings of this research may help with understanding the role complementary medicine plays for Australians, and may help to improve the health care Australians receive.

This envelope contains an information sheet about the research so you can decide if you'd like to complete the questionnaire. You can take this home with you, so I won't even know whether or not you've participated in the research. If you've already been given this survey, please let me know and do not take it again. If you decide to fill it in, I ask that you do so within 24 hours of this consultation. If you forget, you can still complete the survey, but within 24 hours is preferred. Once it is completed, you can seal it in this envelope and drop it into a post box. There is also a link on the survey where you can enter a draw online to win a \$100 gift voucher. If you decide not to participate, you can just put the survey in a recycling bin.

Dear Applicant

[External Ratification: 1) Endeavour College of Natural Health Human Research Ethics Committee  
2) Charles Sturt University Human Research Ethics Committee, HREC approval 1) 20170242  
2) H17048 - 1) 23 March 2017 - 23 March 2020  
2) 30 May 2018]

The UTS Human Research Ethics Expedited Review Committee has reviewed your application titled, "Complementary medicine use, health literacy and disclosure in the Australian population", and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that your external ethics approval has been ratified.

Your approval number is UTS HREC REF NO. ETH17-1564.

Approval will be for the period specified above and subject to the provision of annual reports and evidence of continued support from the above-named Committee.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au).

To access this application, please follow the URLs below:

\* if accessing within the UTS network: <https://rm.uts.edu.au>

\* if accessing outside of UTS network: <https://vpn.uts.edu.au>, and click on "RM6 – Production" after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to: <http://surveys.uts.edu.au/surveys/onlineethics/index.cfm>

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au).

Yours sincerely,

Associate Professor Beata Bajorek  
Chairperson  
UTS Human Research Ethics Committee  
C/- Research & Innovation Office  
University of Technology, Sydney  
E: [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)

## APPENDIX 3.7 PHASE ONE ECNH HREC ETHICS APPROVAL

Study Group Australia:  
Higher Education Division



### Human Research Ethics Committee - Approval to Conduct Experimentation on Humans

**Project Title:** Complementary medicine use, health literacy and disclosure in the Australian population

**Chief Investigator (s):** Dr Erica McIntyre

**Co-Investigator(s):** Dr Amie Steel, Dr Joanna Hartnett, Miss Hope Foley & Distinguished Professor Jon Adams

**Approval Number:** 20170242

**Duration of ethical clearance:** 3 years

The application for research proposal '*Complementary medicine use, health literacy and disclosure in the Australian population*' has been approved on the 23 March 2017 and is subject to the following conditions:

#### Conditions of approval

- You will conduct the project according to the principles outlined in the NHMRC's [National Statement on Ethical Conduct in Human Research 2007 \(Updated May 2015\)](#) and the [Australian Code for the Responsible Conduct of Research](#)
- You will notify the HREC of any adverse effects reported during the project
- You will notify the HREC of any changes in team, protocol or if you abandon the project
- You will submit annual report every year before the 3 October
- You will submit a final report at the completion of your research

If you have any questions or concerns regarding your application or this email, please don't hesitate to contact [HREC@endeavour.edu.au](mailto:HREC@endeavour.edu.au)

Kind regards,

Production Note:

Signature removed prior to publication.

Rebecca Reid

*On behalf of the Endeavour Human Research Ethics Committee*

## APPENDIX 3.8 PHASE ONE CSU HREC ETHICS APPROVAL



**OFFICE OF GOVERNANCE AND  
CORPORATE AFFAIRS**  
GOVERNANCE SERVICES

Private Mail Bag 29  
Panorama Avenue  
Bathurst NSW 2795

Tel: +61 2 6338 4628

Fax: +61 2 6338 4194

Email: [ethics@csu.edu.au](mailto:ethics@csu.edu.au)

[http://www.csu.edu.au/acad\\_sec](http://www.csu.edu.au/acad_sec)

8 May 2017

Dr A Steel  
By email: [amie.steel@endeavour.edu.au](mailto:amie.steel@endeavour.edu.au)

Dear Dr Steel,

Thank you for advising the Charles Sturt University Human Research Ethics Committee that your research proposal has been approved by Endeavour College of Natural Health Human Research Ethics Committee.

The Charles Sturt University Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's [National Statement on Ethical Conduct in Human Research](#) (*National Statement*) and as such, accepts other fully constituted Human Research Ethics Committee's determinations.

Consequently, I am pleased to advise the Committee has approved your research proposal. Please see below details of your research project:

**Project Title:** Complementary medicine use, health literacy and disclosure in the Australian population

**Approved until:** 30 May 2018 (subject to annual progress reports)

**Protocol Number:** H17048 (to be included in all correspondence to the Committee)

**Progress Report due by:** 20 April 2018

You must report to the Committee at least annually, and as soon as possible in relation to the following, by completing the 'Report on Research Project' form:

- any serious and/or unexpected adverse events or outcomes which occur associated with the research project that might affect participants, therefore, the ethical acceptability of the project;
- amendments to the research design and/or any changes to the project (Committee approval required);
- extensions to the approval period (Committee approval required); and
- notification of project completion.

This approval constitutes ethical approval in relation to humans only. If your research involves the use of radiation, biochemical materials, chemicals or animals, separate approval is required by the appropriate University Committee.

Please contact the Governance Office on (02) 6338 4628 or [ethics@csu.edu.au](mailto:ethics@csu.edu.au) if you have any queries.

The Committee wishes you well with your research.

Sincerely

Production Note:

Signature removed prior to publication.

Mrs Sue Price  
Governance Officer

## APPENDIX 3.9 PHASE TWO UTS HREC ETHICS APPROVAL

04/10/2018

Mail - Hope.M.Foley@student.uts.edu.au

### HREC Approval Granted - ETH18-2769

Research.Ethics@uts.edu.au

Thu 27/09/2018 5:07 PM

To: Amie Steel <Amie.Steel@uts.edu.au>; Jon Adams <Jon.Adams@uts.edu.au>; Hope Foley <Hope.M.Foley@student.uts.edu.au>; Research Ethics <research.ethics@uts.edu.au>;

Dear Applicant

Thank you for your response to the Committee's comments for your project titled, "Patient Experiences of the Complementary Medicine Consultation". The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application, subject to any conditions detailed in this document.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (<http://www.gsu.uts.edu.au/policies/research-management-policy.html>).

Your approval number is UTS HREC REF NO. ETH18-2769.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.
- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat (Research.Ethics@uts.edu.au).
- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found at <https://staff.uts.edu.au/topic/sub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2>
- The Principal Investigator will promptly report adverse events to the Ethics Secretariat (Research.Ethics@uts.edu.au). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.
- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.
- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).
- The Principal Investigator will notify the UTS HREC of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.



I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au).

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au).

Yours sincerely,

<https://outlook.office.com/owa/?realm=student.uts.edu.au>

1/2

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04/10/2018

Mail - [Hope.M.Foley@student.uts.edu.au](mailto:Hope.M.Foley@student.uts.edu.au)

Dr Tim Lockett  
(Acting) Chairperson  
UTS Human Research Ethics Committee  
C/- Research & Innovation Office  
University of Technology, Sydney  
E: [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)

REF: E38

## APPENDIX 4. PUBLISHED MANUSCRIPT ASSOCIATED WITH RESULTS REPORTED IN CHAPTER 4.

Complementary Therapies in Clinical Practice 40 (2020) 101194



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### Complementary medicine practitioner consultations amongst 1,314 individuals with chronic conditions: Characteristics of users, reasons for and predictors of use

Hope Foley <sup>a,b,\*</sup>, Amie Steel <sup>a</sup>, Erica McIntyre <sup>a</sup>, Joanna Harnett <sup>a,c</sup>, David Sibbritt <sup>a</sup>, Jon Wardle <sup>a</sup>, Jon Adams <sup>a</sup>

<sup>a</sup> Australian Research Centre in Complementary and Integrative Medicine, Faculty of Health, University of Technology Sydney, Ultimo, Australia

<sup>b</sup> Office of Research, Endeavour College of Natural Health, Brisbane, Australia

<sup>c</sup> The University of Sydney, Faculty of Medicine and Health, School of Pharmacy, Sydney, New South Wales, Australia

#### ARTICLE INFO

**Keywords:**  
Chronic illness  
Complementary medicine  
Health services  
Quality of life  
Health care seeking  
Social determinants of health

#### ABSTRACT

**Background:** The complexity of chronic conditions challenges health systems and patients. Patients with chronic conditions often consult complementary medicine (CM) practitioners. Optimal care of chronic conditions requires understanding of the characteristics and consultation behaviours of these patients.

**Methods:** Cross-sectional survey (n = 2025 adults), broadly representative of the Australian population. Measures included sociodemographics, health status and health service utilisation. Data from participants with chronic conditions were analysed.

**Results:** Of the 1314 participants reporting chronic conditions, 38.4% consulted a CM practitioner. Significant differences were observed between participants who did/did not consult CM practitioners, across all socio-demographics and some health status items. The most reported reason for consultation was to support wellbeing. Predictors of consultation were younger age, employment, and private health insurance coverage for CM, however, predictors varied by profession consulted.

**Conclusion:** CM consultations amongst those with chronic conditions appear to be influenced by sociodemographic and economic factors, and quality of life needs.

#### 1. Introduction

Chronic conditions are prolonged health conditions, often involving complex causes, requiring ongoing medical care, and limiting an individual's functional capacity [1]. Rates of chronic conditions are rising, increasingly contributing to the burden of disease and incurring substantial economic, personal and social costs to public health systems, individuals and their communities [2]. The rising prevalence of chronic conditions is influenced by post-industrial shifts in societal lifestyle and dietary habits not conducive to health maintenance [3], alongside advancements in medical science resulting in reduced burden from acute and infectious diseases, and subsequently increased life expectancy [3].

While recognition of the burden of chronic conditions has led to their prioritisation in public health policy [2,3]. Even so, the complex, protracted nature of chronic conditions (which, unlike acute conditions, often include multiple morbidities) presents challenges to health care

models built on strategies targeting acute, infectious diseases [4]. Individuals with chronic conditions often require multifactorial, coordinated approaches to care accounting for the various difficulties impacting on health and daily life [2], particularly in multimorbidity where concurrent conditions add to complexity of needs and care [5]. For many individuals with chronic conditions, the challenges of their health needs are further compounded by socioeconomic consequences arising from reduced capacity to engage in employment and social activities [6]. Combined, the challenges facing both health systems and individuals regarding management of chronic conditions can result in unmet health-related needs for the chronically ill [2].

Efforts made by people living with chronic conditions to address their own unmet needs can lead to seeking additional care outside of conventional medicine, often in the form of complementary medicine (CM)—practices, paradigms and products defined as “complementary” by their general exclusion from the medical curriculum and mainstay of

\* Corresponding author. Office of Research, Endeavour College of Natural Health, Level 2/269 Wickham St, Fortitude Valley, Qld, 4006, Australia.  
E-mail address: [hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au) (H. Foley).

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conventional medical practice [7]. While CM can be self-prescribed, they are also provided by practitioners trained in CM professions, and are included in treatment by some conventional medical providers [7]. Use of CM in the Australian general population is high, with 12-month prevalence estimates over 60% and consultation with CM practitioners reported by more than half of CM users [8]. Individuals with chronic conditions have shown higher rates of CM use, including CM practitioner services [9]. CM practitioners may be especially attractive to individuals with complex needs due to the holistic approach inherent to many CM philosophies [10], which seek to address the varied factors directly and indirectly influencing health and wellbeing [11].

The value of formally including CM in management and prevention of chronic conditions has been acknowledged in international public health guidelines [12]. Nevertheless, such inclusion remains ad-hoc and beyond formal practice in Australia, particularly regarding services delivered by CM practitioners, leaving patients to coordinate their own care with little guidance [13]. To date, what is known about the context and nature of service delivery by CM practitioners in Australia or the role it plays in wider care for those with chronic conditions is limited [9]. Empirically examining CM practitioner use by this clinical sub-population is imperative to develop and evaluate possibilities of more formal integrated care in accordance with current evidence-based, person-centred guidelines [8]. In direct response to this empirical gap, this paper describes the characteristics and CM practitioner consultation behaviours of individuals with chronic conditions.

## 2. Materials and methods

### 2.1. Study design and setting

The Complementary and Alternative Medicine Use, Health Literacy and Disclosure (CAMUHL) project was conducted as a cross-sectional survey, online, between 26 July and 28 August 2017. This paper reports analyses of data provided by respondents who indicated having chronic conditions.

### 2.2. Participants and recruitment

Participants were adults (aged 18 and over), invited to participate through membership with research recruitment company Qualtrics. Purposive convenience sampling was employed to achieve a sample broadly representative of the Australian population regarding gender, age and state of residence. As part of the benefits involved with being a Qualtrics database member, participants who completed the survey were provided a small financial compensation. Participants provided consent after reading an information sheet. Survey completion time was approximately 15 min. A sample of 2025 was drawn, producing 2019 cases after removal of six respondents, deemed unreliable due to discrepancies in their data. This final sample size was considered adequate to provide statistical power for inferential analyses, based on previous literature reporting CM use in Australia [9]. Of the 2019 respondents included in the CAMUHL project, 1314 reported having one or more chronic conditions to comprise the sample for analyses reported here.

### 2.3. Instrument

The survey was comprised of 50 items encompassing sociodemographics, health status, health service utilisation, health literacy and health communication. Items applicable to analyses presented here included sociodemographics, health status and health service utilisation.

Sociodemographics covered gender, age, state of residence, financial manageability, educational qualification, employment status, marital status, private health insurance (PHI) coverage, and possession of a Health Care Card (provided to low-income earners and welfare recipients in Australia for financial concessions on health care and

medicines). Respondents indicated (yes/no) which chronic condition/s they had been diagnosed with or treated for within the preceding 3 years from a list of common chronic health conditions, alongside an open-text option of *other health condition (please specify)*, and an option for *none of the above* (details in Table 1). Health status was assessed with the 20-item short-form health survey (SF-20) which assesses self-perceived health status across six domains (physical functioning, role functioning, social functioning, mental health, current health perceptions, pain) [14]. The SF-20 has been shown to be a valid and reliable measure of self-perceived health status that balances breadth and depth of measurement in a short form [14].

Health service utilisation items asked respondents whether they had consulted with a range of conventional medicine providers and CM practitioners within the previous 12 months, and the reasons for consultation. These items were adapted from the International Complementary and Alternative Medicine Questionnaire (I-CAM-Q) [15], with modifications to ensure cultural relevance in the Australian context and suitability for online delivery. The I-CAM-Q was developed to allow consistency in collection of information about CM use across different populations [15]. Formatting of the online instrument encouraged respondents to complete all items relevant to the individual and allowed for open-text responses where suitable, limiting occurrence of missing responses.

**Table 1**  
Chronic conditions presented in survey and categorisation of conditions for analysis.

Condition categories	Specific conditions as listed on survey
Cardiovascular	Heart disease Hypertension Dyslipidaemia
Diabetes	Type 1 diabetes Non-insulin dependent type 2 diabetes Insulin dependent type 2 diabetes
Cancer	Cancer (benign) Cancer (malignant)
Female reproductive	Endometriosis Polycystic ovarian syndrome Other female reproductive disorder
Male reproductive	Benign prostatic hyperplasia Other male reproductive disorder
Respiratory	Asthma Bronchitis Other respiratory disorder
Gastrointestinal	Irritable bowel syndrome (IBS) Inflammatory bowel disease (Crohn's disease, ulcerative colitis) Coeliac disease Gastro-oesophageal reflux disease (GORD/GERD) Chronic constipation Other gastrointestinal/digestive disorder
Mental Health	Mood disorder (e.g. depression) Anxiety disorder Sleep disorder Substance use disorder Schizophrenia or other psychotic disorder Other mental health disorder
Musculoskeletal	Osteoarthritis Other musculoskeletal disorder
Other	Other chronic health condition/s (not listed above)

## 2.4. Data analysis

Analyses were conducted with Stata/IC-14 (StataCorp LC 2015) software. Categorical variables detailing service utilization of health care providers were recoded to binaries (consulted/did not consult), and a binary variable was generated to describe the presence of chronic condition/s (yes/no). Chronic condition variables were also collapsed into categories (e.g. cardiovascular, gastrointestinal) for analyses, as shown in Table 1.

Associations between having consulted a CM practitioner and sociodemographic/health status variables were assessed using chi-square tests (categorical/binary variables) and independent t-tests (continuous variables). Potential predictors for having consulted with the most commonly accessed CM professions were determined using reverse stepwise logistic regression, producing adjusted odds ratios (aOR) in the most parsimonious model accounting for the influence of sociodemographic and health status factors. Statistical significance was set at  $p < 0.05$ . Missing data were excluded from analysis.

## 2.5. Ethics

Ethical approval was obtained from the [institution blinded for review purposes] Human Research Ethics Committee ([HREC/approval number blinded for review purposes]). The study was approved and conducted in accordance with the Declaration of Helsinki.

## 3. Results

## 3.1. Participant characteristics

Amongst respondents with chronic conditions ( $n = 1314$ ) a slight majority were female (54.0%). The most commonly reported age group was 60 and over (31.9%), and most respondents resided in the states of New South Wales (27.3%), Victoria (25.2%) or Queensland (24.7%). They were most commonly married (43.7%), not in the paid workforce (42.4%) and held a post-secondary school trade or vocational qualification as their highest educational level (36%). When asked how they were managing financially, the most frequently recorded response was it is difficult some of the time (37.8%). PHI was held by 47.7% of the sample,

Table 2  
Sociodemographics of participants with chronic conditions.

Sociodemographic category	Full sample $n = 1314$	Consulted CM practitioner $n = 505$ (38.4%)	Didn't consult CM practitioner $n = 809$ (61.6%)	Chi [2] P value
<b>Gender</b>				
Female	709 (54.0%)	298 (59.0%)	411 (50.8%)	.004
Male	604 (46.0%)	207 (41.0%)	397 (49.1%)	
Other <sup>†</sup>	1 (0.1%)	0 (0.0%)	1 (0.1%)	
<b>Age</b>				
18-29	264 (20.1%)	133 (26.3%)	131 (16.2%)	<.001
30-39	182 (13.9%)	90 (17.8%)	92 (11.4%)	
40-49	229 (17.4%)	99 (19.6%)	130 (16.1%)	
50-59	220 (16.7%)	74 (14.7%)	146 (18.1%)	
60 and over	419 (31.9%)	109 (21.6%)	310 (38.3%)	
<b>State</b>				
NSW	359 (27.3%)	145 (28.7%)	214 (26.5%)	.01
VIC	331 (25.2%)	145 (28.7%)	186 (23.0%)	
QLD	325 (24.7%)	125 (24.8%)	200 (24.7%)	
SA	122 (9.3%)	44 (8.7%)	78 (9.6%)	
NT	4 (0.3%)	1 (0.2%)	3 (0.4%)	
WA	125 (9.5%)	31 (6.1%)	94 (11.6%)	
TAS	31 (2.4%)	7 (1.4%)	24 (3.0%)	
ACT	17 (1.3%)	7 (1.4%)	10 (1.2%)	
<b>Managing financially</b>				
It is impossible	50 (3.8%)	13 (2.6%)	37 (4.6%)	.041
It is difficult all of the time	273 (20.8%)	90 (17.8%)	183 (22.6%)	
It is difficult some of the time	496 (37.8%)	197 (39.0%)	299 (37.0%)	
It is not too bad	420 (32.0%)	170 (33.7%)	250 (30.9%)	
It is easy	75 (5.7%)	35 (6.9%)	40 (4.9%)	
<b>Education level</b>				
Up to year 10	236 (18.0%)	66 (13.1%)	170 (21.0%)	<.001
Year 12 or equivalent	260 (19.8%)	88 (17.4%)	172 (21.3%)	
Trade/VET	473 (36.0%)	177 (35.1%)	296 (36.6%)	
University degree	345 (26.3%)	174 (34.5%)	171 (21.1%)	
<b>Employment status</b>				
Full time work	327 (24.9%)	176 (34.9%)	151 (18.7%)	<.001
Part time work	236 (18.0%)	109 (21.6%)	127 (15.7%)	
Casual/temporary work	84 (6.4%)	33 (6.5%)	51 (6.3%)	
Looking for work	110 (8.4%)	28 (5.5%)	82 (10.1%)	
Not in paid workforce	557 (42.4%)	159 (31.5%)	398 (49.2%)	
<b>Marital status</b>				
Never married	328 (25.0%)	139 (27.5%)	189 (23.4%)	.048
Married	574 (43.7%)	231 (45.7%)	343 (42.4%)	
De facto (opposite sex)	139 (10.6%)	46 (9.1%)	93 (11.5%)	
De facto (same sex)	21 (1.6%)	9 (1.8%)	12 (1.5%)	
Separated/divorced/widowed	252 (19.2%)	80 (15.8%)	172 (21.3%)	
<b>PHI status</b>				
Has PHI	627 (47.7%)	301 (59.6%)	326 (40.3%)	<.001
PHI covers any CM	417 (31.8%)	242 (47.9%)	175 (21.6%)	<.001
HCC status	503 (38.3%)	204 (40.4%)	299 (37.0%)	.212

Note. <sup>†</sup>Excluded from analyses of gender due to small cell size.

with 31.8% including cover for CM services, and Health Care Cards were held by 38.3%.

Of the 1314 respondents, 505 (38.4%) had consulted a CM practitioner one or more times in the preceding 12 months, while 809 (61.6%) had not. The two groups were significantly different across all sociodemographic domains excluding possession of a Health Care Card ( $p = 0.212$ ). Those who had consulted a CM practitioner were more commonly: female ( $p = 0.004$ ), of younger age (49 years or below) ( $p < 0.001$ ), located in New South Wales or Victoria ( $p = 0.01$ ), in possession of university-level qualifications ( $p < 0.001$ ), employed ( $p < 0.001$ ), managing better financially ( $p = 0.041$ ), and single or married (as opposed to de facto, separated, divorced or widowed) ( $p = 0.048$ ). Those who consulted CM practitioners more commonly had PHI ( $p < 0.001$ ) and higher rates of PHI coverage for CM services ( $p < 0.001$ ). Full sociodemographics are presented in Table 2.

### 3.2. Participant health status

The most commonly reported category of chronic conditions was mental health (48.8%), followed by cardiovascular (33.9%), respiratory (26.9%), musculoskeletal (24.1%) and gastrointestinal (22.3%) conditions. Multimorbidity was common with almost two-thirds (65.3%) reporting two or more concurrent chronic conditions (see Table 3).

Compared to respondents who did not consult CM practitioners, those who did consult had lower rates of reported cardiovascular disease ( $p = 0.016$ ), and higher rates of reported female reproductive ( $p < 0.001$ ), gastrointestinal ( $p < 0.001$ ), mental health ( $p = 0.004$ ) and respiratory conditions ( $p = 0.019$ ), as well as higher odds of reporting multimorbidity involving five or more conditions ( $p = 0.001$ ). While those who consulted with CM practitioners reported higher levels of general health status ( $p = 0.011$ ), they also reported lower scores of physical functioning ( $p = 0.006$ ), social functioning ( $p < 0.001$ ) and mental health ( $p < 0.001$ ), and higher levels of bodily pain ( $p = 0.002$ )

(see Table 3).

### 3.3. Health service utilisation and reasons for consultation

Of the CM professions consulted, the most common was massage therapy ( $n = 284$ , 21.6%), followed by chiropractic ( $n = 188$ , 14.3%), acupuncture ( $n = 123$ , 9.4%), yoga ( $n = 110$ , 9.0%), naturopathy ( $n = 94$ , 7.2%) and osteopathy (91, 6.9%). The least commonly utilized CM professions were traditional medicine (other than traditional Chinese medicine) ( $n = 2$ , 0.2%) and "other" natural medicine professions ( $n = 8$ , 0.6%). Consulting with CM practitioners to support general wellbeing was common, being the most frequently reported reason for consulting with traditional medicine practitioners (100%), yoga teachers (77.0%), massage therapists (62.0%), aromatherapists (59.7%), traditional Chinese medicine practitioners (50.3%), Western herbalists (54.4%) and naturopaths (54.3%). Seeking treatment for long-term conditions was the most frequently reported reason for consulting with acupuncturists (63.4%), osteopaths (55.0%), chiropractors (53.7%) and homeopaths (38.0%). Seeking treatment for acute conditions or for "other" reasons were less commonly reported across all CM professions.

Conventional medical services were heavily utilised within the sample with the most commonly consulted profession being general practitioners (GPs) ( $n = 1,257$ , 95.7%), followed by pharmacists ( $n = 1,105$ , 84.1%), specialist doctors ( $n = 719$ , 54.7%) and hospital doctors ( $n = 472$ , 35.9%). Across all four conventional medical professions, the most frequently reported reason for consultation was to seek treatment for a long-term condition. Further details in Table 4.

### 3.4. Predictors of consultation with CM professions

The regression model found respondents who consulted with CM practitioners had approximately half the odds of being from older age groups of 50–59 years ( $aOR = 0.52$ ) or 60 years and older ( $aOR = 0.48$ )

Table 3  
Health Status and Personal Wellbeing of Participants who did and did not Consult with CM Practitioners.

	Full sample <i>n</i> = 1314	Consulted CM practitioner <i>n</i> = 505 (38.4%)	Did not consult CM practitioner <i>n</i> = 809 (61.6%)	<i>P</i> value <sup>1</sup>
<b>Condition</b>				
Cardiovascular	445 (33.9%)	151 (29.9%)	294 (36.3%)	.016
Diabetes	176 (13.4%)	70 (13.9%)	106 (13.1%)	.694
Cancer	132 (10.1%)	52 (10.3%)	80 (9.9%)	.811
Female reproductive	112 (8.5%)	61 (12.1%)	51 (6.3%)	<.001
Male reproductive	48 (3.7%)	20 (4.0%)	28 (3.5%)	.639
Respiratory	353 (26.9%)	154 (30.5%)	199 (24.6%)	.019
Gastrointestinal	293 (22.3%)	141 (27.9%)	152 (18.8%)	<.001
Mental Health	641 (48.8%)	272 (53.9%)	369 (45.6%)	.004
Musculoskeletal	317 (24.1%)	124 (24.6%)	193 (23.9%)	.774
Other	148 (11.3%)	52 (10.3%)	96 (11.9%)	.381
<b>Multimorbidity</b>				
1 condition	455 (34.6%)	165 (32.7%)	290 (35.9%)	.001
2 conditions	284 (21.6%)	92 (18.2%)	192 (23.7%)	
3 conditions	184 (14.0%)	81 (16.0%)	103 (12.7%)	
4 conditions	145 (11.0%)	49 (9.7%)	96 (11.9%)	
5+ conditions	246 (18.7%)	118 (23.4%)	128 (15.8%)	
<b>SF-20</b>				
General health	45.22 ± 26.96	47.62 ± 28.20	43.73 ± 26.06	.011
Physical functioning	66.20 ± 32.05	63.15 ± 31.36	68.10 ± 32.34	.006
Role functioning	61.43 ± 42.04	59.06 ± 40.50	62.92 ± 42.92	.053
Social functioning	71.60 ± 30.36	65.82 ± 31.63	75.20 ± 28.99	<.001
Mental health	59.91 ± 23.79	57.12 ± 21.71	61.65 ± 24.86	<.001
Health perception	48.04 ± 26.12	47.71 ± 25.94	48.24 ± 26.24	.72
Pain	57.99 ± 25.67	55.17 ± 25.70	59.75 ± 25.50	.002

Note. <sup>1</sup>Chi-square association used for binary and categorical variables (condition, multimorbidity), independent *t*-test used for continuous variables (SF-20 scores).

**Table 4**  
Health professions consulted and reasons for consultation.

	Profession Consulted		Reasons for consulting with a CM practitioner								No. reasons <sup>1</sup>	
	n	%	Long-term condition		Acute condition		Wellbeing		Other		Mean	SD
			n	%	n	%	n	%	n	%		
<b>Complementary medicine</b>												
Massage therapist	284	21.6	108	38.0	47	16.6	176	62.0	6	2.1	1.20	0.46
Chiropractor	188	14.3	101	53.7	46	24.5	69	36.7	6	3.2	1.18	0.47
Acupuncturist	123	9.4	78	63.4	27	22.0	36	29.3	1	0.8	1.17	0.44
Yoga teacher	118	9.0	32	27.1	13	11.0	91	77.0	0	0.0	1.15	0.44
Naturopath	94	7.2	43	45.7	17	18.1	51	54.3	1	1.1	1.19	0.49
Osteopath	91	6.9	50	55.0	23	25.3	27	29.7	2	2.2	1.15	0.39
TCM practitioner	72	5.5	32	44.4	19	26.4	42	58.3	0	0.0	1.29	0.59
Aromatherapist	62	4.7	24	38.7	14	22.6	37	59.7	0	0.0	1.21	0.48
Western herbalist	57	4.3	17	29.8	15	26.3	31	54.4	0	0.0	1.12	0.31
Homeopath	50	3.8	19	38.0	15	30.0	18	36.0	0	0.0	1.06	0.24
Other natural medicine	8	0.6	4	50.0	1	12.5	6	75.0	0	0.0	1.38	0.74
Traditional medicine	2	0.2	0	0.0	0	0.0	2	100.0	0	0.0	1.00	0.00
<b>Conventional medicine</b>												
GP	1257	95.7	804	64.0	332	26.4	358	28.5	96	7.6	1.26	0.52
Specialist doctor	719	54.7	539	75.0	137	19.1	145	20.2	27	3.8	1.18	0.44
Hospital doctor	472	35.9	229	48.5	226	47.9	69	14.6	12	2.5	1.14	0.40
Pharmacist	1105	84.1	642	58.1	250	22.6	327	29.6	140	12.7	1.23	0.52

Note. <sup>1</sup>Average number of reasons provided by participants.

than those who did not consult with CM practitioners. The odds of them being unemployed were also lower (looking for work aOR = 0.39 or not in the workforce aOR = 0.57) and they had twice the odds of managing well financially (it is not too bad aOR = 2.01; it is easy aOR = 2.65). Respondents who consulted with CM practitioners had increased odds by almost half of reporting gastrointestinal conditions (aOR = 1.49) and by more than one-third of reporting mental health conditions (aOR = 1.35). They were approaching three times the odds of PHI coverage for CM services (aOR = 2.65). Further details in Table 5.

Respondents consulting a chiropractor had increased odds by almost two-thirds of being male (aOR = 1.64) and by more than three-quarters of having five or more multimorbid conditions (aOR = 1.77), while their odds of being from older age groups were reduced by more than half (50–59 years aOR = 0.46; 60 years and older aOR = 0.41). Having consulted an osteopath was associated with decreased odds by more than half of reporting cardiovascular conditions (aOR = 0.47) and of being from older age groups (50–59 years aOR = 0.40; 60 years and older aOR = 0.22).

Respondents who had visited a massage therapist had decreased odds by almost half of being from older age groups (50–59 years aOR = 0.57; 60 years and older aOR = 0.51) and by more than half of being unemployed (looking for work aOR = 0.41 or not in the workforce aOR = 0.49). More than twice the odds of reporting a cancer diagnosis (aOR = 2.32) and almost three times the odds of reporting male reproductive conditions (aOR = 2.93) were found amongst respondents consulting an acupuncturist. Their odds of being married were twice that of being single (aOR = 2.01), while their odds of being from older age groups were substantially reduced (50–59 years aOR = 0.37; 60 years and older aOR = 0.22).

Respondents who had utilized the services of a yoga teacher had reduced odds by almost half of being male (aOR = 0.52) and substantially reduced odds of being unemployed (looking for work aOR = 0.34 or not in the workforce aOR = 0.24) or casually/temporarily employed (aOR = 0.33). They were found to have reduced odds by half of being aged 30–39 (aOR = 0.50) and by more than two-thirds of being aged 50–59 (aOR = 0.28), while their odds of holding university-level qualifications were increased by more than two-fold (aOR = 2.64) and odds of holding a Health Care Card were reduced by almost half (aOR = 0.52).

Odds of being not in the workforce were reduced by more than two-thirds (aOR = 0.29) for respondents consulting a naturopath. While holding PHI generally was not found to be a predictor of consulting a CM

practitioner, the odds of having PHI coverage for the specific profession utilised was increased across all six professions, ranging from aOR = 2.63 for yoga to aOR = 6.09 for osteopathy. Full details of adjusted odds ratios are presented in Table 5.

#### 4. Discussion

This paper is the first to present a detailed description of the characteristics of individuals with chronic conditions who consult with CM practitioners in Australia, alongside indications of the motivation for seeking such care. This provides insight into the dynamics of the relationship between chronic illness and CM use in the Australian health care landscape. There appear to be a number of sociodemographic factors influencing both utilisation of CM practitioner services generally, and utilisation of specific CM professions, which speak to the complex interplay of physical, economic and psychosocial determinants of health associated with living with chronic conditions.

The finding that participants consulting any CM practitioner had higher odds of being younger, employed, able to manage financially and in possession of PHI coverage for CM is consistent with what is known about CM practitioner service users in the general population [9]. Differences, however, were noted regarding use of specific CM professions, highlighting the nuanced nature of the field of CM and significant heterogeneity between CM professions and practices. Additionally, while employment status predicted utilisation of some CM professions by study participants, financial management status did not, nor did general PHI cover status. Considered together, these economic factors suggest a more complex relationship between financial status and CM use than a direct correlation with income. Previous research shows the economic burden of managing chronic conditions can affect an individual's financial management and create greater perceived necessity for PHI coverage, regardless of income or employment status [16]. Consequently, it may be that individuals in our study were encouraged to consult CM practitioners by the potential cost-reduction afforded by PHI coverage for CM. Additionally, participant employment could possibly have been influential, as CM practitioners often build a client-base via word-of-mouth referrals [17,18], which are more likely to occur during social interaction such as the interaction that occurs when working with others in employment.

We also found the associations between consultation behaviour and chronic condition categories differed depending on which CM

**Table 5**  
 Predictors of consulting with complementary medicine (CM) practitioners: Results of reverse stepwise logistic regression.

	Any CM			Chiropractic			Osteopathic			Massage therapy			Acupuncture			Yoga			Naturopathy		
	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI
<b>Gender</b>																					
Female	Ref	-	-	Ref	-	-	-	-	-	-	-	-	-	-	-	-	-	-	Ref	-	-
Male				1.64	.006	1.16, 2.34									0.52	.005	0.33, 0.82				
<b>Age range</b>																					
18-29	Ref	-	-	Ref	-	-	-	-	-	-	-	-	-	-	-	-	-	-	Ref	-	-
30-39	1.04	.855	0.68, 1.59	0.86	.591	0.50, 1.48	1.46	.302	0.71, 2.98	1.38	.158	0.88, 2.15	0.64	.175	0.33, 1.22	0.50	.025	0.27, 0.92			
40-49	0.77	.217	0.52, 1.16	0.71	.195	0.42, 1.19	0.77	.491	0.36, 1.63	0.98	.935	0.64, 1.52	0.67	.191	0.36, 1.22	0.62	.115	0.35, 1.12			
50-59	0.52	.003	0.33, 0.79	0.46	.007	0.27, 0.81	0.40	.049	0.16, 1.00	0.57	.026	0.35, 0.93	0.37	.006	0.18, 0.76	0.28	.002	0.12, 0.62			
60+	0.48	.001	0.32, 0.74	0.41	<.001	0.25, 0.66	0.22	.002	0.08, 0.60	0.51	.008	0.31, 0.84	0.22	<.001	0.11, 0.45	0.48	.061	0.23, 1.03			
<b>Employment status</b>																					
Full time work	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Part time work	1.04	.826	0.72, 1.52							0.99	.942	0.66, 1.46			0.68	.168	0.39, 1.17	0.96	.895	0.55, 1.70	
Casual/temp work	0.70	.195	0.41, 1.20							0.57	.077	0.31, 1.06			0.33	.013	0.13, 0.79	0.58	.252	0.23, 1.47	
Looking for work	0.39	.001	0.23, 0.67							0.41	.004	0.22, 0.75			0.34	.013	0.15, 0.79	0.63	.259	0.28, 1.41	
Not in workforce	0.57	.003	0.40, 0.83							0.49	.001	0.32, 0.73			0.24	<.001	0.12, 0.49	0.29	<.001	0.16, 0.54	
<b>Managing financially</b>																					
It is impossible	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Difficult all the time	1.40	.365	0.67, 2.92																		
Difficult sometimes	1.96	.065	0.96, 4.00																		
It is not too bad	2.10	.047	1.01, 4.35																		
It is easy	2.68	.03	1.10, 6.52																		
<b>Educational qual</b>																					
Up to year 10	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Year 12 or equivalent															0.95	.908	0.38, 2.38				
Trade/Vocational															1.55	.291	0.69, 3.52				
University															2.64	.021	1.16, 6.00				
<b>Marital status</b>																					
Never married	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Married															2.01	.011	1.17, 3.44				
De facto, opposite sex															0.41	.08	0.15, 1.11				
De facto, same sex															1.19	.831	0.25, 5.65				
Separated/Divorced/ Widowed															1.85	.072	0.95, 3.60				

(continued on next page)

Table 5 (continued)

	Any CM			Chiropractic			Osteopathic			Massage therapy			Acupuncture			Yoga			Naturopathy		
	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI	aOR	P	CI
Cardiovascular condition							0.47	.025	0.25, 0.91												
Cancer diagnosis													2.32	.006	1.28, 4.21						
Male reproductive condition													2.93	.016	1.22, 7.03						
Gastrointestinal condition	1.49	.008	1.11, 2.00																		
Mental health condition	1.35	.029	1.03, 1.77																		
Multimorbidity																					
1 condition	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
2 conditions				1.04	.877	0.64, 1.68															
3 conditions				1.35	.268	0.80, 2.28															
4 conditions				0.62	.173	0.32, 1.23															
5+ conditions				1.77	.026	1.07, 2.94															
PHI covers this	2.85	<.001	2.17, 3.72	3.25	<.001	2.28, 4.63	6.09	<.001	3.42, 10.85	3.69	<.001	2.62, 5.21	3.68	<.001	2.29, 5.91	2.63	.003	1.39, 5.00	2.64	.003	1.40, 4.95
Health Care Card holder															0.52	.007	0.33, 0.84				

Note. aOR = Odds ratio adjusted for sociodemographic and health status variables.



professions were consulted, indicating potential relationships between profession-specific treatments and condition-specific needs. Those consulting with osteopaths had lower odds than other respondents of reporting cardiovascular conditions, which is not unexpected given the general focus of osteopaths on musculoskeletal conditions [19]. Nonetheless, these lower odds may represent missed opportunities for cardiovascular management, considering that osteopaths report provision of patient education on modifiable factors that contribute to cardiovascular disease such as exercise, stress management and nutrition [19]. Participants who had consulted with acupuncturists had higher odds than those who had not consulted acupuncturists of reporting cancer. This may be due to growing recognition of acupuncture as a suitable adjunct treatment with low risk of conventional treatment interactions for numerous cancer symptoms [20], as well as its inclusion in some Australian oncology centre programs [21–23]. Male reproductive conditions were also reported at higher odds amongst those who had consulted acupuncturists compared to those who had not, possibly a result of men with conditions such as benign prostatic hyperplasia seeking alternatives to pharmacological treatment, which has low adherence due to drug side-effects impacting on sexual function [24]. Participants consulting with chiropractors exhibited higher odds of multimorbidity (five or more conditions), which may relate to the high incidence of back pain in those with multimorbidities [25], reflecting the prevalence of back problems amongst chiropractic users [26] as well as the diverse therapeutic tools employed by chiropractors in Australia [27].

Odds of consulting any CM practitioner were higher for those with gastrointestinal and mental health conditions—two fields in which patients receiving conventional medical care often have unmet needs [28–31]. In fact, prevalence of mental health problems is particularly high amongst individuals with chronic conditions, which is likely a bidirectional relationship, exacerbated by the burden and reduced quality of life associated with prolonged illness [32]. Yet, individuals with chronic conditions report difficulty in addressing comorbid mental health problems through conventional care due to limited consultation time, perceived provider reliance on pharmaceuticals, and poor patient-provider communication [33]. Such difficulties may lead these individuals to seek care from CM practitioners specifically to address mental health needs, as CM practitioners are often perceived as being notably empathic and supportive [10].

It was common for people in our study to seek care from CM practitioners to treat long-term conditions. However, seeking support for general wellbeing was a more frequently reported reason for CM consultation, particularly amongst participants visiting health professionals for whom there were no increased odds of users reporting any specific chronic condition (massage therapy, naturopathy, yoga). As perceptions of wellness reflect health-related quality of life [34], care sought to improve general wellbeing may be addressing unmet quality of life needs. The identification of wellness as a predominant motivator could also suggest users of these professions consider them to be personal treats or luxuries [35]. The legitimacy of CM professions as therapeutic resources may be undermined by prevailing perceptions of health care as disease treatment, rather than as a holistic means of addressing the many factors that contribute to a state of health and overall quality of life [35]. Despite this, there is emerging evidence for effectiveness of some CM in certain chronic conditions; for example, massage therapy for various symptoms in fibromyalgia [36] and other pain-related conditions [37]; naturopathy for management of anxiety, menopausal symptoms [38] and diabetes [39]; and yoga for chronic obstructive pulmonary disease [40] and post-traumatic stress disorder [41].

While the findings of our study add to current knowledge of the role of CM practitioners in chronic health management in Australia, study limitations must be considered. Due to the unavailability of existing data describing the sociodemographic profile of individuals with chronic conditions as a comprehensive group in Australia, it was not possible to determine the representativeness of the sub-sample used in these

analyses. The full CAMUHLID sample was broadly representative of the national population, yet due to the online and self-report nature of the study, responder and recall bias may still be present. Survey items regarding health service utilisation were limited to the preceding 12 months to reduce recall bias, with the exception of the item asking about chronic condition diagnosis, which extended to 3 years to reflect the temporal reality of chronic illness. Additionally, chronic conditions were grouped into categories for analysis—such categorisation differs between studies when conditions broach more than one category, limiting the accuracy of comparisons with other relevant research. Lastly, the cross-sectional design and lack of post-treatment health outcome measures of our dataset prevents speculation about the value of treatments provided by CM practitioners. Understanding of the intersection of chronic disease and use of CM practitioner services would benefit from research using longitudinal design to further explore the role and value of CM in the care of those with chronic conditions. Such research could include more extensive evaluation of effectiveness, safety, and the psychosocial impact of patient-practitioner relationships in CM clinical care on health-related quality of life.

## 5. Conclusion

The use of CM practitioner services by individuals with chronic conditions is highly prevalent and appears to be driven by sociodemographic factors relating to social determinants of health, alongside a desire for improved wellbeing. CM practitioners providing these services may be addressing unmet needs within a population that represents a growing burden to a public health system challenged by the complexity and protracted nature of their health needs. The current and future contributions of CM professions should be systematically acknowledged and examined as potentially invaluable resources for managing the changing landscape of health care as it becomes increasingly dominated by chronic illness. There is a pressing need for public health practice to better align with policy acknowledging the potential value of integrated medicine for chronic health management.

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## Ethics

Ethical approval for the project was obtained from the Endeavour College of Natural Health Human Research Ethics Committee (EC00358) (#20170242).

## Declaration of competing interest

The authors declare that there is no conflict of interest.

### CRedit authorship contribution statement

**Hope Foley:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization, Project administration. **Amie Steel:** Conceptualization, Methodology, Formal analysis, Investigation, Writing - review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Erica McIntyre:** Conceptualization, Methodology, Investigation, Resources, Data curation, Writing - review & editing, Project administration. **Joanna Harnett:** Conceptualization, Methodology, Writing - review & editing. **David Sibbritt:** Conceptualization, Methodology, Writing - review & editing. **Jon Wardle:** Methodology, Writing - review & editing. **Jon Adams:** Conceptualization, Resources, Writing - review & editing, Supervision, Project administration, Funding acquisition.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ctcp.2020.101194>.

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## APPENDIX 5. PUBLISHED MANUSCRIPT ASSOCIATED WITH RESULTS REPORTED IN CHAPTER 5.

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### Consultation with complementary medicine practitioners by individuals with chronic conditions: Characteristics and reasons for consultation in Australian clinical settings

Hope Foley BHSc (Hons)<sup>1,2</sup> | Amie Steel PhD<sup>1</sup> | Jon Adams PhD<sup>1</sup>

<sup>1</sup>Australian Research Centre in Complementary and Integrative Medicine, Faculty of Health, University of Technology Sydney, Ultimo, Australia

<sup>2</sup>Office of Research, Endeavour College of Natural Health, Brisbane, Australia

#### Correspondence

Hope Foley, Office of Research, Endeavour College of Natural Health, Level 2/269 Wickham St, Fortitude Valley, Qld 4121, Australia.  
Email: hope.m.foley@student.uts.edu.au

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#### Abstract

The duration and complexity of chronic conditions leads patients to consult complementary medicine (CM) practitioners, yet such care-seeking by this clinical population has not been thoroughly examined. This study describes characteristics and reasons for consultation amongst those with chronic conditions who consult CM practitioners. A cross-sectional study surveyed patients in clinics of 39 CM practitioners from the five most accessed CM professions in Australia (chiropractic, massage, osteopathy, acupuncture, naturopathy). Between November 2018 and March 2019, CM practitioners invited 15 consecutive adult patients ( $n = 585$  invited) to a self-administered, hard-copy survey covering socio-demographics, chronic condition diagnoses, CM service utilisation and reasons for consulting the CM practitioner. In total, 199 surveys were returned, producing a final sample of  $n = 191$ . Chronic conditions were reported by 153 (80.1%) participants, who were most commonly female (82.4%), aged over 65 years (29.0%), married (55.9%), vocational/trade qualified (40.1%), employed (62.5%), reported financial manageability as *not too bad* (48.0%), held private health insurance generally (79.0%) and specifically for CM (71.1%). Some socio-demographic differences were found depending on the profession consulted. Most participants (75.0%) had attended five or more consultations with the CM practitioner. The reasons most commonly given by participants with chronic conditions for consulting the CM practitioner were *This healthcare professional is supportive and compassionate* ( $n = 136$ , 97.1%), *I believe this type of healthcare is safe* ( $n = 131$ , 95.6%), *Improve general wellbeing and prevent future health problems* ( $n = 125$ , 89.3%) and *This type of healthcare gives me hope about my future health* ( $n = 108$ , 85.7%). These findings suggest that individuals with chronic conditions may consult CM practitioners to address unmet well-being or quality of life needs and for compassionate support. The role CM practitioners fill for those with chronic conditions requires further exploration to develop optimal policy and services to manage the growing challenges chronic conditions present to health systems.

#### KEYWORDS

chronic illness, complementary medicine, health behaviour, healthcare utilisation, patient care

## 1 | INTRODUCTION

Chronic conditions – which limit functional capacity and require prolonged medical management over time (Goodman, Posner, Huang, Parekh, & Koh, 2013) – present a substantial and growing burden of disease (World Health Organization, 2011). More than half of the Australian population live with at least one chronic condition (Australian Health Ministers' Advisory Council, 2017). Prevalence of chronic conditions is increasing as the landscape of disease shifts away from acute and infectious diseases towards chronic and non-communicable conditions, precipitated by post-industrial lifestyle and environmental changes, and increased life expectancy (World Health Organization, 2011). However, health systems face many challenges in meeting the complex, ongoing health needs of individuals with chronic conditions (Australian Health Ministers' Advisory Council, 2017; World Health Organization, 2011).

Those with chronic conditions report a number of physical, psychosocial and financial challenges and unmet needs impacting on their health, healthcare experiences, and quality of life (Griffith et al., 2017; Liddy, Blazkho, & Mill, 2014; Paez, Zhao, & Hwang, 2009). The complexity and protracted nature of chronic conditions creates a need for multi-factorial approaches to care and self-management (Australian Health Ministers' Advisory Council, 2017) which often leads individuals to supplement medical care with additional services, such as those provided by complementary medicine (CM) practitioners (Armstrong, Thiébaud, Brown, & Nepal, 2011). CM refers to health practices, paradigms and products generally found outside of mainstream medical practice and training (World Health Organization, 2016). CM may be self-prescribed, but is also commonly provided by practitioners of CM professions, as well as some conventional medical providers (World Health Organization, 2016). Australians demonstrate particularly high rates of CM use – estimated at approximately 63% for CM use overall and 36% for CM practitioner use (Steel et al., 2018). Consultations with CM practitioners appear to be even higher amongst Australians with chronic conditions (Steel et al., 2018).

The decision to consult with CM practitioners is reportedly driven by a number of motivations, including the patient's attraction to the holistic approach of many CM professions which seek to "treat the whole person" (Sirois, 2008). Holistic approaches may be particularly useful in chronic condition management as they involve a person-centred consideration of the many ways in which a patient's daily life is affected by their condition, rather than solely treating the disease process (Foley & Steel, 2017a). Other motivations which have been reported by patients as reasons to consult a CM practitioner include a desire to take an active role in their own health, dissatisfaction with conventional medicine or its side-effects, a desire for preventive healthcare, a perception of CM as safe, a perceived ability of CM to provide hope and control and a perception of CM practitioners as being especially supportive (Reid, Steel, Wardle, Trubody, & Adams, 2016; Sirois, 2008).

The high prevalence of CM use by those with chronic conditions suggests many amongst these sufferers perceive value in

### What is already known about this topic

- Chronic conditions present a substantial and growing challenge to health systems, leaving many patients with unmet needs.
- Individuals with chronic conditions appear to consult with complementary medicine practitioners at higher rates than the general population.

### What this paper adds

- Complementary medicine practitioners provide valued, ongoing care for some individuals with chronic conditions.
- Individuals with chronic conditions who seek complementary medicine practitioners appear to do so for compassionate support, to improve well-being and for preventive care.
- Further research is required to determine how the existing services provided by complementary medicine practitioners can be better utilised to optimise provision of care for those with chronic conditions to achieve more favourable health outcomes.

CM for managing their health, and this potential value has been acknowledged in global public health guidelines (World Health Organization, 2016). Limited research has explored some drivers of CM utilisation in Australia by individuals with specific chronic conditions, such as diabetes and cardiovascular disease (Spinks, Hollingsworth, Manderson, Lin, & Canaway, 2013). Yet the factors surrounding CM practitioner consultation by individuals with chronic conditions as a wider clinical population in Australia have not been examined thus far (Armstrong et al., 2011; Reid et al., 2016). Understanding the profile and motivations of those with chronic conditions who consult with CM practitioners is integral in order to develop more comprehensive models of care delivery to this increasingly important clinical population, as well as to ensure the health needs of those with chronic conditions are adequately met. Consequently, the aim of the study reported here is to describe the characteristics and reasons for consultation amongst those with chronic conditions who consult with CM practitioners in clinical settings.

## 2 | METHODS

### 2.1 | Study design and setting

A cross-sectional survey was conducted in community-based CM clinics throughout Australia between November 2018 and March 2019. The five most-commonly consulted clinical CM professions in Australia – massage therapy, chiropractic, acupuncture, naturopathy

and osteopathy – were selected based on previous research (Steel et al., 2018). Practitioners of these professions were invited to assist with patient recruitment through three practitioner-based research networks (PBRNs): the Practitioner Research and Collaboration Initiative (PRACI)(Steel et al., 2017), the Osteopathy Research and Innovation Network (ORION)(Adams, Sibbritt, Steel, & Peng, 2018; Australian Research Centre in Complementary & Integrative Medicine, 2017), and the Australian Chiropractic Research Network (ACORN) (Adams et al., 2017).

## 2.2 | Participants and recruitment

CM practitioners who were active clinicians and members of one of the participating PBRNs completed an online expression of interest and consent form to participate in the study. Seven to eight practitioners of each profession were selected on the basis of geographical location and were provided with hardcopy study materials (information sheets, surveys, and detailed instructions regarding the study protocol, the recruitment process and communication about the study with patients to ensure consistency in patient recruitment). The selected practitioners each provided 15 consecutive eligible patients with an information sheet about the study, a consent form and a hardcopy of the survey instrument, to be self-administered from home if the patient chose to participate. Participation was anonymous. This approach reduced selection bias, allowed patients to provide or withhold consent without coercion, and blinded practitioners to recruitment outcomes in order to preserve the integrity of patient-practitioner relationships (practitioners were not aware of who did or did not participate). Patients were considered eligible to participate if they were adults (aged 18 and over), fluent English speakers, capable of providing informed consent and had not already participated during previous consultations with the recruiting practitioner.

Each survey was provided with a reply-paid postage envelope to return completed surveys to the research team at no cost to practitioners or patients. The surveys also included a link to a separate online form where participants could choose to enter a draw to win a \$100 gift voucher as an incentive to participate. Personal details collected through the online form included only a name and contact point (phone or email), with the winner chosen randomly. A sample of 400 patients was sought to achieve a 5.0% margin of error, calculated using conservative estimates of chronic condition prevalence and response rates based on previous research in a similar population (Foley & Steel, 2017b).

## 2.3 | Instrument

The survey was comprised of 29 questions, covering socio-demographics, chronic condition diagnoses, details of CM care-seeking, experiences of care received and communication about treatments used by patients. Respondents who did not have a chronic condition diagnosis completed only socio-demographic items; these data were

taken in order to establish the prevalence of chronic condition diagnoses amongst those consulting with CM practitioners and to identify potential socio-demographic differences between those with or without chronic conditions. All other variables were responded to only by participants with chronic conditions. Items applicable to the analyses presented here included socio-demographics, chronic condition diagnoses and details of CM care-seeking.

Socio-demographics encompassed age, gender, state of residence, marital status, educational qualification level, employment status, financial manageability, private health insurance coverage, and possession of a Health Care Card (card provided to low-income earners in Australia for health and medical financial concessions). Current chronic condition diagnoses were identified by respondents from a list, with additional options for open-text responses alongside a “none of the above” option. Care-seeking items included profession of the CM practitioner who provided the survey, number of visits ever attended with the CM practitioner consulted (to determine whether the patient-practitioner relationship is new or ongoing), and a list of reasons for seeking care from the CM practitioner. The list of reasons was informed by existing research (Reid et al., 2016; Sirois, 2008), subjected to face validity testing by researchers with expertise in the subject matter, and scored using a five-point Likert scale from *Strongly disagree* to *Strongly agree* with an additional *Doesn't apply* option.

## 2.4 | Data handling and analysis

Data analysis was undertaken with StataC 14 (StataCorp LC 2015). In order to produce adequate cell sizes, some variables were recoded to collapse response options where appropriate (age, marital status, educational qualification, employment status, financial manageability). Chronic condition diagnoses, including those reported by participants in open text responses, were recoded from specific conditions into broader condition categories as binary variables. Professions consulted were coded as binaries to allow comparison between participants who had consulted with a particular profession and participants who had not consulted that profession.

Descriptive statistics were tabulated as frequencies and percentages, and Fisher's exact test was used to test associations and compare groups. Comparisons were drawn between participants with and without chronic conditions for socio-demographics, and between groups delineated by the profession consulted by those with chronic conditions for all variables. Missing responses were excluded from analysis, as were *Does not apply* responses for items describing reasons for consultation.

## 2.5 | Ethics

Ethical approval was granted by the Human Research Ethics Committee, University of Technology Sydney (ETH18-2769). This study conforms to the standards of the Declaration of Helsinki.

**TABLE 1** Sociodemographics of full sample

	All respondents n = 191 (100%)	Chronic condition/s n = 153 (80.1%)	No chronic condition n = 38 (19.9%)	P value
<b>Gender (n = 191)</b>				
Female	152 (79.6%)	126 (82.4%)	26 (68.4%)	.042
Male	38 (19.9%)	26 (17.0%)	12 (31.6%)	
Transgender*	1 (0.5%)	1 (0.7%)	0 (0.0%)	
<b>Age (n = 190)</b>				
18–34	22 (11.6%)	15 (9.9%)	7 (18.4%)	.358
35–44	31 (16.3%)	25 (16.5%)	6 (15.8%)	
45–54	44 (23.2%)	35 (23.0%)	9 (23.7%)	
55–64	43 (22.6%)	33 (21.7%)	10 (26.3%)	
65+	50 (26.3%)	44 (29.0%)	6 (15.8%)	
<b>State (n = 185)</b>				
ACT	8 (4.3%)	4 (2.7%)	4 (10.5%)	.181
NSW	48 (26.0%)	40 (27.2%)	8 (21.1%)	
VIC	33 (17.8%)	26 (17.7%)	7 (18.4%)	
QLD	43 (23.2%)	31 (21.1%)	12 (31.6%)	
SA	16 (8.7%)	13 (8.8%)	3 (7.9%)	
WA	10 (5.4%)	10 (6.8%)	0 (0.0%)	
TAS	27 (14.6%)	23 (15.7%)	4 (10.5%)	
NT	0 (0.0%)	0 (0.0%)	0 (0.0%)	
<b>Relationship status (n = 190)</b>				
Never married	29 (15.3%)	25 (16.5%)	4 (10.5%)	.198
Married	109 (57.4%)	85 (55.9%)	24 (63.2%)	
De facto	22 (11.6%)	15 (9.9%)	7 (18.4%)	
Separated/divorced/widowed	30 (15.9%)	27 (17.8%)	3 (7.9%)	
<b>Education (n = 190)</b>				
Up to year 12	42 (22.1%)	36 (23.7%)	6 (15.8%)	.569
VET/trade	77 (40.5%)	61 (40.1%)	16 (42.1%)	
Higher education	71 (37.4%)	55 (36.2%)	16 (42.1%)	
<b>Employment status (n = 189)</b>				
Full time work	64 (33.9%)	47 (30.9%)	17 (46.0%)	.211
Part time work	47 (24.9%)	38 (25.0%)	9 (24.3%)	
Casual/temporary work	13 (6.9%)	10 (6.6%)	3 (8.1%)	
Not in paid workforce	65 (34.4%)	57 (37.5%)	8 (21.6%)	
<b>Financial status (n = 187)</b>				
It is impossible/difficult all of the time	18 (9.6%)	16 (10.7%)	2 (5.4%)	.641
It is difficult some of the time	39 (20.9%)	33 (22.0%)	6 (16.2%)	
It is not too bad	92 (49.2%)	72 (48.0%)	20 (54.1%)	
It is easy	38 (20.3%)	29 (19.3%)	9 (24.3%)	
PHI cover (n = 190)	148 (77.9%)	120 (79.0%)	28 (73.7%)	.309
PHI cover for CM (n = 190)	135 (71.1%)	108 (71.1%)	27 (71.1%)	.573
Health care card (n = 187)	62 (33.2%)	56 (37.6%)	6 (15.8%)	.007

\*Excluded from analyses of gender due to small cell size.

### 3 | RESULTS

A total of 39 CM practitioners participated in the recruitment process (seven chiropractors and eight practitioners from each other profession) and confirmed distribution of the survey materials by emailing the research team. Of the 585 surveys distributed to patients, 199 were returned, providing a 34.0% response rate. Five returned surveys were excluded due to being incomplete and three others were excluded due to inconsistent responses which challenged reliability of the data (responses to some items contradicted responses to others), producing a final sample of 191 patients.

#### 3.1 | Participant characteristics

Within the full sample, 153 (80.1%) patients reported at least one diagnosed chronic condition. Participants with chronic conditions were more commonly female (82.4%) compared to participants with no chronic conditions (68.4%) ( $p = .042$ ). Participants with chronic conditions also reported higher rates of Health Care Card cover (37.6%) compared to those with no chronic conditions (15.8%) ( $p = .007$ ). No other statistically significant socio-demographic differences were found between the two groups (see Table 1).

Participants who reported at least one chronic condition diagnosis were most commonly female (82.4%), aged 65 years and over (29.0%), residing in New South Wales (27.2%), married (55.9%), vocational or trade qualified (40.1%) and employed (30.9% full time, 25.0% part time, 6.6% casually/temporarily). Participants most commonly reported financial manageability as *not too bad* (48.0%), held private health insurance cover generally (79.0%) and held private health insurance cover specifically for CM (71.1%), with 37.6% reporting Health Care Card cover. Full socio-demographic details are presented in Table 1.

For each of the five professions, a substantial majority of participants reported a chronic condition diagnosis, ranging from 76.3% of those who had consulted a massage therapist to 93.3% of those who had consulted a chiropractor. Between-group comparisons based on the profession consulted found a higher proportion of men amongst those who consulted chiropractors compared to those consulting the other four professions ( $p = .024$ ). Those who consulted a massage therapist had lower rates of Health Care Card coverage ( $p = .027$ ) compared to those consulting with the other four professions. Participants who had consulted a naturopath had a higher representation from the 65 years and over age group ( $p = .023$ ) and significantly lower rates of private health insurance coverage, both generally ( $p < .001$ ) and for CM ( $p = .001$ ). Full details in Table 2.

#### 3.2 | Health service utilisation

A majority of participants were repeat patients to their CM practitioner with 75.0% indicating they had attended five or more

consultations. Between group comparisons found a significant difference in number of consults for those who had consulted a naturopath as only 56.7% of participants consulting this profession had attended five or more consultations. No other significant differences were seen in the frequency of service utilisation (see Table 3).

#### 3.3 | Chronic condition diagnoses

The most commonly reported chronic condition diagnoses were musculoskeletal conditions (60.8%), mental health conditions (47.7%), cardiovascular conditions (27.5%) and gastrointestinal conditions (18.3%). There were few statistically significant differences in the categories of conditions reported by participants across the different professions – higher rates of female reproductive conditions were found amongst those who had consulted an acupuncturist ( $p = .042$ ), while those who had consulted a naturopath demonstrated higher rates of reported mental health conditions ( $p < .001$ ) and gastrointestinal conditions ( $p = .043$ ) (see Table 3).

#### 3.4 | Reasons for consultation

Of the 153 participants with chronic conditions, 150 (98.04%) selected at least one reason for their consultation. The reason with which respondents most commonly reported they strongly agreed or agreed was *This healthcare professional is supportive and compassionate* ( $n = 136$ ). A majority of respondents also strongly agreed or agreed with the items: *I believe this type of healthcare is safe* ( $n = 131$ ), *To improve general wellbeing and prevent future health problems* ( $n = 125$ ), *This type of healthcare gives me hope about my future health* ( $n = 108$ ) and *This type of healthcare gives me a sense of control about my health* ( $n = 105$ ). The reason with which respondents most commonly reported they strongly disagreed or disagreed was *To seek treatment for an acute illness lasting less than one month* ( $n = 42$ ), followed by *To reduce side-effects of my current medical treatments/medicines* ( $n = 38$ ) and *I was dissatisfied with my conventional medical treatment and wanted to try something different* ( $n = 27$ ). Full details in Table 4.

##### 3.4.1 | Reasons for consulting an acupuncturist

All 24 participants who had consulted an acupuncturist selected at least one reason for consultation. Amongst those who had consulted an acupuncturist, the reason for which respondents most commonly selected Strongly agree or Agree was *This healthcare professional is supportive and compassionate* ( $n = 22$ ), followed by *I believe this type of healthcare is safe* ( $n = 21$ ) and *To improve general well-being and prevent future health problems* ( $n = 21$ ). The reasons with which respondents consulting an acupuncturist most commonly strongly disagreed or disagreed were *To seek treatment for an acute illness lasting less*

**TABLE 2** Sociodemographics of respondents with chronic conditions, by profession consulted

	Acupuncture n = 24 (77.4%) <sup>a</sup>	P	Chiropractic n = 28 (93.3%) <sup>a</sup>	P	Massage n = 29 (76.3%) <sup>a</sup>	P	Naturopathy n = 33 (80.5%) <sup>a</sup>	P	Osteopathy n = 39 (76.5%) <sup>a</sup>	P
<b>Gender (n = 153)</b>										
Female	21 (87.5%)	.376	19 (67.9%)	.024	26 (89.7%)	.216	28 (84.9%)	.313	32 (82.1%)	.523
Male	3 (12.5%)		9 (32.1%)		3 (10.3%)		4 (12.1%)		7 (17.9%)	
Transgender <sup>b</sup>	0 (0.0%)		0 (0.0%)		0 (0.0%)		1 (3.0%)		0 (0.0%)	
<b>Age (n = 152)</b>										
18–34	3 (12.5%)	.849	3 (10.7%)	.455	3 (10.3%)	.153	2 (6.1%)	.023	4 (10.5%)	.071
35–44	3 (12.5%)		6 (21.4%)		4 (13.8%)		6 (18.2%)		6 (15.8%)	
45–54	5 (20.8%)		9 (32.1%)		11 (37.9%)		7 (21.2%)		3 (7.9%)	
55–64	7 (29.2%)		5 (17.9%)		7 (24.1%)		2 (6.1%)		12 (31.6%)	
65+	6 (25.0%)		5 (17.9%)		4 (13.8%)		16 (48.5%)		13 (34.2%)	
<b>Relationship status (n = 152)</b>										
Never married	2 (8.3%)	.388	3 (10.7%)	.247	7 (24.1%)	.219	5 (15.2%)	.088	8 (21.1%)	.243
Married	13 (54.2%)		20 (71.4%)		13 (44.8%)		15 (45.5%)		24 (63.2%)	
De facto	2 (8.3%)		3 (10.7%)		5 (17.2%)		2 (6.1%)		3 (7.9%)	
Separated/ divorced/ widowed	7 (29.2%)		2 (7.1%)		4 (13.8%)		11 (33.3%)		3 (7.9%)	
<b>Education (n = 152)</b>										
Up to year 12	6 (25.0%)	.454	7 (25.0%)	1.00	3 (10.3%)	.175	8 (24.2%)	.723	12 (31.6%)	.424
VET/trade	7 (29.2%)		11 (39.3%)		14 (48.3%)		15 (45.5%)		14 (36.8%)	
Higher education	11 (45.8%)		10 (35.7%)		12 (41.4%)		10 (30.3%)		12 (31.6%)	
<b>Employment status (n = 152)</b>										
Full time work	10 (41.7%)	.231	12 (42.9%)	.350	12 (41.4%)	.111	7 (21.2%)	.163	6 (15.8%)	.109
Part time work	5 (20.8%)		4 (14.3%)		10 (34.5%)		7 (21.2%)		12 (31.6%)	
Casual/ temporary work	3 (12.5%)		2 (7.1%)		1 (3.5%)		1 (3.0%)		3 (7.9%)	
Not in paid workforce	6 (25.0%)		10 (35.7%)		6 (20.7%)		18 (54.6%)		17 (44.7%)	
<b>Financial manageability (n = 150)</b>										
It is impossible/ difficult all of the time	3 (12.5%)	.181	3 (11.1%)	.895	2 (6.9%)	.698	5 (15.6%)	.620	3 (7.9%)	.375
It is difficult some of the time	8 (33.3%)		7 (25.9%)		6 (20.7%)		7 (21.9%)		5 (13.2%)	
It is not too bad	7 (29.2%)		13 (48.2%)		17 (58.6%)		13 (40.6%)		22 (57.9%)	
It is easy	6 (25.0%)		4 (14.8%)		4 (13.8%)		7 (21.9%)		8 (21.1%)	
<b>Health care cost subsidies (n = 152)</b>										
PHI cover	22 (91.7%)	.075	24 (85.7%)	.242	24 (82.8%)	.391	18 (54.6)	<.001	32 (84.2%)	.250

(Continues)



TABLE 2 (Continued)

	Acupuncture n = 24 (77.4%) <sup>a</sup>	P	Chiropractic n = 28 (93.3%) <sup>a</sup>	P	Massage n = 29 (76.3%) <sup>a</sup>	P	Naturopathy n = 33 (80.5%) <sup>a</sup>	P	Osteopathy n = 39 (76.5%) <sup>a</sup>	P
PHI for this profession (n = 152)	19 (86.4%)	.628	24 (96%)	.089	22 (92.7%)	.297	10 (55.6%)	.001	29 (90.6%)	.286
Health care card (n = 149)	8 (33.3%)	.411	10 (38.5%)	.543	6 (20.7%)	.027	16 (48.5%)	.104	16 (43.2%)	.265

<sup>a</sup>Percentage of participants who consulted this profession.

<sup>b</sup>Excluded from analysis of gender due to small cell size.

than one month (n = 10) and *To reduce side-effects of my current medical treatments/medicines* (n = 8) (see Table 4).

### 3.4.2 | Reasons for consulting a chiropractor

Of the 28 respondents who had consulted a chiropractor, 27 provided at least one reason for consultation. Respondents consulting a chiropractor most commonly selected strongly agree or agree for items *To improve general wellbeing and prevent future health problems* (n = 22), *This healthcare professional is supportive and compassionate* (n = 21) and *I believe this type of healthcare is safe* (n = 20). The items for which they most commonly selected strongly disagree or disagree were *To reduce side-effects of my current medical treatments/medicines* (n = 13) and *To enhance the effectiveness of my current medical treatments/medicines* (n = 10) (see Table 4).

### 3.4.3 | Reasons for consulting a massage therapist

At least one reason for consultation was provided by all 29 respondents who had visited a massage therapist. The reasons for which respondents consulting a massage therapist most commonly selected strongly agree or agree were *This healthcare professional is supportive and compassionate* (n = 26) and *I believe this type of healthcare is safe* (n = 26), followed by *To improve general well-being and prevent future health problems* (n = 22) and *This type of healthcare gives me hope about my future health* (n = 21). The item for which respondents consulting a massage therapist most commonly selected strongly disagree or disagree was *To seek treatment for an acute illness lasting less than one month* (n = 10), followed by *To reduce side-effects of my current medical treatments/medicines* (n = 8), *I was dissatisfied with my conventional medical treatment and wanted to try something different* (n = 6), and *To seek treatment for a long-term illness lasting more than one month* (n = 5) (see Table 4).

### 3.4.4 | Reasons for consulting a naturopath

Of the 33 participants who had visited a naturopath, 31 provided at least one reason for the consultation. Amongst respondents

consulting a naturopath, the reasons most commonly selected as strongly agree or agree were *This healthcare professional is supportive and compassionate* (n = 29), *I believe this type of healthcare is safe* (n = 28) and *This type of healthcare gives me a sense of control about my health*. Very few respondents in this group selected strongly disagree or disagree for any items, with the most common being *To seek treatment for an acute illness lasting less than one month* (n = 4) and *I was dissatisfied with my conventional medical treatment and wanted to try something different* (n = 4) (see Table 4).

### 3.4.5 | Reasons for consulting an osteopath

All 39 respondents consulting an osteopath provided at least one reason for their consultation. Those respondents who had consulted an osteopath most commonly strongly agreed or agreed with the reasons *This healthcare professional is supportive and compassionate* (n = 38), *I believe this type of healthcare is safe* (n = 36), *To improve general well-being and prevent future health problems* (n = 35) and *This type of healthcare gives me a sense of control about my health* (n = 30). The reasons with which respondents in this group most commonly strongly disagreed or disagreed were *To seek treatment for an acute illness lasting less than one month* (n = 9) and *To reduce side-effects of my current medical treatments/medicines* (n = 6) (see Table 4).

## 4 | DISCUSSION

This paper presents novel insights into the characteristics and motivations surrounding CM practitioner consultations in Australia by individuals with chronic conditions – a substantial clinical population representing a growing public health burden (Australian Health Ministers' Advisory Council, 2017). Our results suggest that Australians with chronic conditions who consult CM practitioners do so repeatedly over time and with a wide range of conditions. Patients visiting CM practitioners are motivated by a desire for supportive, compassionate, safe healthcare to improve their wellbeing. While there were many commonalities amongst our participants, there were also some key differences in characteristics between those consulting with practitioners of different CM professions.

TABLE 3 Service utilisation frequency and chronic condition diagnoses

	All professions	Acupuncture	P	Chiropractic	P	Massage	P	Naturopathy	P	Osteopathy	P
Number of visits (n = 148)											
First visit	13 (8.8%)	3 (12.5%)	.933	1 (3.7%)	.314	2 (7.1%)	.827	5 (16.7%)	.008	2 (5.1%)	.147
Two times	9 (6.1%)	1 (4.2%)		0 (0.0%)		1 (3.6%)		3 (10.0%)		4 (10.3%)	
Three times	6 (4.1%)	1 (4.2%)		0 (0.0%)		0 (0.0%)		4 (13.3%)		1 (2.6%)	
Four times	9 (6.1%)	1 (4.2%)		1 (3.7%)		1 (3.6%)		1 (3.3%)		5 (12.8%)	
Five or more	111 (75.0%)	18 (75.0%)		25 (92.6%)		24 (85.7%)		17 (56.7%)		27 (69.2%)	
Condition category (n = 153)											
Musculoskeletal conditions	93 (60.8%)	14 (58.3%)	.479	16 (57.1%)	.408	20 (69.0%)	.216	19 (57.6%)	.408	24 (61.5%)	.534
Mental health conditions	73 (47.7%)	9 (37.5%)	.193	10 (35.7%)	.115	13 (44.8%)	.446	26 (78.8%)	<.001	15 (38.5%)	.124
Cardiovascular conditions	42 (27.5%)	5 (20.8%)	.301	7 (25.0%)	.474	10 (34.5%)	.235	11 (33.3%)	.259	9 (23.1%)	.313
Gastrointestinal conditions	28 (18.3%)	6 (25.0%)	.254	5 (17.9%)	.594	3 (10.3%)	.168	10 (30.3%)	.043	4 (10.3%)	.099
Respiratory conditions	25 (16.3%)	5 (20.8%)	.349	6 (21.4%)	.291	6 (20.7%)	.324	4 (12.1%)	.328	4 (10.3%)	.175
Female reproductive conditions	23 (15.0%)	7 (29.2%)	.042	3 (10.7%)	.354	3 (10.3%)	.323	6 (18.2%)	.371	4 (10.3%)	.245
Cancer or related complications	8 (5.3%)	1 (4.2%)	.634	2 (7.1%)	.449	1 (3.5%)	.531	1 (3.0%)	.453	3 (7.7%)	.332
Diabetes mellitus (type I or II)	6 (3.9%)	0 (0.0%)	.353	1 (3.6%)	.698	3 (10.3%)	.082	1 (3.0%)	.616	1 (2.6%)	.520
Male reproductive conditions	4 (2.6%)	1 (4.2%)	.498	1 (3.6%)	.558	1 (3.5%)	.573	0 (0.0%)	.374	1 (2.6%)	.731
Other conditions	59 (38.6%)	9 (37.5%)	.549	9 (32.1%)	.292	13 (44.8%)	.286	13 (39.4%)	.533	15 (38.5%)	.572

There appears to be little difference in socio-demographic characteristics between CM practitioner service users with and without chronic condition diagnoses. However, the high prevalence of chronic conditions within our sample and across the sub-groups consulting with each of the five professions, together with the high rates of repeat consultation, indicate that CM practitioners may be an important resource for some people living with chronic conditions. Indeed, recent Australian-based research identified that individuals with chronic conditions are more likely to consult CM practitioners than individuals with no chronic conditions (Steel et al., 2018). While seeking treatment specifically for a chronic condition was a widely reported reason for CM practitioner consultation, seeking improved well-being and preventive care was more consistently reported. This indicates that our participants also use the services of CM practitioners to manage their general health and improve their wider quality of life, rather than exclusively as a form of direct disease treatment. Such use reflects an understanding of CM as a health resource used as a complement to conventional medicine and implies CM practitioners may be addressing gaps in wider care provision (Liddy et al., 2014). These patterns of use and motivation are also reflective of the philosophical focus on well-being and preventive care inherent to many CM professions (Schuster, Dobson, Jauregui, & Blanks, 2004). Such a philosophical focus may hold special appeal to individuals who face challenges around well-being while living with chronic conditions, particularly as health systems face their own challenges in addressing quality of life needs for this population (Australian Health Ministers' Advisory Council, 2017).

Regarding the consistency with which participants indicated they visit their CM practitioner due to viewing them as supportive and compassionate, it may be that individuals with chronic conditions seek CM practitioners for care regarding psychosocial health needs (Franzel, Schwiegershausen, Heusser, & Berger, 2013). This is also reflected in our participants' perceptions that the CM practitioner instils hope and a sense of control for the individual over their own health; the CM clinician may influence self-efficacy amongst their patients. Due to the protracted and often complex nature of chronic conditions, alongside the impact on an individual's capacity to engage in work and social activities, health-related psychosocial challenges are frequently faced within this population (Australian Health Ministers' Advisory Council, 2017; Furler et al., 2008; Hall et al., 2012). The holistic philosophies of CM professions which seek to treat the "whole person" (Foley & Steel, 2017a), as well as the typically longer consultation times provided by CM professionals (Alami et al., 2011; Oberg et al., 2014), may produce an environment conducive to addressing psychosocial needs by allowing patients the time and space to be heard. This environment could facilitate exploration of potential solutions to challenges outside of direct, immediate medical needs.

Patients consulting naturopaths more frequently reported having been diagnosed with mental health conditions, which require substantial psychosocial support, as well as gastrointestinal conditions, which often impact on psychosocial well-being (Hauser, Janke, Klump, & Hinz, 2011). While patients with such conditions

have previously reported having needs which are not met by conventional medical treatment (Dickman, Maradey-Romero, Gingold-Belfer, & Fass, 2015; Prins, Verhaak, van der Meer, Penninx, & Bensing, 2009), there is emerging evidence to support the efficacy of naturopathic whole practice and associated treatments, such as herbal medicines, in the treatment of mental health and gastrointestinal conditions (Myers & Vigar, 2019; Ottillinger, Storr, Malfertheiner, & Allescher, 2013). There was also substantive agreement among our respondents consulting with a naturopath that their clinician is supportive and compassionate, which is consistent with previous research (Foley & Steel, 2017b) and naturopathic training (Connolly, 2014). The finding that fewer participants consulting naturopaths had attended five or more consultations, compared to participants consulting the other four professions, is notable and may relate to differences in the models of care provided by the different CM professions. Naturopathy holds, as a core philosophical principle, the intention to educate patients about their health management (Foley & Steel, 2017a; Hausser et al., 2017), and thus may facilitate development of greater patient autonomy with a subsequently reduced need for regular consultations. Further research investigating psychosocial outcomes of treatment, including patient autonomy, in a variety of CM professions would assist in identifying which CM resources might best suit the specific psychosocial needs of individual patients.

CM professions using manual therapeutic approaches (e.g. chiropractic, osteopathy, massage therapy) can be perceived by patients as serving similar treatment purposes (Brown, Dean, Hay-Smith, Taylor, & Baxter, 2010). However, our findings noted variations in reasons for consulting with practitioners of different manual therapies. Reports of seeking care for acute illnesses were notably low amongst our study participants, with the exception of those consulting osteopaths. With musculoskeletal conditions being the most reported diagnoses in our sample, the acute illnesses experienced by participants consulting osteopaths may have been acute symptom flares of underlying chronic conditions involving musculoskeletal complaints and pain. This is likely, considering that 98% of osteopaths recently surveyed in Australia reported these as the types of conditions most often treated in their clinical practice (Adams et al., 2018). However, it is unclear as to why these reasons were not reported in a similar manner by respondents consulting chiropractors, as musculoskeletal complaints also predominate within Australian chiropractic practice (Adams et al., 2017) and chiropractors are one of the most frequently consulted CM practitioners for back pain in Australia (Murthy et al., 2014).

In contrast with osteopaths, participants consulting massage therapists less commonly reported seeking treatment for illness (chronic or acute) as a reason for consultation. This may indicate that some participants using massage therapy perceive this service as a luxury (Bishop, Yardley, & Lewith, 2008). The finding that participants using massage therapy had significantly lower rates of low-income Health Care Card cover implies these participants may also have more disposable income to spend on luxuries – a finding consistent with previous research identifying a correlation between use

TABLE 4 Reasons for consultation

Reason	All professions (n = 150)			Acupuncture (n = 24)			Chiropractic (n = 27)	
	Strongly agree/ Agree n (%)	Neutral n (%)	Disagree/ Strongly disagree n (%)	Strongly agree/ Agree n (%)	Neutral n (%)	Disagree/ Strongly disagree n (%)	Strongly agree/ Agree n (%)	Neutral n (%)
To seek treatment for an acute illness lasting less than one month (n = 81)	33 (40.7)	6 (7.4)	42 (51.9)	5 (31.3)	1 (6.3)	10 (62.5)	6 (35.3)	2 (11.8)
To seek treatment for a long-term illness lasting more than one month (n = 119)	98 (82.4)	7 (5.9)	14 (11.8)	14 (82.4)	0 (0.0)	3 (17.7)	17 (77.3)	3 (13.6)
I was dissatisfied with my conventional medical treatment and wanted to try something different (n = 108)	55 (50.9)	26 (24.1)	27 (25.0)	7 (36.8)	6 (31.6)	6 (31.6)	6 (33.3)	4 (22.2)
To reduce side-effects of my current medical treatments/ medicines (n = 87)	33 (37.9)	16 (18.4)	38 (43.7)	3 (23.1)	2 (15.4)	8 (61.5)	3 (16.7)	2 (11.1)
To enhance the effectiveness of my current medical treatments/ medicines (n = 104)	73 (70.2)	14 (13.5)	17 (16.4)	13 (68.4)	2 (10.5)	4 (21.1)	9 (42.9)	2 (9.5)
To improve general wellbeing and prevent future health problems (n = 140)	125 (89.3)	9 (6.4)	6 (4.3)	21 (91.3)	1 (4.4)	1 (4.4)	22 (91.7)	1 (4.2)
I was seeking holistic/ natural treatments (n = 125)	92 (73.6)	23 (18.4)	10 (8.0)	17 (77.3)	5 (22.7)	0 (0.0)	10 (45.5)	6 (27.3)
This type of health care suits my personal belief system (n = 123)	94 (76.4)	21 (17.1)	8 (6.5)	14 (73.7)	5 (26.3)	0 (0.0)	11 (52.4)	5 (23.8)
I believe this type of health care is safe (n = 137)	131 (95.6)	5 (3.7)	1 (0.7)	21 (95.5)	1 (4.5)	0 (0.0)	20 (95.2)	1 (4.8)
This type of health care gives me hope about my future health (n = 126)	108 (85.7)	17 (13.5)	1 (0.8)	17 (85.0)	3 (15.0)	0 (0.0)	16 (80.0)	4 (20.0)
This type of health care gives me a sense of control about my health (n = 129)	105 (81.4)	22 (17.1)	2 (1.6)	16 (80.0)	4 (20.0)	0 (0.0)	14 (66.7)	6 (28.6)
This health care professional is supportive and compassionate (n = 140)	136 (97.1)	2 (1.4)	2 (1.4)	22 (95.7)	1 (4.4)	0 (0.0)	21 (95.5)	1 (4.6)

of massage and greater financial manageability (Steel et al., 2014). However, there is an emerging body of research to support the use of massage as a therapeutic treatment, particularly for individuals experiencing pain (Crawford et al., 2016) and other musculoskeletal conditions (Bervoets, Luijsterburg, Alessie, Buijs, & Verhagen, 2015).

Further research exploring the strengths of different manual therapies and their discrete value in treating different health conditions would be of great benefit to assist patients and medical professionals in decision-making around the use of CM practitioner services, particularly in the context of chronic disease.

	Massage (n = 29)			Naturopathy (n = 31)			Osteopathy (n = 39)			
	Disagree/ Strongly disagree	Strongly agree/ Agree	Neutral	Disagree/ Strongly disagree	Strongly agree/ Agree	Neutral	Disagree/ Strongly disagree	Strongly agree/ Agree	Neutral	Disagree/ Strongly disagree
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
	9 (52.9)	5 (31.3)	1 (6.3)	10 (62.5)	3 (33.3)	2 (22.2)	4 (44.4)	14 (60.9)	0 (0.0)	9 (39.1)
	2 (9.1)	17 (73.9)	1 (4.4)	5 (21.7)	25 (92.6)	1 (3.7)	1 (3.7)	25 (83.3)	2 (6.7)	3 (10.0)
	8 (44.4)	7 (36.8)	6 (31.6)	6 (31.6)	17 (63.0)	6 (22.2)	4 (14.8)	18 (72.0)	4 (16.0)	3 (12.0)
	13 (72.2)	7 (38.9)	3 (16.7)	8 (44.4)	14 (70.0)	3 (15.0)	3 (15.0)	6 (33.3)	6 (33.3)	6 (33.3)
	10 (47.6)	16 (76.2)	4 (19.1)	1 (4.8)	20 (87.0)	3 (13.0)	0 (0.0)	15 (75.0)	3 (15.0)	2 (10.0)
	1 (4.2)	22 (81.5)	4 (14.8)	1 (3.7)	25 (89.3)	1 (3.6)	2 (7.1)	35 (92.1)	2 (5.3)	1 (2.6)
	6 (27.3)	19 (82.6)	2 (8.7)	2 (8.7)	25 (86.2)	3 (10.3)	1 (3.5)	21 (72.4)	7 (24.1)	1 (3.5)
	5 (23.8)	19 (79.2)	3 (12.5)	2 (8.3)	25 (86.2)	4 (13.8)	0 (0.0)	25 (83.3)	4 (13.3)	1 (3.3)
	0 (0.0)	26 (96.3)	0 (0.0)	1 (3.7)	28 (93.3)	2 (6.7)	0 (0.0)	36 (97.3)	1 (2.7)	0 (0.0)
	0 (0.0)	21 (87.5)	2 (8.3)	1 (4.2)	25 (89.3)	3 (10.7)	0 (0.0)	29 (85.3)	5 (14.7)	0 (0.0)
	1 (4.8)	18 (78.3)	4 (17.4)	1 (4.4)	27 (93.1)	2 (6.9)	0 (0.0)	30 (83.3)	6 (16.7)	0 (0.0)
	0 (0.0)	26 (92.9)	0 (0.0)	2 (7.1)	29 (100.0)	0 (0.0)	0 (0.0)	38 (100.0)	0 (0.0)	0 (0.0)

#### 4.1 | Limitations

While our study provides valuable observations about CM practitioner consultation by Australians with chronic conditions and a useful platform from which to develop research aimed at better serving

the needs of this population, certain limitations must be noted in the interpretation of results. The small sample size limits the capacity for generalisation. However, the broad geographical spread of the sample mediates this limitation somewhat. While the recruitment process employed a consecutive approach to participant invitation in

order to reduce the risk of sampling bias and a hard-copy instrument to optimise response rates, the anonymity and self-report nature of the survey may still have resulted in sampling bias that failed to include important members of the target population. Identification of the presence of chronic condition diagnoses was achieved through presentation of a list of chronic conditions, however, it is not clear whether all respondents had experienced the condition for a prolonged duration at the time of surveying, thus the impact of chronicity may not be accurately reflected in the data. Additionally, missing responses to items relating to reasons for consultation, and the finite nature of the list of reasons presented to participants (which did not allow open text responses), prevent definitive interpretations of these data and statistical validation of the instrument. Nonetheless, as almost all participants responded to at least one item in this measure, it is likely that the responses provided reflect the reasons considered most important by participants. Larger studies using a similar sampling frame, as well as inclusion of open-text response options to reasons for consultation, would be advantageous to develop a deeper and more nuanced understanding of the research topic.

## 5 | CONCLUSION AND IMPLICATIONS

Our findings suggest that for some individuals with chronic conditions, CM practitioners provide an important ongoing service towards the management of chronic conditions, which may be sought especially to improve well-being through access to supportive, compassionate care. There appear to be differences in the nature of the services provided by various CM professions, which could be utilised to provide targeted care to address the diverse and specific needs of individuals with chronic conditions. This paper presents an opportunity for further research to examine the utility and value of CM practitioners as an existing, established resource to address the unmet needs experienced by those with chronic conditions. Such examination would facilitate development of policy and health services better positioned to optimally manage the needs of this clinical population.

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### CONFLICT OF INTEREST

The authors have no conflicts to declare.

### ORCID

Hope Foley  <https://orcid.org/0000-0003-4901-8300>

Amie Steel  <https://orcid.org/0000-0001-6643-9444>

Jon Adams  <https://orcid.org/0000-0002-9901-5717>

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# APPENDIX 6.1 PUBLISHED MANUSCRIPT ASSOCIATED WITH RESULTS REPORTED IN CHAPTER 6.

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## Perceptions of person-centred care amongst individuals with chronic conditions who consult complementary medicine practitioners



Hope Foley<sup>a,b,\*</sup>, Amie Steel<sup>a</sup>, Jon Adams<sup>a</sup>

<sup>a</sup> Australian Research Centre in Complementary and Integrative Medicine, Faculty of Health, University of Technology Sydney, Ultimo, Australia  
<sup>b</sup> Office of Research, Endeavour College of Natural Health, Brisbane, Australia

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### ABSTRACT

**Objective:** Chronic conditions require continuous, multi-factorial care – such as person-centred care – to address patients' individual health needs and quality of life. Many patients with chronic conditions seek additional care outside mainstream medicine, often consulting complementary medicine (CM) practitioners. This study examines person-centred care experienced by patients with chronic conditions consulting CM practitioners.

**Design:** Cross-sectional survey.

**Setting:** CM clinics around Australia, conducted November 2018 to March 2019.

**Participants:** Patients with chronic conditions (n = 153) consulting osteopaths (n = 39), naturopaths (n = 33), massage therapists (n = 29), chiropractors (n = 28) and acupuncturists (n = 24).

**Main outcome measures:** Patient-Centred Care Scale, Perceived Provider Support Scale, Empowerment Scale, and Patient Assessment of Chronic Illness Care measure.

**Results:** Patient perceptions of person-centred care were consistently high during consultation with CM practitioners (Patient-centred Care scale mean range 4.22–4.70; Perceived Provider Support scale mean range 4.39–4.69; Empowerment scale mean range 2.20–2.50; Patient Assessment of Chronic Illness Care mean summary 3.33). Ratings of person-centred care were higher for consultations with CM practitioners than for medical doctors. Patients of naturopaths reported the highest means for perceived person-centred care. Variation in participant ratings for different items between professions indicate nuance in consultation experiences across different CM professions.

**Conclusions:** Person-centred care appears characteristic of CM consultation, which may reflect holistic philosophies. Variations in patient experiences suggest diverse practices across CM professions. CM practitioners may present a resource of person-centred care for addressing unmet needs of individuals with chronic conditions, and reducing the health burden associated with rising rates of chronic conditions.

### 1. Introduction

Rates of chronic condition diagnoses have risen in recent years and increasingly contribute substantial burden to health care systems globally.<sup>1</sup> Chronic conditions are prolonged in duration, typically complex in causes and symptoms, and impact on patients' lives in a variety of ways.<sup>2</sup> As well as requiring direct medical intervention, many chronic conditions leave patients with reduced functional, social and economic capacity which can further impact families and communities.<sup>3</sup> Optimal chronic disease management requires continuous, individualised and multi-faceted approaches to clinical care beyond treatment of pathology in order to address the prolonged, complex nature of chronic conditions and to account for the pervasive effects on patients' quality of life.<sup>3</sup> In particular, comprehensive, individualised

consultation approaches<sup>4</sup> and interventions designed to strengthen patient-provider relationships<sup>5</sup> show favourable effects on clinical outcomes in chronic conditions.

Due to the historical and contemporary primary focus of health care systems upon treating acute and infectious diseases – previously presenting the greatest contribution to the burden of disease<sup>1</sup> – there are numerous challenges to adjusting to better manage chronic conditions.<sup>6,7</sup> Person-centred care (PCC) has been recognised in a number of public health policies and guidelines as a paradigm of clinical care with potential to provide the necessary adjustments to care provision for this purpose.<sup>3,8</sup> PCC seeks to account for the multifactorial aspects of health management by delivering clinical care that is “respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”.<sup>9</sup> This respect and

\* Corresponding author at: Office of Research, Endeavour College of Natural Health Level 2/269 Wickham St, Fortitude Valley, Qld 4121, Australia.  
E-mail address: [hope.m.foley@student.uts.edu.au](mailto:hope.m.foley@student.uts.edu.au) (H. Foley).

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responsiveness to individual patient circumstances in PCC attends to the complexity of chronic conditions<sup>3</sup> and could facilitate development of the efficiency and sustainability required for health systems to adequately manage increasing chronic illness.<sup>8</sup>

An unmet desire for respectful, responsive, individualised clinical care can lead patients with chronic conditions to seek such care outside of mainstream health care systems, often via consultation with complementary medicine (CM) practitioners.<sup>10</sup> Those with chronic conditions may seek the care of CM practitioners specifically to address side-effects from, or dissatisfaction with, conventional treatment, as well as for management of their condition from an holistic perspective.<sup>11</sup> Many CM professions adhere to practices founded upon the philosophy of holism, which seeks to treat the “whole person” rather than simply addressing a patient’s pathology.<sup>12</sup> Holism is well-aligned with PCC due to this whole-person approach<sup>12</sup> which may lead to PCC being consequently delivered in CM clinical practice. As patients with chronic conditions tend to demonstrate higher utilisation of CM practitioner services than the general population,<sup>13</sup> it is imperative to determine whether CM clinical practice translates to experiences of PCC for patients.

## 2. Methods

The present study sought to determine the extent to which patients with chronic conditions experience PCC during consultation with CM practitioners.

### 2.1. Study design and setting

A cross-sectional survey was conducted between November 2018 and March 2019, in CM clinics throughout Australia. The CM professions chosen for the study were identified through previous research<sup>13</sup> as the five most frequently consulted clinical CM professions in Australia and included chiropractic, massage therapy, osteopathy, acupuncture and naturopathy. Invitations to assist with study patient recruitment were sent to practitioners of these professions through three practitioner-based research networks (PBRNs): the Practitioner Research and Collaboration Initiative (PRACI),<sup>14</sup> the Osteopathy Research and Innovation Network (ORION),<sup>15</sup> and the Australian Chiropractic Research Network (ACORN).<sup>16</sup>

### 2.2. Participants and recruitment

Expressions of interest and consent forms were submitted online by CM practitioners who were members of the participating PBRNs and were in active clinical practice. From each of the five professions, seven to eight practitioners were selected based on location to achieve a broad geographical spread. Selected practitioners were provided with hard-copy study materials which included information sheets, surveys to distribute, and instructions detailing the study protocol, recruitment process and scripted guidelines for communicating with patients about the study. Each practitioner then distributed a study information sheet, consent form and hardcopy survey to 15 consecutive eligible patients, who were invited to self-administer the survey at a time and place convenient to them after leaving the clinic. This approach allowed patients to participate (or not) anonymously (blinding practitioners to recruitment outcomes) and without practitioner coercion to reduce selection bias. This recruitment process was chosen to ensure the integrity of patient-practitioner relationships was not affected by the study.

Eligibility criteria for patient participation required that patients be adults (aged 18 and over), fluent in the English language, capable of providing consent, and had not already completed the survey during a previous consultation with the CM practitioner. The surveys included a reply-paid postage envelope for return directly to the research team at no cost to patients or recruiting practitioners. Each survey included a

web-link where participating patients could enter a draw to win a \$100 gift-voucher as an incentive to participate. Sample size calculations were undertaken based on response rates from previous research<sup>17</sup> conducted with a similar population and conservative estimates of chronic condition prevalence, resulting in a desired sample of 377 patients being sought to achieve a 5.0 % margin of error.

### 2.3. Instrument

The survey included 29 questions in total, covering socio-demographics, current chronic condition diagnoses, details of CM practitioner service utilisation, patient experiences of care in CM and conventional medical settings with medical doctors (MDs - general practitioners or specialist doctors), and patient-practitioner communication about patient treatment and medication use. Respondents who did not report a current chronic condition diagnosis were only asked to complete socio-demographic items. Items applicable to the analyses presented here included socio-demographics, chronic condition diagnoses and patient experiences of care.

Socio-demographics covered age, gender, state of residence, relationship status, educational qualification level, employment status, financial manageability, private health insurance (PHI) coverage, and possession of a Health Care Card (provided to low-income earners and welfare recipients in Australia for health and medical financial concessions). Diagnoses of chronic conditions were identified by respondents from a list (arthritis, asthma, cancer or post-cancer treatment complications, chronic obstructive pulmonary disease, diabetes type 1, diabetes type 2, heart disease/cardiovascular disease, hypertension/high blood pressure, musculoskeletal condition, chronic pain, depression, anxiety, other mental health condition, insomnia or other sleep disorder, obesity, Alzheimer’s disease or dementia, congenital condition, chronic kidney disease, endometriosis, polycystic ovarian syndrome, other female reproductive disorder, inflammatory bowel disease, irritable bowel syndrome, fibromyalgia of chronic fatigue syndrome/myalgic encephalomyelitis, other autoimmune disease), with additional options for open-text responses.

Measures pertaining to patient experiences of care included the Patient-Centred Care Scale (PCCS), Perceived Provider Support Scale (PPSS), Empowerment Scale and the Patient Assessment of Chronic Illness Care (PACIC) measure. The PCCS, PPSS and Empowerment Scale are designed to be co-administered interdependently.<sup>18</sup> The PCCS (ten items) and PPSS (seven items) allow patients to rate aspects of person-centred care and perceived emotional support from the provider (respectively) across a five-point Likert scale from *Strongly disagree* (value of 1) to *Strongly agree* (value of 5), while the Empowerment Scale (five items) allows patients to rate the sense of health-related empowerment resulting from the consultation across a three-point scale of *No* (value of 1), *Yes a little* (value of 2), and *Yes a lot* (value of 3) (see Fig. 1).<sup>18</sup> The PACIC measure includes twenty items using a five-point scale ranging from *Almost never* (value of 1) to *Almost always* (value of 5) which allow patients to rate five domains of actions and clinical care qualities of person-centred care as they relate specifically to management of chronic conditions (patient activation, delivery system design/decision support, goal setting/tailoring, contextual problem-solving, follow-up/coordination) (see Fig. 2).<sup>19</sup> The survey asked patients to complete these four measures in response to the consultation they had just attended with their CM practitioner, as well as in relation to their most recent consultation with their MD (general practitioner or specialist doctor, if applicable).

### 2.4. Data handling and analysis

Analyses were completed using StataIC 14 (StataCorp LC 2015). Analyses presented here utilised data from respondents who reported one or more chronic condition diagnoses. Some socio-demographic variables were collapsed and recoded to produce adequate cell sizes,

<b>Patient Centred Care Scale (PCCS)</b>	
When thinking about your consultation today, how much do you agree or disagree with the following statements?	
Item	Response options
I feel seen and heard as a unique individual by my practitioner/doctor	
My practitioner/doctor has a full picture of me as an individual	
My practitioner/doctor is really interested in finding and addressing my health problems	5-point Likert scale:
The root causes of my problems are identified by my practitioner/doctor	Strongly disagree = 1
The root causes of my problems are being treated by my practitioner/doctor	Disagree = 2
The treatment is individualised for me at each session	Neutral = 3
My practitioner/doctor receives feedback from my body that guides treatment	Agree = 4
My practitioner/doctor asks me for feedback from my body that guides treatment	Strongly agree = 5
I know what to expect during treatment sessions	
My practitioner/doctor teaches me ways to relieve symptoms myself	
<b>Perceived Provider Support Scale (PPSS)</b>	
When thinking about your consultation today, how much do you agree or disagree with the following statements?	
Item	Response options
My practitioner/doctor cares about me	
I feel cared for during treatment	5-point Likert scale:
My practitioner/doctor accepts me as I am	Strongly disagree = 1
I receive personal attention during treatment	Disagree = 2
I can talk openly with my practitioner/doctor	Neutral = 3
My practitioner/doctor gives me hope	Agree = 4
I trust my practitioner/doctor	Strongly agree = 5
<b>Empowerment Scale</b>	
When thinking about what has happened for you as a result of today's consultation, how would you describe the following?:	
Item	Response options
Do you feel more in control of your health?	
Do you know what to do to take care of your health problem?	3-point Likert scale:
Do you believe that your health problem will improve?	No = 1
Do you advocate more for yourself?	Yes, a little = 2
Do you have techniques you can use when your symptoms get worse?	Yes, a lot = 3

Fig. 1. Details of interdependent measures.

Patient Centred Care Scale, Perceived Provider Support Scale, and Empowerment Scale items and scoring structure.

when appropriate (age, relationship status, educational qualification, employment status, financial manageability). CM professions consulted were recoded as binaries to allow comparisons between characteristics of participants who had consulted with different professions using Fisher's exact test.

Descriptive statistics were tabulated as frequencies and percentages, while summary statistics were calculated as means and standard deviations. Summary statistics were calculated for each item in the PCCS, PPSS and Empowerment Scale with missing responses excluded from analysis for that item. The PACIC measure was scored by calculating means for each item and each domain, as well as across the full measure to provide a summary score, in accordance with the measure's intended use and previous validation.<sup>19</sup> During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in

single item calculations.

## 2.5. Ethics

Ethical approval was granted by the Human Research Ethics Committee, University of Technology Sydney (ETH18-2769).

## 3. Results

Thirty-nine CM practitioners (seven chiropractors and eight practitioners from each other profession) assisted with recruitment of patients by distributing surveys and confirming recruitment completion. In total, 585 patient surveys were distributed and 199 were returned to the research team (response rate 34.0%). Of the returned surveys, eight were excluded due to an excess of missing responses or contradictory

Patient Assessment of Chronic Illness Care (PACIC)	
Over the past 6 months, when receiving medical care for my chronic condition, I was:	
Items for domain of Patient Activation	Response options
Asked for my ideas when we made a treatment plan	
Given choices about treatment to think about	
Asked to talk about any problems with my medicines/treatments or their effects	
Items for domain of Delivery and Practice	
Given a written list of things I should do to improve my health	
Satisfied that my care was well organised	
Shown how what I did to take care of my illness influenced my condition	
Items for domain of Goal Setting and Tailoring	5-point Likert scale:
Asked to talk about my goals in caring for my illness	Almost never = 1
Helped to set specific goals to improve my eating or exercise	Generally not = 2
Given a copy of my treatment plan	Sometimes = 3
Encouraged to go to a specific group or class to help me cope with my chronic illness	Most of the time = 4
Asked questions, either directly or on a survey, about my health habits	Almost always = 5
Items for domain of Problem-Solving and Contextual Counselling	
Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me	
Helped to make a treatment plan that I could do in my daily life	
Helped to plan ahead so I could take care of my illness even in hard times	
Asked how my chronic illness affects my life	
Items for domain of Follow-Up and Coordination	
Contacted after a visit to see how things were going	
Encouraged to attend programs in the community that could help me	
Referred to a dietitian, health educator, or counsellor	
Told how my visits with other types of practitioners, like doctors or specialists, helped my treatment	
Asked how my visits with other doctors/practitioners were going	

Fig. 2. Details of Patient Assessment of Chronic Illness Care (PACIC). PACIC domains, items and response option scoring structure.

responses which threatened data reliability. Of the remaining 191 surveys, 38 reported no chronic condition diagnoses and were excluded from the present analyses, producing a final sample of 153.

### 3.1. Participant characteristics

Participants with chronic conditions were most commonly female ( $n = 126$ , 82.4%), aged 65 years and over ( $n = 44$ , 29.0%), married ( $n = 85$ , 55.9%), vocationally or trade qualified ( $n = 61$ , 40.1%), not in the paid workforce ( $n = 57$ , 37.5%) and reported financial manageability to be *Not too bad* ( $n = 72$ , 48.0%). Participants predominantly held PHI cover generally ( $n = 120$ , 79.0%) and specifically for the CM profession they were consulting ( $n = 108$ , 71.1%), while just over one-third held Health Care Cards ( $n = 56$ , 37.6%).

Comparisons between those consulting practitioners from different professions found a higher proportion of men consulting chiropractors ( $p = 0.024$ ) and a higher proportion of participants from the 65 years and over age group consulting naturopaths ( $p = 0.023$ ). Those consulting naturopaths also had a significantly lower rate of PHI coverage

both generally ( $p < 0.001$ ) and for the CM profession specifically ( $p = 0.001$ ). Those consulting massage therapists had lower rates of Health Care Card coverage ( $p = 0.027$ ). See Table 1.

### 3.2. Patient-centred care

Perceptions of PCC during consultation with CM practitioners were consistently high across the PCCS. For the total sample (consulting any CM practitioner), the highest mean score (of a possible 5.00) was for the item *My practitioner is really interested in finding and addressing my health problems* (mean 4.70), and the lowest was for *The root causes of my problems are being treated by my practitioner* (mean 4.22) (full details in Table 2). Those within the total sample who had consulted a MD reported lower perceptions of PCC for MD consultations, with the highest mean at 4.18 for item *My doctor is really interested in finding and addressing my health problems*, ranging to the lowest mean of 3.45 for item *My doctor teaches me ways to relieve symptoms myself*.

Table 2 also reports the profession-specific results for whole-system CM professions - acupuncture and naturopathy. Patients consulting

**Table 1**  
Sociodemographics of respondents with chronic conditions, by profession consulted.

Item	Total sample n = 153 (100.0 %)	Acupuncture n = 24 (77.4 %) <sup>1</sup>	P*	Chiropractic n = 28 (93.3 %) <sup>1</sup>	P*	Massage n = 29 (76.3 %) <sup>1</sup>	P*	Naturopathy n = 33 (80.5 %) <sup>1</sup>	P*	Osteopathy n = 39 (76.5 %) <sup>1</sup>	P*
<b>Gender (n = 153)</b>											
Female	126 (82.4 %)	21 (87.5 %)	0.376	19 (67.9 %)	0.024	26 (89.7 %)	0.216	28 (84.9 %)	0.313	32 (82.1 %)	0.523
Male	26 (17.0 %)	3 (12.5 %)		9 (32.1 %)		3 (10.3 %)		4 (12.1 %)		7 (17.9 %)	
Transgender <sup>2</sup>	1 (0.7 %)	0 (0.0 %)		0 (0.0 %)		0 (0.0 %)		1 (3.0 %)		0 (0.0 %)	
<b>Age (n = 152)</b>											
18–34	15 (9.9 %)	3 (12.5 %)	0.849	3 (10.7 %)	0.455	3 (10.3 %)	0.153	2 (6.1 %)	0.023	4 (10.5 %)	0.071
35–44	25 (16.5 %)	3 (12.5 %)		6 (21.4 %)		4 (13.8 %)		6 (18.2 %)		6 (15.8 %)	
45–54	35 (23.0 %)	5 (20.8 %)		9 (32.1 %)		11 (37.9 %)		7 (21.2 %)		3 (7.9 %)	
55–64	33 (21.7 %)	7 (29.2 %)		5 (17.9 %)		7 (24.1 %)		2 (6.1 %)		12 (31.6 %)	
65+	44 (29.0 %)	6 (25.0 %)		5 (17.9 %)		4 (13.8 %)		16 (48.5 %)		13 (34.2 %)	
<b>Relationship status (n = 152)</b>											
Never married	25 (16.5 %)	2 (8.3 %)	0.388	3 (10.7 %)	0.247	7 (24.1 %)	0.219	5 (15.2 %)	0.088	8 (21.1 %)	0.243
Married	85 (55.9 %)	13 (54.2 %)		20 (71.4 %)		13 (44.8 %)		15 (45.5 %)		24 (63.2 %)	
De facto	15 (9.9 %)	2 (8.3 %)		3 (10.7 %)		5 (17.2 %)		2 (6.1 %)		3 (7.9 %)	
Separated/divorced/ widowed	27 (17.8 %)	7 (29.2 %)		2 (7.1 %)		4 (13.8 %)		11 (33.3 %)		3 (7.9 %)	
<b>Education (n = 152)</b>											
Up to year 12	36 (23.7 %)	6 (25.0 %)	0.454	7 (25.0 %)	1.00	3 (10.3 %)	0.175	8 (24.2 %)	0.723	12 (31.6 %)	0.424
VET/trade	61 (40.1 %)	7 (29.2 %)		11 (39.3 %)		14 (48.3 %)		15 (45.5 %)		14 (36.8 %)	
Higher education	55 (36.2 %)	11 (45.8 %)		10 (35.7 %)		12 (41.4 %)		10 (30.3 %)		12 (31.6 %)	
<b>Employment status (n = 152)</b>											
Full time work	47 (30.9 %)	10 (41.7 %)	0.231	12 (42.9 %)	0.350	12 (41.4 %)	0.111	7 (21.2 %)	0.163	6 (15.8 %)	0.109
Part time work	38 (25.0 %)	5 (20.8 %)		4 (14.3 %)		10 (34.5 %)		7 (21.2 %)		12 (31.6 %)	
Casual/temporary work	10 (6.6 %)	3 (12.5 %)		2 (7.1 %)		1 (3.5 %)		1 (3.0 %)		3 (7.9 %)	
Not in paid workforce	57 (37.5 %)	6 (25.0 %)		10 (35.7 %)		6 (20.7 %)		18 (54.6 %)		17 (44.7 %)	
<b>Financial manageability (n = 150)</b>											
It is impossible/difficult all of the time	16 (10.7 %)	3 (12.5 %)	0.181	3 (11.1 %)	0.895	2 (6.9 %)	0.698	5 (15.6 %)	0.620	3 (7.9 %)	0.375
It is difficult some of the time	33 (22.0 %)	8 (33.3 %)		7 (25.9 %)		6 (20.7 %)		7 (21.9 %)		5 (13.2 %)	
It is not too bad	72 (48.0 %)	7 (29.2 %)		13 (48.2 %)		17 (58.6 %)		13 (40.6 %)		22 (57.9 %)	
It is easy	29 (19.3 %)	6 (25.0 %)		4 (14.8 %)		4 (13.8 %)		7 (21.9 %)		8 (21.1 %)	
<b>Health care cost subsidies (n = 152)</b>											
PHI cover	120 (79.0 %)	22 (91.7 %)	0.075	24 (85.7 %)	0.242	24 (82.8 %)	0.391	18 (54.6 %)	< 0.001	32 (84.2 %)	0.250
PHI for this profession	108 (71.1 %)	19 (86.4 %)	0.628	24 (96 %)	0.089	22 (92.7 %)	0.297	10 (55.6 %)	0.001	29 (90.6 %)	0.286
<b>Health care cost (n = 149)</b>											
Health care cost	56 (37.6 %)	8 (33.3 %)	0.411	10 (38.5 %)	0.543	6 (20.7 %)	0.027	16 (48.5 %)	0.104	16 (43.2 %)	0.265

<sup>1</sup>Percentage of the participants who consulted this profession and reported having a chronic condition.

<sup>2</sup>Excluded from analysis of gender due to small cell size.

\*P values from Fisher's exact test comparing responses from participants consulting with different professions.

acupuncturists reported higher means for items such as *I know what to expect during treatment sessions* and lower means for items such as *My practitioner teaches me ways to relieve my symptoms myself*. Those consulting naturopaths reported a higher mean for the item *My practitioner teaches me ways to relieve my symptoms myself* and a lower mean for *My practitioner receives feedback from my body that guides treatment*. When compared to the total sample, patients of naturopaths reported lower means for their MD consultations across all items of the PCCS.

Table 3 reports the profession-specific results for manual therapy CM professions - massage therapy, osteopathy and chiropractic. Patients of massage therapists reported higher means for MD consultations across all items and patients of osteopaths reported higher means for eight out of ten items. Patients of chiropractors and osteopaths reported higher means for item *The root causes of my problems are identified by my practitioner*, while patients of massage therapists and osteopaths reported higher means for *My practitioner receives feedback from my body that guides treatment*.

### 3.3. Perceived provider support

For the total sample consulting any CM practitioner, perceptions of provider support were strong, with the highest mean (of a possible 5.00) recorded for the item *I trust my practitioner* (mean 4.69) and the lowest mean for *My practitioner gives me hope* (mean 4.39) (full details in Table 2). *Strongly agree/agree* responses to the PPSS items were highly consistent, recorded by a majority of respondents across all items. No respondents selected *Strongly disagree/disagree* for any PPSS items regarding consultations with their CM practitioner (see Supplementary Table S1).

In comparison to CM consultations, respondents who had consulted a MD reported lower means for their medical consultation across all PPSS items. The items attracting the highest and lowest means were *I trust my doctor* (4.32) and *My doctor gives me hope* (3.77) respectively (see Table 2).

Compared to the total sample, participants consulting acupuncturists and massage therapists reported higher means across all items of the PPSS for their CM consultation, while all means for those consulting chiropractors were slightly lower. Naturopathy patients reported lower

Table 2

Interdependent measures: Patient-centred care scale, Perceived provider support scale, and Empowerment scale results for total sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.

Measure items	Consulted Any CM practitioner		Consulted acupuncturists		Consulted naturopaths	
	CM practitioner (n = 149)	Medical doctor (n = 92)	Acupuncturist (n = 23)	Medical doctor (n = 16)	Naturopath (n = 32)	Medical doctor (n = 25)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<b>Patient-centred care scale</b>						
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n = 148)</i>	4.70, 0.50	4.12, 0.89	4.65, 0.57	3.87, 1.06	4.74, 0.45	3.84, 1.03
<i>My practitioner/doctor has a full picture of me as an individual (n = 147)</i>	4.47, 0.68	3.98, 1.03	4.52, 0.59	3.80, 1.15	4.29, 0.78	3.72, 1.14
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n = 148)</i>	4.70, 0.49	4.18, 0.86	4.83, 0.39	4.06, 0.93	4.61, 0.50	3.76, 1.09
<i>The root causes of my problems are identified by my practitioner/doctor (n = 148)</i>	4.22, 0.76	3.78, 1.07	4.00, 0.90	3.63, 1.26	4.16, 0.82	3.48, 1.16
<i>The root causes of my problems are being treated by my practitioner/doctor (n = 148)</i>	4.22, 0.81	3.77, 1.10	4.17, 0.65	3.67, 1.18	4.19, 0.83	3.60, 1.19
<i>The treatment is individualised for me at each session (n = 148)</i>	4.58, 0.56	3.87, 0.91	4.57, 0.59	3.87, 0.83	4.58, 0.56	3.52, 1.00
<i>My practitioner/doctor receives feedback from my body that guides treatment (n = 148)</i>	4.44, 0.66	3.84, 0.94	4.52, 0.51	4.00, 0.93	4.03, 0.75	3.63, 0.82
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n = 148)</i>	4.41, 0.70	3.95, 0.90	4.43, 0.66	3.88, 1.20	4.10, 0.78	3.67, 0.92
<i>I know what to expect during treatment sessions (n = 148)</i>	4.49, 0.61	4.02, 0.79	4.65, 0.49	4.07, 0.59	4.23, 0.62	3.76, 0.93
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n = 148)</i>	4.31, 0.76	3.45, 1.09	3.96, 0.93	3.47, 1.13	4.48, 0.63	3.40, 0.87
<b>Perceived provider support scale</b>						
<i>My practitioner/doctor cares about me (n = 149)</i>	4.62, 0.53	4.24, 0.76	4.70, 0.47	4.13, 0.96	4.66, 0.48	4.16, 0.80
<i>I feel cared for during treatment (n = 149)</i>	4.64, 0.52	4.22, 0.79	4.78, 0.42	4.25, 0.93	4.66, 0.48	4.04, 0.89
<i>My practitioner/doctor accepts me as I am (n = 149)</i>	4.62, 0.53	4.22, 0.72	4.70, 0.56	4.31, 0.79	4.59, 0.50	4.08, 0.70
<i>I receive personal attention during treatment (n = 149)</i>	4.62, 0.51	4.24, 0.75	4.65, 0.49	4.25, 0.68	4.66, 0.48	4.12, 0.78
<i>I can talk openly with my practitioner/doctor (n = 149)</i>	4.62, 0.55	4.24, 0.87	4.70, 0.47	4.13, 1.15	4.56, 0.56	4.08, 1.00
<i>My practitioner/doctor gives me hope (n = 149)</i>	4.39, 0.71	3.77, 1.00	4.43, 0.73	3.63, 1.15	4.38, 0.66	3.58, 1.18
<i>I trust my practitioner/doctor (n = 149)</i>	4.69, 0.46	4.32, 0.77	4.78, 0.42	4.50, 0.73	4.72, 0.46	4.04, 0.89
<b>Empowerment scale</b>						
<i>Do you feel more in control of your health? (n = 124)</i>	2.43, 0.57	2.16, 0.67	2.52, 0.59	2.50, 0.63	2.53, 0.57	1.96, 0.68
<i>Do you know what to do to take care of your health problem? (n = 124)</i>	2.50, 0.53	2.35, 0.58	2.48, 0.59	2.56, 0.51	2.53, 0.57	2.24, 0.60
<i>Do you believe that your health problem will improve? (n = 124)</i>	2.32, 0.70	1.88, 0.68	2.48, 0.67	1.94, 0.68	2.34, 0.70	1.96, 0.79
<i>Do you advocate more for yourself? (n = 120)</i>	2.20, 0.67	2.18, 0.67	2.32, 0.57	2.33, 0.72	2.38, 0.71	2.16, 0.69
<i>Do you have techniques you can use when your symptoms get worse? (n = 122)</i>	2.29, 0.57	2.04, 0.68	2.14, 0.64	2.12, 0.72	2.42, 0.56	2.00, 0.71

Note. Scale values for Patient-Centred Care Scale and Perceived Provider Support Scale: Strongly disagree = 1 (Min), Strongly agree = 5 (Max).

Note. Scale values for Empowerment Scale: No = 1 (Min), Yes a little = 2, Yes a lot = 3 (Max).

**Table 3**  
Interdependent measures: Patient-centred care scale, Perceived provider support scale, and Empowerment scale results for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.

Measure items	Consulted chiropractor		Consulted massage therapist		Consulted osteopath	
	Chiropractor (n = 27)	Medical doctor (n = 16)	Massage therapist (n = 29)	Medical doctor (n = 13)	Osteopath (n = 38)	Medical doctor (n = 22)
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD
<b>Patient-centred care scale</b>						
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n = 148)</i>	4.67, 0.48	4.25, 0.68	4.76, 0.44	4.69, 0.48	4.68, 0.57	4.18, 0.80
<i>My practitioner/doctor has a full picture of me as an individual (n = 147)</i>	4.48, 0.70	4.00, 0.89	4.55, 0.57	4.62, 0.65	4.51, 0.69	4.00, 1.02
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n = 148)</i>	4.59, 0.57	4.19, 0.54	4.69, 0.47	4.77, 0.44	4.76, 0.49	4.41, 0.67
<i>The root causes of my problems are identified by my practitioner/doctor (n = 148)</i>	4.33, 0.68	3.69, 0.87	4.14, 0.79	4.38, 0.77	4.37, 0.63	3.95, 1.00
<i>The root causes of my problems are being treated by my practitioner/doctor (n = 148)</i>	4.22, 0.97	3.50, 0.97	4.07, 0.84	4.38, 0.65	4.37, 0.75	3.86, 1.17
<i>The treatment is individualised for me at each session (n = 148)</i>	4.41, 0.64	3.63, 0.72	4.66, 0.48	4.46, 0.78	4.66, 0.53	4.09, 0.87
<i>My practitioner/doctor receives feedback from my body that guides treatment (n = 148)</i>	4.30, 0.72	4.00, 0.52	4.72, 0.53	4.23, 0.93	4.61, 0.55	3.64, 1.22
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n = 148)</i>	4.41, 0.64	4.00, 0.52	4.62, 0.62	4.23, 0.93	4.47, 0.69	4.09, 0.81
<i>I know what to expect during treatment sessions (n = 148)</i>	4.30, 0.78	3.94, 0.57	4.62, 0.49	4.23, 0.73	4.63, 0.54	4.23, 0.87
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n = 148)</i>	4.22, 0.75	3.50, 1.03	4.34, 0.72	3.62, 1.19	4.42, 0.76	3.36, 1.33
<b>Perceived provider support scale</b>						
<i>My practitioner/doctor cares about me (n = 149)</i>	4.44, 0.64	4.06, 0.57	4.66, 0.48	4.54, 0.66	4.63, 0.54	4.36, 0.79
<i>I feel cared for during treatment (n = 149)</i>	4.44, 0.58	4.06, 0.57	4.72, 0.45	4.62, 0.51	4.63, 0.59	4.29, 0.78
<i>My practitioner/doctor accepts me as I am (n = 149)</i>	4.48, 0.64	4.00, 0.63	4.72, 0.45	4.54, 0.66	4.63, 0.49	4.27, 0.77
<i>I receive personal attention during treatment (n = 149)</i>	4.52, 0.58	4.06, 0.68	4.66, 0.48	4.46, 0.78	4.63, 0.54	4.36, 0.79
<i>I can talk openly with my practitioner/doctor (n = 149)</i>	4.44, 0.64	4.19, 0.66	4.72, 0.45	4.54, 0.66	4.66, 0.58	4.36, 0.73
<i>My practitioner/doctor gives me hope (n = 149)</i>	4.15, 0.82	3.81, 0.91	4.45, 0.74	4.08, 0.76	4.50, 0.65	3.86, 0.89
<i>I trust my practitioner/doctor (n = 149)</i>	4.48, 0.51	4.19, 0.66	4.76, 0.44	4.69, 0.63	4.71, 0.46	4.36, 0.73
<b>Empowerment scale</b>						
<i>Do you feel more in control of your health? (n = 124)</i>	2.04, 0.59	1.94, 0.57	2.45, 0.51	2.23, 0.73	2.55, 0.50	2.27, 0.63
<i>Do you know what to do to take care of your health problem? (n = 124)</i>	2.22, 0.42	2.00, 0.52	2.55, 0.51	2.46, 0.52	2.66, 0.48	2.50, 0.60
<i>Do you believe that your health problem will improve? (n = 124)</i>	2.07, 0.62	1.81, 0.66	2.28, 0.80	1.92, 0.49	2.42, 0.68	1.77, 0.69
<i>Do you advocate more for yourself? (n = 120)</i>	1.68, 0.56	1.80, 0.68	2.38, 0.62	2.38, 0.65	2.19, 0.66	2.24, 0.54
<i>Do you have techniques you can use when your symptoms get worse? (n = 122)</i>	2.07, 0.47	1.75, 0.58	2.28, 0.59	2.00, 0.58	2.42, 0.55	2.27, 0.70

Note. Scale values for Patient-Centred Care Scale and Perceived Provider Support Scale: Strongly disagree = 1 (Min), Strongly agree = 5 (Max).

Note. Scale values for Empowerment Scale: No = 1 (Min), Yes a little = 2, Yes a lot = 3 (Max).

means for all items in response to their consultations with MDs (Table 2), while patients of massage therapists and osteopaths reported higher means for their MDs for all items in the PPSS (Table 3), compared with the total sample.

#### 3.4. Patient empowerment

Responses to the Empowerment Scale for respondents consulting any CM practitioner were typically favourable, with the highest mean (of a possible 3.00) reported for item *Do you know what to do to take care of your health problem* (mean 2.50) and the lowest mean reported for *Do you advocate more for yourself* (mean 2.20) (Table 2). The categorical presentation of these items are reported in Supplementary Table S1.

For participants who responded to the Empowerment Scale regarding consultations with MDs, means were lower than those for CM consultations for all items. The item *Do you know what to do to take care of your health problem* achieved the highest mean (2.35), while item *Do you believe your health problem will improve* achieved the lowest mean (1.88) (Table 2).

Higher means were reported for all five items by patients consulting naturopaths (Table 2) and for four items by those consulting osteopaths (Table 3), compared to the total sample for CM consultations. Regarding MD consultations, higher means were reported by those consulting acupuncturists (Table 2), massage therapists and osteopaths, while lower means were reported by those consulting chiropractors (Table 3), compared to the total sample.

#### 3.5. Patient assessment of chronic illness care

The total summary score mean for the PACIC measure, across the total sample, was 3.33 for consultations with any CM practitioner, and 2.95 for consultations with a MD. The highest summary score mean was reported for consultations with naturopaths (4.04) while the lowest was reported by patients of naturopaths for consultations with their MDs (2.84). Of the five PACIC domains, the domain attracting the highest summary score for consultations with CM practitioners was *Delivery and practice* (mean 3.87), while the domain attracting the highest summary score for consultations with MDs was *Patient activation* (mean 3.38). The domain *Follow up and coordination* attracted the lowest summary score for both CM consultations (mean 2.66) and conventional medicine consultations (mean 2.52) (Table 4). A general trend demonstrated higher summary scores for consultations with CM practitioners compared to consultations with MDs, with the exception of responses from patients of massage therapists, who reported slightly higher total scores for their MD (mean 3.27) compared to their massage therapist (mean 3.23) (Table 5).

Domain summary score means were highest for consultations with naturopaths across all five domains, ranging from 3.34 for *Follow up and coordination* to 4.50 for *Delivery and practice* (Table 4). The lowest summary scores for domains *Patient activation* (mean 3.02) and *Delivery and practice* (mean 3.13) were both recorded for MD consultations for chiropractic patients (Table 5). The lowest summary scores for domains *Goal setting and tailoring* (mean 2.66) and *Problem-solving and contextual counselling* (mean 2.93) were both recorded for MD consultations for naturopathy patients (Table 4), while the lowest summary score for domain *Follow up and coordination* (mean 2.34) was recorded for chiropractic consultations (Table 5).

## 4. Discussion

This study is the first to provide detailed reporting of experiences of PCC specific to individuals with chronic conditions who consult with CM practitioners, across a variety of clinical professional settings. Many participants reported experiencing PCC during consultation with CM practitioners. While there was some nuanced variation between groups consulting with different CM professions, each of the five professions

attracted consistently high ratings of PCC overall from patients for all four measures. This is reflective of existing literature suggesting that PCC is generally characteristic of CM consultations.<sup>17,20</sup>

Across all measures assessing patient perceptions of the care they received, respondents also consistently reported higher ratings for their experience of consultations with CM practitioners compared to consultations with MDs, which may be influenced by different practical approaches within conventional and complementary medicine systems. Due to its development being centred on addressing the historical burdens of acute and infectious diseases, the conventional medical system faces many challenges in moving toward a model of care provision that adequately addresses the needs of those with chronic conditions.<sup>1</sup> In contrast, it has been suggested that CM philosophies have contributed to the development of PCC,<sup>21</sup> which as a paradigm of clinical care is particularly well-suited to chronic illness management.<sup>22</sup> Indeed, the philosophy of holism which underlies many CM professions appears to correlate closely in principle with PCC.<sup>12</sup> CM practitioners also tend to provide longer consultations than MDs,<sup>20</sup> allowing more time for patients and practitioners to explore the complex, multifactorial needs of individuals with chronic conditions. Previous studies have identified the lengthier consultations of CM services such as naturopathy and acupuncture as contributing to patients feeling heard, and to patients perceiving CM practitioners as caring and trustworthy,<sup>23,24</sup> which is congruous with the perceptions of CM practitioners reported by our participants. Thus, it may be that applied holistic philosophy and lengthier consultation time both contributed to our participants' reporting higher PCC in CM consultations compared to those with MDs. Clinical settings which provide holistic CM care alongside conventional medicine have demonstrated that such integration of services may be an avenue through which to enhance patient-centredness, as well as both patient and provider satisfaction.<sup>25,26,27</sup>

For the majority of items across the survey, care received from naturopaths was rated most highly by respondents. While there are any number of factors that may be contributing to this finding, a previous review of patient perceptions of care in CM proposed the importance of patient empowerment and facilitation of patient self-efficacy in some CM professions may be key.<sup>17</sup> The other four CM professions consulted by our participants employ primarily practitioner-enacted treatments during consultation (e.g. direct application of manual therapies or acupuncture needles), demonstrated in the lower mean reported by acupuncture patients for the item *My practitioner teaches me ways to relieve symptoms myself* and higher means reported by patients of massage therapists and osteopaths for the item *My practitioner receives feedback from my body that guides treatment*. Naturopaths, however, rely largely on patient-enacted treatments (e.g. remedies or dietary/lifestyle advice that patients must self-administer outside of the consultation) – an approach requiring the naturopath to engage the patient in the treatment process, which typically involves provision of patient education and detailed discussion of the patient's individual circumstances.<sup>28</sup> Previous studies show such patient education by naturopaths may improve the patient's self-efficacy and sense of empowerment, while time spent discussing the patient's needs may result in the patient feeling heard and supported,<sup>17,23</sup> leading to a particularly high degree of perceived PCC during consultation with naturopaths.

While care provided by CM practitioners was typically rated more highly than care provided by MDs, patients of different CM professions differed slightly in the domains and items for which they gave lower ratings to their MDs. For example, across the PACIC measure, compared to patients of other CM professions, patients of naturopaths rated their MDs lower in the domain of *Problem solving and contextual counselling* and patients of chiropractors rated their MDs lower in *Patient activation*. This may speak to differences in patients' unmet needs potentially prompting patients to seek care from particular CM professions – with those professions possibly being perceived as more likely to meet a specific unmet need. The individualised approach of PCC, however, is intended to facilitate the meeting of individual needs regardless of the

Table 4

Patient Assessment of Chronic Illness Care (PACIC) Measure results for total sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.

PACIC domain items	Consulted Any CM practitioner		Consulted acupuncturists		Consulted naturopaths	
	CM practitioner (n = 146) Mean, SD	Medical doctor (n = 90) Mean, SD	Acupuncturist (n = 23) Mean, SD	Medical doctor (n = 14) Mean, SD	Naturopath (n = 31) Mean, SD	Medical doctor (n = 25) Mean, SD
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>						
<b>Patient activation</b>						
<i>Asked for my ideas when we made a treatment plan (n = 146)</i>	3.75, 1.09	3.09, 1.22	3.78, 1.17	3.07, 1.33	3.97, 1.02	2.88, 1.13
<i>Given choices about treatment to think about (n = 145)</i>	3.88, 1.09	3.52, 1.06	3.95, 0.95	3.29, 1.07	4.39, 0.80	3.50, 0.93
<i>Asked to talk about any problems with my medicines/treatments or their effects (n = 142)</i>	3.85, 1.22	3.52, 1.26	4.00, 1.20	3.36, 1.55	4.57, 0.68	3.38, 1.13
<b>Patient activation domain score</b>	<b>3.83, 0.97</b>	<b>3.38, 1.05</b>	<b>3.92, 0.98</b>	<b>3.24, 1.26</b>	<b>4.30, 0.67</b>	<b>3.26, 0.89</b>
<b>Delivery and practice</b>						
<i>Given a written list of things I should do to improve my health (n = 143)</i>	3.17, 1.35	2.72, 1.23	3.09, 1.27	2.57, 1.45	4.63, 0.72	3.08, 1.19
<i>Satisfied that my care was well organized (n = 146)</i>	4.53, 0.69	3.79, 1.04	4.52, 0.59	3.79, 1.12	4.71, 0.46	3.44, 1.19
<i>Shown how what I did to take care of my illness influenced my condition (n = 141)</i>	3.92, 1.06	3.24, 1.11	3.68, 1.39	3.14, 1.23	4.17, 0.79	3.24, 0.93
<b>Delivery and practice domain score</b>	<b>3.87, 0.76</b>	<b>3.25, 0.91</b>	<b>3.76, 0.90</b>	<b>3.17, 1.15</b>	<b>4.50, 0.47</b>	<b>3.25, 0.93</b>
<b>Goal setting and tailoring</b>						
<i>Asked to talk about my goals in caring for my illness (n = 143)</i>	3.61, 1.23	2.94, 1.20	3.68, 1.36	3.00, 1.47	4.20, 1.06	2.80, 1.04
<i>Helped to set specific goals to improve my eating or exercise (n = 142)</i>	3.42, 1.28	2.72, 1.22	3.32, 1.55	2.46, 1.51	4.41, 0.82	2.63, 1.10
<i>Given a copy of my treatment plan (n = 142)</i>	2.85, 1.49	2.66, 1.39	2.73, 1.49	2.93, 1.54	4.65, 0.66	2.30, 1.40
<i>Encouraged to go to a specific group or class to help me cope with my chronic illness (n = 138)</i>	2.66, 1.28	2.46, 1.32	1.95, 1.07	2.50, 1.56	3.36, 1.13	2.42, 1.18
<i>Asked questions, either directly or on a survey, about my health habits (n = 144)</i>	3.48, 1.36	3.11, 1.32	3.41, 1.56	2.86, 1.41	4.33, 0.71	3.28, 1.24
<b>Goal setting and tailoring domain score</b>	<b>3.21, 1.03</b>	<b>2.78, 1.04</b>	<b>3.05, 1.20</b>	<b>2.76, 1.32</b>	<b>4.21, 0.58</b>	<b>2.66, 0.95</b>
<b>Problem-solving and contextual counselling</b>						
<i>Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n = 144)</i>	4.09, 1.15	3.52, 1.29	3.86, 1.32	3.29, 1.59	4.67, 0.66	3.64, 1.11
<i>Helped to make a treatment plan that I could do in my daily life (n = 143)</i>	3.71, 1.21	3.03, 1.21	3.27, 1.49	3.14, 1.17	4.52, 0.77	2.71, 1.20
<i>Helped to plan ahead so I could take care of my illness even in hard times (n = 140)</i>	3.56, 1.21	3.05, 1.21	3.14, 1.49	3.07, 1.27	4.29, 0.81	2.59, 1.05
<i>Asked how my chronic illness affects my life (n = 141)</i>	3.79, 1.17	3.21, 1.27	3.77, 1.34	3.07, 1.27	4.14, 1.11	2.91, 1.31
<b>Problem-solving and contextual counselling domain score</b>	<b>3.80, 0.96</b>	<b>3.19, 1.06</b>	<b>3.52, 1.24</b>	<b>3.14, 1.21</b>	<b>4.42, 0.61</b>	<b>2.93, 0.97</b>
<b>Follow-up and coordination</b>						
<i>Contacted after a visit to see how things were going (n = 140)</i>	2.57, 1.28	2.16, 1.29	2.68, 1.29	2.71, 1.64	3.11, 1.23	2.08, 1.38
<i>Encouraged to attend programs in the community that could help me (n = 137)</i>	2.55, 1.25	2.22, 1.24	2.19, 1.25	2.14, 1.17	3.15, 1.16	2.17, 1.19
<i>Referred to a dietitian, health educator, or counsellor (n = 137)</i>	2.22, 1.20	2.56, 1.49	2.10, 1.22	2.85, 1.63	3.15, 1.32	2.58, 1.38
<i>Told how my visits with other types of practitioners/doctors helped my treatment (n = 138)</i>	2.83, 1.34	2.75, 1.34	2.67, 1.28	2.64, 1.55	3.71, 1.08	2.90, 1.09
<i>Asked how my visits with other doctors/practitioners were going (n = 142)</i>	3.26, 1.42	2.86, 1.32	3.57, 1.33	2.79, 1.37	3.87, 1.06	3.04, 1.27
<b>Follow up and coordination domain score</b>	<b>2.66, 1.02</b>	<b>2.52, 1.09</b>	<b>2.62, 1.04</b>	<b>2.63, 1.16</b>	<b>3.34, 0.89</b>	<b>2.59, 1.05</b>
<b>PACIC total summary score</b>	<b>3.33, 0.82</b>	<b>2.95, 0.96</b>	<b>3.19, 0.95</b>	<b>2.94, 1.14</b>	<b>4.04, 0.54</b>	<b>2.84, 0.94</b>

Note: Scale values for PACIC: Almost never = 1 (Min), Almost always = 5 (Max).

Note: During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.



**Table 5**  
Patient Assessment of Chronic Illness Care (PACIC) Measure results for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.

PACIC domain items	Consulted a chiropractor		Consulted a massage therapist		Consulted an osteopath	
	Chiropractor (n = 25) Mean, SD	Medical doctor (n = 16) Mean, SD	Massage therapist (n = 29) Mean, SD	Medical doctor (n = 13) Mean, SD	Osteopath (n = 38) Mean, SD	Medical doctor (n = 22) Mean, SD
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>						
<b>Patient activation</b>						
Asked for my ideas when we made a treatment plan (n = 146)	3.64, 1.15	2.69, 1.14	3.79, 1.11	3.62, 1.12	3.58, 1.06	3.32, 1.32
Given choices about treatment to think about (n = 145)	3.68, 1.03	3.19, 1.05	3.86, 1.19	4.15, 0.80	3.58, 1.22	3.59, 1.22
Asked to talk about any problems with my medicines/treatments or their effects (n = 142)	3.64, 1.15	3.19, 1.28	3.62, 1.32	4.00, 1.08	3.50, 1.36	3.73, 1.28
<b>Patient activation domain score</b>	<b>3.65, 1.01</b>	<b>3.02, 1.04</b>	<b>3.76, 1.03</b>	<b>3.92, 0.81</b>	<b>3.57, 1.01</b>	<b>3.55, 1.14</b>
<b>Delivery and practice</b>						
Given a written list of things I should do to improve my health (n = 143)	2.54, 1.10	2.56, 1.36	2.52, 1.12	2.69, 1.25	2.95, 1.25	2.55, 1.01
Satisfied that my care was well organized (n = 146)	4.36, 0.91	3.69, 0.95	4.66, 0.67	4.15, 0.90	4.39, 0.72	4.05, 0.90
Shown how what I did to take care of my illness influenced by condition (n = 141)	3.83, 1.09	3.13, 1.20	3.71, 1.05	3.58, 1.24	4.08, 0.98	3.18, 1.14
<b>Delivery and practice domain score</b>	<b>3.6, 0.78</b>	<b>3.13, 0.91</b>	<b>3.62, 0.61</b>	<b>3.45, 0.86</b>	<b>3.81, 0.71</b>	<b>3.26, 0.79</b>
<b>Goal setting and tailoring</b>						
Asked to talk about my goals in caring for my illness (n = 143)	3.24, 1.39	2.81, 1.38	3.46, 1.14	3.46, 0.97	3.45, 1.13	2.86, 1.21
Helped to set specific goals to improve my eating or exercise (n = 142)	3.08, 0.95	2.81, 1.47	3.07, 1.44	2.92, 0.95	3.21, 1.14	2.77, 1.19
Given a copy of my treatment plan (n = 142)	2.20, 1.26	2.81, 1.42	2.12, 1.14	2.58, 1.38	2.39, 1.15	2.81, 1.29
Encouraged to go to a specific group or class to help me cope with my chronic illness (n = 138)	2.28, 1.10	2.53, 1.46	2.67, 1.30	2.50, 1.38	2.78, 1.34	2.41, 1.30
Asked questions, either directly or on a survey, about my health habits (n = 144)	3.16, 1.43	3.31, 1.25	3.66, 1.26	3.42, 1.31	2.92, 1.36	2.77, 1.41
<b>Goal setting and tailoring domain score</b>	<b>2.79, 0.79</b>	<b>2.87, 1.09</b>	<b>2.99, 0.92</b>	<b>2.97, 0.92</b>	<b>2.96, 0.97</b>	<b>2.73, 1.05</b>
<b>Problem-solving and contextual counselling</b>						
Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n = 144)	3.76, 1.20	3.00, 1.21	4.21, 1.18	3.85, 1.41	3.89, 1.18	3.73, 1.24
Helped to make a treatment plan that I could do in my daily life (n = 143)	3.60, 1.15	3.00, 1.21	3.43, 1.20	3.42, 1.08	3.59, 1.14	3.14, 1.32
Helped to plan ahead so I could take care of my illness even in hard times (n = 140)	3.40, 1.22	3.00, 1.15	3.34, 1.20	3.58, 1.00	3.54, 1.10	3.23, 1.38
Asked how my chronic illness affects my life (n = 141)	3.52, 1.23	3.19, 1.28	3.93, 1.07	4.17, 0.72	3.62, 1.11	3.09, 1.31
<b>Problem-solving and contextual counselling domain score</b>	<b>3.57, 0.91</b>	<b>3.05, 1.08</b>	<b>3.74, 0.86</b>	<b>3.77, 0.76</b>	<b>3.66, 0.96</b>	<b>3.30, 1.13</b>
<b>Follow-up and coordination</b>						
Contacted after a visit to see how things were going (n = 140)	2.44, 1.36	2.13, 1.20	2.61, 1.31	1.92, 0.79	2.16, 1.14	2.05, 1.21
Encouraged to attend programs in the community that could help me (n = 137)	2.08, 1.08	2.31, 1.25	2.61, 1.26	2.42, 1.44	2.62, 1.30	2.14, 1.32
Referred to a dietitian, health educator, or counsellor (n = 137)	1.80, 2.72	2.69, 1.70	2.00, 1.05	2.50, 1.62	2.06, 1.17	2.32, 1.39
Told how my visits with other types of practitioners/doctors helped my treatment (n = 138)	2.72, 1.46	2.50, 1.55	2.71, 1.21	3.33, 1.23	2.39, 1.34	2.55, 1.34
Asked how my visits with other doctors/practitioners were going (n = 142)	2.68, 1.49	2.56, 1.50	3.59, 1.45	3.17, 1.03	2.69, 1.39	2.76, 1.41
<b>Follow up and coordination domain score</b>	<b>2.34, 0.95</b>	<b>2.44, 1.27</b>	<b>2.67, 0.90</b>	<b>2.67, 0.84</b>	<b>2.37, 1.02</b>	<b>2.35, 1.15</b>
<b>PACIC total summary score</b>	<b>3.06, 0.72</b>	<b>2.86, 1.00</b>	<b>3.23, 0.69</b>	<b>3.27, 0.73</b>	<b>3.14, 0.80</b>	<b>2.95, 0.96</b>

Note. Scale values for PACIC: Almost never = 1 (Min), Almost always = 5 (Max).

Note. During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

care provider's profession.<sup>29</sup>

#### 4.1. Implications

Our finding that CM practitioner consultations were characteristically person-centred for our participants correlates with the existing body of literature identifying aspects of CM consultation which are aligned with PCC.<sup>20</sup> Patients with chronic conditions have expressed a desire and need for more person-centred approaches to their care,<sup>30</sup> while person-centred aspects of clinical care such as provider empathy, strong communication<sup>5</sup> and personalised consultations/treatments<sup>6</sup> have been correlated with favourable health and psychosocial outcomes. The utility and importance of PCC in management of chronic conditions has been recognised in international<sup>31</sup> and national<sup>32</sup> health policy and guidelines, due to its capacity to address complex presentations or underlying aspects of illness such as those seen in chronic conditions. As chronic illness increasingly contributes to the burden of disease, and as patients with chronic conditions continue to seek multiple sources of care to manage their complex needs, it should be considered that CM practitioners may represent an existing resource of person-centred clinical management to address otherwise unmet aspects of care for this patient population.

#### 4.2. Limitations

The results of this study provide promising insights into the potential benefits of CM consultations for individuals with chronic conditions, yet certain limitations must be noted. The small sample size and convenience sampling method preclude the use of more robust statistical analyses, while a suboptimal response rate potentially indicates presence of non-response bias, limiting the capacity for generalisation of findings. However, the broad geographical spread of clinic locations enhances representativeness, while the consecutive approach to recruitment moderates risk of sampling bias.

Due to small numbers in sub-groups delineated by CM profession consulted, alongside dependency of sub-groups separated by CM vs. MD consults (i.e. patients consulting MDs were the same patients consulting CM practitioners), statistical tests of association or comparison regarding the four measures used were not possible. Future research examining such comparisons should be conducted using larger, independent samples. Additionally, participant responses rating consultations with CM practitioners and with MDs may be impacted by recall bias as the survey was administered directly following CM consultation and the time period between survey and consultations with MDs will have been more extensive (in some cases perhaps sizeable). While self-report survey research always carries a risk of response and non-response bias, the consistency of results demonstrated by this study provide compelling rationale for further attention to and research in this area.

#### 5. Conclusion

Our findings demonstrate notably favourable and consistent patient perceptions of PCC in CM clinical settings for individuals with chronic conditions. It appears the patient experience of PCC is characteristic of CM clinical care to a greater extent than in conventional medical settings. In light of the challenges presented to health systems by the rising rates, complexity and ongoing nature of chronic conditions, consideration should be given to the value CM professionals may contribute to addressing such challenges by providing individualised, tailored care to their patients.

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#### Declaration of Competing Interest

None.

#### CRediT authorship contribution statement

**Hope Foley:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization, Project administration, Funding acquisition. **Amie Steel:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Jon Adams:** Conceptualization, Methodology, Writing - review & editing, Supervision, Project administration, Funding acquisition.

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#### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ctim.2020.102518>.

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Table S1. Categorical data for Patient-centred care scale, Perceived provider support scale, and Empowerment scale results. Presented for full sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.

Measure Items	Consulted Any CM practitioner						Consulted acupuncturists						Consulted naturopaths					
	CM practitioner (n=149)			Medical doctor (n=92)			Acupuncturist (n=23)			Medical doctor (n=16)			Naturopath (n=32)			Medical doctor (n=25)		
	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree
<b>Patient-centred care scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n=148)</i>	145 (98.0)	3 (2.0)	0 (0.0)	74 (81.3)	10 (11.0)	7 (7.7)	22 (95.7)	1 (4.4)	0 (0.0)	10 (66.7)	3 (20.0)	2 (13.3)	31 (100.0)	0 (0.0)	0 (0.0)	18 (72.0)	3 (12.0)	4 (16.0)
<i>My practitioner/doctor has a full picture of me as an individual (n=147)</i>	134 (91.2)	12 (8.2)	1 (0.7)	66 (72.5)	16 (17.6)	9 (9.9)	22 (95.7)	1 (4.4)	0 (0.0)	10 (66.7)	2 (13.3)	3 (20.0)	27 (87.1)	3 (9.7)	1 (3.2)	16 (64.0)	5 (20.0)	4 (16.0)
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n=148)</i>	146 (98.7)	2 (1.4)	0 (0.0)	76 (82.6)	12 (13.0)	4 (4.4)	23 (100.0)	0 (0.0)	0 (0.0)	12 (75.0)	3 (18.8)	1 (6.3)	31 (100.0)	0 (0.0)	0 (0.0)	16 (64.0)	6 (24.0)	3 (12.0)
<i>The root causes of my problems are identified by my practitioner/doctor (n=148)</i>	122 (82.4)	24 (16.2)	2 (1.4)	60 (65.2)	22 (23.9)	10 (10.9)	16 (69.6)	6 (26.1)	1 (4.4)	9 (56.3)	4 (25.0)	3 (18.8)	25 (80.7)	5 (16.1)	1 (3.2)	15 (60.0)	5 (20.0)	5 (20.0)
<i>The root causes of my problems are being treated by my practitioner/doctor (n=148)</i>	123 (83.1)	21 (14.2)	4 (2.7)	60 (65.9)	19 (20.9)	12 (13.2)	20 (87.0)	3 (13.0)	0 (0.0)	9 (60.0)	4 (26.7)	2 (13.3)	27 (87.1)	2 (6.5)	2 (6.5)	17 (68.0)	3 (12.0)	5 (20.0)
<i>The treatment is individualised for me at each session (n=148)</i>	143 (96.6)	5 (3.4)	0 (0.0)	57 (62.6)	29 (31.9)	5 (5.5)	22 (95.7)	1 (4.4)	0 (0.0)	9 (60.0)	6 (40.0)	0 (0.0)	30 (96.8)	1 (3.2)	0 (0.0)	12 (48.0)	9 (36.0)	4 (16.0)
<i>My practitioner/doctor receives feedback from my body that guides treatment (n=148)</i>	134 (90.5)	14 (9.5)	0 (0.0)	62 (68.9)	20 (22.2)	8 (8.9)	23 (100.0)	0 (0.0)	0 (0.0)	11 (73.3)	3 (20.0)	1 (6.7)	23 (74.2)	8 (25.8)	0 (0.0)	14 (58.3)	8 (33.3)	2 (8.3)
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n=148)</i>	130 (87.8)	18 (12.2)	0 (0.0)	67 (73.6)	18 (19.8)	6 (6.6)	21 (91.3)	2 (8.7)	0 (0.0)	11 (68.8)	3 (18.8)	2 (12.5)	23 (74.2)	8 (25.8)	0 (0.0)	15 (62.5)	6 (25.0)	3 (12.5)
<i>I know what to expect during treatment sessions (n=148)</i>	141 (95.3)	6 (4.1)	1 (0.7)	70 (76.9)	18 (19.8)	3 (3.3)	23 (100.0)	0 (0.0)	0 (0.0)	13 (86.7)	2 (13.3)	0 (0.0)	28 (90.3)	3 (9.7)	0 (0.0)	15 (60.0)	8 (32.0)	2 (8.0)
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n=148)</i>	125 (84.5)	21 (14.2)	2 (1.4)	47 (51.7)	26 (28.6)	18 (19.8)	15 (65.2)	7 (30.4)	1 (4.4)	9 (60.0)	3 (20.0)	3 (20.0)	29 (93.6)	2 (6.5)	0 (0.0)	12 (48.0)	9 (36.0)	4 (16.0)
<b>Perceived provider support scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>My practitioner/doctor cares about me (n=149)</i>	146 (98.0)	3 (2.0)	0 (0.0)	77 (83.7)	13 (13.1)	2 (2.2)	23 (100.0)	0 (0.0)	0 (0.0)	12 (75.0)	3 (18.8)	1 (6.3)	32 (100.0)	0 (0.0)	0 (0.0)	19 (76.0)	6 (24.0)	0 (0.0)

Measure Items	Consulted Any CM practitioner						Consulted acupuncturists						Consulted naturopaths					
	CM practitioner (n=149)			Medical doctor (n=92)			Acupuncturist (n=23)			Medical doctor (n=16)			Naturopath (n=32)			Medical doctor (n=25)		
	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree
<i>I feel cared for during treatment (n=149)</i>	146 (98.0)	3 (2.0)	0 (0.0)	77 (84.6)	11 (12.1)	3 (3.3)	23 (100.0)	0 (0.0)	0 (0.0)	13 (81.3)	2 (12.5)	1 (6.3)	32 (100.0)	0 (0.0)	0 (0.0)	18 (72.0)	6 (24.0)	1 (4.0)
<i>My practitioner/doctor accepts me as I am (n=149)</i>	146 (98.0)	3 (2.0)	0 (0.0)	78 (84.8)	13 (14.1)	1 (1.1)	22 (95.7)	1 (4.4)	0 (0.0)	13 (81.3)	3 (18.8)	0 (0.0)	32 (100.0)	0 (0.0)	0 (0.0)	20 (80.0)	5 (20.0)	0 (0.0)
<i>I receive personal attention during treatment (n=149)</i>	147 (98.7)	2 (1.3)	0 (0.0)	77 (83.7)	14 (15.2)	1 (1.1)	23 (100.0)	0 (0.0)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	32 (100.0)	0 (0.0)	0 (0.0)	19 (76.0)	6 (24.0)	0 (0.0)
<i>I can talk openly with my practitioner/doctor (n=149)</i>	144 (96.6)	5 (3.4)	0 (0.0)	79 (85.9)	8 (8.7)	5 (5.4)	23 (100.0)	0 (0.0)	0 (0.0)	12 (75.0)	3 (18.8)	1 (6.3)	31 (96.9)	1 (3.1)	0 (0.0)	20 (80.0)	2 (8.0)	3 (12.0)
<i>My practitioner/doctor gives me hope (n=149)</i>	129 (86.6)	20 (13.4)	0 (0.0)	56 (61.5)	25 (27.5)	10 (11.0)	20 (87.0)	3 (13.0)	0 (0.0)	9 (56.3)	5 (31.3)	2 (12.5)	29 (90.6)	3 (9.4)	0 (0.0)	13 (54.2)	5 (20.8)	6 (25.0)
<i>I trust my practitioner/doctor (n=149)</i>	149 (100.0)	0 (0.0)	0 (0.0)	81 (88.0)	8 (8.7)	3 (3.3)	23 (100.0)	0 (0.0)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	32 (100.0)	0 (0.0)	0 (0.0)	20 (80.0)	3 (12.0)	2 (8.0)
	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No
<b>Empowerment scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Do you feel more in control of your health? (n=124)</i>	63 (50.8)	57 (46.0)	4 (3.2)	28 (36.8)	39 (51.3)	9 (11.8)	13 (56.5)	9 (39.1)	1 (4.4)	9 (56.3)	6 (37.5)	1 (6.3)	14 (63.6)	7 (31.8)	1 (4.6)	5 (27.8)	11 (61.1)	2 (11.1)
<i>Do you know what to do to take care of your health problem? (n=124)</i>	71 (57.3)	52 (41.9)	1 (0.8)	37 (48.7)	37 (48.7)	2 (2.6)	12 (52.2)	10 (43.5)	1 (4.4)	9 (56.3)	7 (43.8)	0 (0.0)	14 (63.6)	8 (36.4)	0 (0.0)	8 (44.4)	10 (55.6)	0 (0.0)
<i>Do you believe that your health problem will improve? (n=124)</i>	63 (50.8)	47 (37.9)	14 (11.3)	14 (18.4)	42 (55.3)	20 (26.3)	13 (56.5)	8 (34.8)	2 (8.7)	3 (18.8)	9 (56.3)	4 (25.0)	11 (50.0)	9 (40.9)	2 (9.1)	6 (33.3)	7 (38.9)	5 (27.8)
<i>Do you advocate more for yourself? (n=120)</i>	45 (37.5)	62 (51.7)	13 (10.8)	28 (38.4)	36 (49.3)	9 (12.3)	8 (36.4)	13 (59.1)	1 (4.6)	7 (46.7)	6 (40.0)	2 (13.3)	12 (54.6)	7 (31.8)	3 (13.6)	7 (38.9)	8 (44.4)	3 (16.7)
<i>Do you have techniques you can use when your symptoms get worse? (n=122)</i>	46 (37.7)	68 (55.7)	8 (6.6)	23 (30.3)	39 (51.3)	14 (18.4)	6 (27.3)	13 (59.1)	3 (13.6)	5 (31.3)	8 (50.0)	3 (18.8)	10 (47.6)	10 (47.6)	1 (4.8)	6 (33.3)	8 (44.4)	4 (22.2)

**Table S2. Categorical data for Patient-centred care scale, Perceived provider support scale, and Empowerment scale results. Presented for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.**

Measure Items	Consulted chiropractor						Consulted massage therapist						Consulted osteopath					
	Chiropractor (n=27)			Medical doctor (n=16)			Massage therapist (n=29)			Medical doctor (n=13)			Osteopath (n=38)			Medical doctor (n=22)		
	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree
<b>Patient-centred care scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>I feel seen and heard as a unique individual by my practitioner/doctor (n=148)</i>	27 (100.0)	0 (0.0)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	13 (100.0)	0 (0.0)	0 (0.0)	36 (94.7)	2 (5.3)	0 (0.0)	19 (86.4)	2 (9.1)	1 (4.6)
<i>My practitioner/doctor has a full picture of me as an individual (n=147)</i>	24 (88.9)	3 (11.1)	0 (0.0)	12 (75.0)	3 (18.8)	1 (6.3)	28 (96.6)	1 (3.5)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	33 (89.2)	4 (10.8)	0 (0.0)	16 (72.7)	5 (22.7)	1 (4.6)
<i>My practitioner/doctor is really interested in finding and addressing my health problems (n=148)</i>	26 (96.3)	1 (3.7)	0 (0.0)	15 (93.8)	1 (6.3)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	13 (100.0)	0 (0.0)	0 (0.0)	37 (97.4)	1 (2.6)	0 (0.0)	20 (90.9)	2 (9.1)	0 (0.0)
<i>The root causes of my problems are identified by my practitioner/doctor (n=148)</i>	24 (88.9)	3 (11.1)	0 (0.0)	9 (56.3)	6 (37.5)	1 (6.3)	22 (75.9)	7 (24.1)	0 (0.0)	11 (84.6)	2 (15.4)	0 (0.0)	35 (92.1)	3 (7.9)	0 (0.0)	16 (72.7)	5 (22.7)	1 (4.6)
<i>The root causes of my problems are being treated by my practitioner/doctor (n=148)</i>	22 (81.5)	4 (14.8)	1 (3.7)	7 (43.8)	7 (43.8)	2 (12.5)	20 (69.0)	9 (31.0)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	34 (89.5)	3 (7.9)	1 (2.6)	15 (68.2)	4 (18.2)	3 (13.6)
<i>The treatment is individualised for me at each session (n=148)</i>	25 (92.6)	2 (7.4)	0 (0.0)	3 (50.0)	8 (50.0)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	11 (84.6)	2 (15.4)	0 (0.0)	37 (97.4)	1 (2.6)	0 (0.0)	17 (77.3)	4 (18.2)	1 (4.6)
<i>My practitioner/doctor receives feedback from my body that guides treatment (n=148)</i>	23 (85.2)	4 (14.8)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	28 (96.6)	1 (3.5)	0 (0.0)	11 (84.6)	1 (7.7)	1 (7.7)	37 (97.4)	1 (2.6)	0 (0.0)	12 (54.6)	6 (27.3)	4 (18.2)
<i>My practitioner/doctor asks me for feedback from my body that guides treatment (n=148)</i>	25 (92.6)	2 (7.4)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	27 (93.1)	2 (6.9)	0 (0.0)	11 (84.6)	1 (7.7)	1 (7.7)	34 (89.5)	4 (10.5)	0 (0.0)	16 (72.7)	6 (27.3)	0 (0.0)
<i>I know what to expect during treatment sessions (n=148)</i>	24 (88.9)	2 (7.4)	1 (3.7)	13 (81.3)	3 (18.8)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	11 (84.6)	2 (15.4)	0 (0.0)	37 (97.4)	1 (2.6)	0 (0.0)	18 (81.8)	3 (13.6)	1 (4.6)
<i>My practitioner/doctor teaches me ways to relieve symptoms myself (n=148)</i>	22 (81.5)	5 (18.5)	0 (0.0)	9 (56.3)	5 (31.3)	2 (12.5)	25 (86.2)	4 (13.8)	0 (0.0)	8 (61.5)	3 (23.1)	2 (15.4)	34 (89.5)	3 (7.9)	1 (2.6)	9 (40.9)	6 (27.3)	7 (31.8)

Measure Items	Consulted chiropractor						Consulted massage therapist						Consulted osteopath					
	Chiropractor (n=27)			Medical doctor (n=16)			Massage therapist (n=29)			Medical doctor (n=13)			Osteopath (n=38)			Medical doctor (n=22)		
	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree	Strongly agree/agree	Neutral	Strongly disagree/disagree
<b>Perceived provider support scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>My practitioner/doctor cares about me (n=149)</i>	25 (92.6)	2 (7.4)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	37 (97.4)	1 (2.6)	0 (0.0)	20 (90.9)	1 (4.6)	1 (4.6)
<i>I feel cared for during treatment (n=149)</i>	26 (96.3)	1 (3.7)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	13 (100.0)	0 (0.0)	0 (0.0)	36 (94.7)	2 (5.3)	0 (0.0)	19 (90.5)	1 (4.8)	1 (4.8)
<i>My practitioner/doctor accepts me as I am (n=149)</i>	25 (92.6)	2 (7.4)	0 (0.0)	13 (81.3)	3 (18.8)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	38 (100.0)	0 (0.0)	0 (0.0)	20 (90.9)	1 (4.6)	1 (4.6)
<i>I receive personal attention during treatment (n=149)</i>	26 (96.3)	1 (3.7)	0 (0.0)	13 (81.3)	3 (18.8)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	11 (84.6)	2 (15.4)	0 (0.0)	37 (97.4)	1 (2.6)	0 (0.0)	20 (90.9)	1 (4.6)	1 (4.6)
<i>I can talk openly with my practitioner/doctor (n=149)</i>	25 (92.6)	2 (7.4)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	36 (94.7)	2 (5.3)	0 (0.0)	21 (95.5)	1 (4.6)	0 (0.0)
<i>My practitioner/doctor gives me hope (n=149)</i>	20 (74.1)	7 (25.9)	0 (0.0)	10 (62.5)	5 (31.3)	1 (6.3)	25 (86.2)	4 (13.8)	0 (0.0)	10 (76.9)	3 (23.1)	0 (0.0)	35 (92.1)	3 (7.9)	0 (0.0)	14 (63.6)	7 (31.8)	1 (4.6)
<i>I trust my practitioner/doctor (n=149)</i>	27 (100.0)	0 (0.0)	0 (0.0)	14 (87.5)	2 (12.5)	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)	12 (92.3)	1 (7.7)	0 (0.0)	38 (100.0)	0 (0.0)	0 (0.0)	21 (95.5)	1 (4.6)	0 (0.0)
	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No	Yes, a lot	Yes, a little	No
<b>Empowerment scale</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Do you feel more in control of your health? (n=124)</i>	3 (23.1)	8 (61.5)	2 (15.4)	1 (12.5)	5 (62.5)	2 (25.0)	13 (44.8)	16 (55.2)	0 (0.0)	5 (38.5)	6 (46.2)	2 (15.4)	20 (54.1)	17 (46.0)	0 (0.0)	8 (38.1)	11 (52.4)	2 (9.5)
<i>Do you know what to do to take care of your health problem? (n=124)</i>	5 (38.5)	8 (61.5)	0 (0.0)	2 (25.0)	5 (62.5)	1 (12.5)	16 (55.2)	13 (44.8)	0 (0.0)	6 (46.2)	7 (53.9)	0 (0.0)	24 (64.9)	13 (35.1)	0 (0.0)	12 (57.1)	8 (38.1)	1 (4.8)
<i>Do you believe that your health problem will improve? (n=124)</i>	5 (38.5)	8 (61.5)	0 (0.0)	1 (12.5)	6 (75.0)	1 (12.5)	14 (48.3)	9 (31.0)	6 (20.7)	1 (7.7)	10 (76.9)	2 (15.4)	20 (54.1)	13 (35.1)	4 (10.8)	3 (14.3)	10 (47.6)	8 (38.1)
<i>Do you advocate more for yourself? (n=120)</i>	0 (0.0)	9 (81.8)	2 (18.2)	2 (28.6)	3 (42.9)	2 (28.6)	13 (44.8)	14 (48.3)	2 (6.9)	6 (46.2)	6 (46.2)	1 (7.7)	12 (33.3)	19 (52.8)	5 (13.9)	6 (30.0)	13 (65.0)	1 (5.0)
<i>Do you have techniques you can use when your symptoms get worse? (n=122)</i>	3 (23.1)	9 (69.2)	1 (7.7)	1 (12.5)	5 (62.5)	2 (25.0)	10 (34.5)	17 (58.6)	2 (6.9)	2 (15.4)	9 (69.2)	2 (15.4)	17 (46.0)	19 (51.4)	1 (2.7)	9 (42.9)	9 (42.9)	3 (14.3)

**Table S3. Categorical data for Patient Assessment of Chronic Illness Care (PACIC) Measure results. Presented for full sample (any CM practitioner), whole-system CM professions (acupuncture, naturopathy) and conventional medicine providers consulted by the same respondents.**

PACIC domain Items	Consulted Any CM practitioner						Consulted acupuncturists						Consulted naturopaths					
	CM practitioner (n=146)			Medical doctor (n=90)			Acupuncturist (n=23)			Medical doctor (n=14)			Naturopath (n=31)			Medical doctor (n=25)		
	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>																		
<b>Patient activation</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Asked for my ideas when we made a treatment plan (n=146)</i>	22 (15.1)	40 (27.4)	84 (57.5)	34 (37.8)	28 (31.1)	28 (31.1)	4 (17.4)	6 (26.1)	13 (56.5)	5 (35.7)	3 (21.4)	6 (42.9)	3 (9.7)	7 (22.6)	21 (67.7)	13 (52.0)	6 (24.0)	6 (24.0)
<i>Given choices about treatment to think about (n=145)</i>	22 (15.2)	26 (17.9)	97 (66.9)	12 (13.5)	35 (39.3)	42 (47.2)	2 (9.1)	4 (18.2)	16 (72.7)	3 (21.4)	4 (28.6)	7 (50.0)	1 (3.2)	3 (9.7)	27 (87.1)	2 (8.3)	13 (54.2)	9 (37.5)
<i>Asked to talk about any problems with my medicines/treatments of their effects (n=142)</i>	26 (18.3)	22 (15.5)	94 (66.2)	24 (27.0)	18 (20.2)	47 (52.8)	3 (13.6)	3 (13.6)	16 (72.7)	5 (35.7)	2 (14.3)	7 (50.0)	1 (3.3)	0 (0.0)	29 (96.7)	7 (29.2)	6 (25.0)	11 (45.8)
<b>Patient activation domain score</b>	Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD		
	3.83, 0.97			3.38, 1.05			3.92, 0.98			3.24, 1.26			4.30, 0.67			3.26, 0.89		
<b>Delivery and practice</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Given a written list of things I should do to improve my health (n=143)</i>	56 (39.2)	31 (21.7)	56 (38.2)	45 (50.0)	21 (23.3)	24 (26.7)	9 (40.9)	6 (27.3)	7 (31.8)	8 (57.1)	2 (14.3)	4 (28.6)	1 (3.3)	1 (3.3)	28 (93.3)	9 (36.0)	6 (24.0)	10 (40.0)
<i>Satisfied that my care was well organised (n=146)</i>	2 (1.4)	10 (6.9)	134 (91.8)	12 (13.3)	21 (23.3)	57 (63.3)	0 (0.0)	1 (4.4)	22 (95.7)	3 (21.4)	1 (7.1)	10 (71.4)	0 (0.0)	0 (0.0)	31 (100.0)	6 (24.0)	7 (28.0)	12 (48.0)
<i>Shown how what I did to take care of my illness influenced by condition (n=141)</i>	16 (11.4)	30 (21.3)	95 (67.4)	25 (28.1)	30 (33.7)	34 (38.2)	5 (22.7)	4 (18.2)	13 (59.1)	5 (35.7)	3 (21.4)	6 (42.9)	1 (3.3)	4 (13.3)	25 (83.3)	5 (20.0)	12 (48.0)	8 (32.0)
<b>Delivery and practice domain score</b>	Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD		
	3.87, 0.76			3.25, 0.91			3.76, 0.90			3.17, 1.15			4.50, 0.47			3.25, 0.93		
<b>Goal setting and tailoring</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Asked to talk about my goals in caring for my illness (n=143)</i>	32 (22.4)	30 (21.0)	81 (56.6)	38 (42.2)	21 (23.3)	31 (34.4)	4 (18.2)	6 (27.3)	12 (54.6)	6 (42.9)	1 (7.1)	7 (50.0)	3 (10.0)	2 (6.7)	25 (83.3)	12 (48.0)	7 (28.0)	6 (24.0)
<i>Helped to set specific goals to improve my eating or exercise (n=142)</i>	40 (28.2)	34 (23.9)	68 (47.9)	44 (50.0)	23 (26.1)	21 (23.9)	9 (40.9)	2 (9.1)	11 (50.0)	7 (53.9)	3 (23.1)	3 (23.1)	1 (3.5)	3 (10.3)	25 (86.2)	14 (58.3)	5 (20.8)	5 (20.8)
<i>Given a copy of my treatment plan (n=142)</i>	74 (52.1)	13 (9.2)	55 (38.7)	49 (57.0)	15 (17.4)	22 (25.6)	12 (54.6)	4 (18.2)	6 (27.3)	5 (35.7)	4 (28.6)	5 (35.7)	1 (3.2)	0 (0.0)	30 (96.8)	17 (73.9)	2 (8.7)	4 (17.4)



<i>Encouraged to go to a specific group or class to help me cope with my chronic illness (n=138)</i>	75 (54.4)	25 (18.1)	38 (27.5)	52 (59.8)	17 (19.5)	18 (20.7)	17 (81.0)	2 (9.5)	2 (9.5)	8 (57.1)	3 (21.4)	3 (21.4)	7 (25.0)	8 (28.6)	13 (46.4)	15 (62.5)	5 (20.8)	4 (16.7)
<i>Asked questions, either directly or on a survey, about my health habits (n=144)</i>	39 (27.1)	25 (17.4)	80 (55.6)	30 (33.7)	22 (24.7)	37 (41.6)	7 (31.8)	3 (13.6)	12 (54.6)	6 (42.9)	3 (21.4)	5 (35.7)	0 (0.0)	4 (13.3)	26 (86.7)	7 (28.0)	7 (28.0)	11 (44.0)
<b>Goal setting and tailoring domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	3.21, 1.03			2.78, 1.04			3.05, 1.20			2.76, 1.32			4.21, 0.58			2.66, 0.95		
<b>Problem-solving and contextual counselling</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<i>Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n=144)</i>	20 (13.9)	14 (9.7)	110 (76.4)	22 (24.4)	19 (21.1)	49 (54.4)	5 (22.7)	2 (9.1)	15 (68.2)	4 (28.6)	4 (28.6)	6 (42.9)	1 (3.3)	0 (0.0)	29 (96.7)	5 (20.0)	6 (24.0)	14 (56.0)
<i>Helped to make a treatment plan that I could do in my daily life (n=143)</i>	28 (19.6)	26 (18.2)	89 (62.2)	36 (40.9)	21 (23.9)	31 (35.2)	7 (31.8)	4 (18.2)	11 (50.0)	4 (28.6)	5 (35.7)	5 (35.7)	1 (3.2)	2 (6.5)	28 (90.3)	14 (58.3)	4 (16.7)	6 (25.0)
<i>Helped to plan ahead so I could take care of my illness even in hard times (n=140)</i>	29 (20.7)	31 (22.1)	80 (57.1)	33 (38.4)	25 (29.1)	28 (32.6)	8 (38.1)	3 (14.3)	10 (47.6)	6 (42.9)	2 (14.3)	6 (42.9)	1 (3.6)	3 (10.7)	24 (85.7)	12 (54.6)	7 (31.8)	3 (13.6)
<i>Asked how my chronic illness affects my life (n=141)</i>	25 (17.7)	26 (18.4)	90 (63.8)	26 (30.2)	24 (27.9)	36 (41.9)	6 (27.3)	1 (4.6)	15 (68.2)	4 (28.6)	5 (35.7)	5 (35.7)	3 (10.7)	3 (10.7)	22 (78.6)	9 (40.9)	7 (31.8)	6 (27.3)
<b>Problem-solving and contextual counselling domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	3.80, 0.96			3.19, 1.06			3.52, 1.24			3.14, 1.21			4.42, 0.61			2.93, 0.97		
<b>Follow-up and coordination</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<i>Contacted after a visit to see how things were going (n=140)</i>	76 (54.3)	30 (21.4)	34 (24.3)	64 (72.7)	11 (12.5)	13 (14.8)	10 (45.5)	6 (27.3)	6 (27.3)	8 (57.1)	2 (14.3)	4 (28.6)	10 (35.7)	8 (28.6)	10 (35.7)	18 (75.0)	2 (8.3)	4 (16.7)
<i>Encouraged to attend programs in the community that could help me (n=137)</i>	75 (54.7)	28 (20.4)	34 (24.8)	59 (67.8)	15 (17.2)	13 (14.9)	15 (71.4)	3 (14.3)	3 (14.3)	9 (64.3)	4 (28.6)	1 (7.1)	9 (34.6)	7 (26.9)	10 (38.5)	17 (73.9)	3 (13.0)	3 (13.0)
<i>Referred to a dietician, health educator, or counsellor (n=137)</i>	91 (66.4)	27 (19.7)	19 (13.9)	48 (55.2)	14 (16.1)	25 (28.7)	15 (71.4)	4 (19.1)	2 (9.5)	6 (46.2)	2 (15.4)	5 (38.5)	11 (40.7)	5 (18.5)	11 (40.7)	12 (50.0)	6 (25.0)	6 (25.0)
<i>Told how my visits with other types of practitioners/doctors helped my treatment (n=138)</i>	60 (43.5)	33 (23.9)	45 (32.6)	39 (45.9)	21 (24.7)	25 (29.4)	9 (42.9)	7 (33.3)	5 (23.8)	8 (57.1)	2 (14.3)	4 (28.6)	4 (14.3)	6 (21.4)	18 (64.3)	8 (38.1)	6 (28.6)	7 (33.3)
<i>Asked how my visits with other doctors/practitioners were going (n=142)</i>	46 (32.4)	27 (19.0)	69 (48.6)	36 (41.4)	22 (25.3)	29 (33.3)	3 (14.3)	6 (28.6)	12 (57.1)	6 (42.9)	4 (28.6)	4 (28.6)	4 (12.9)	7 (22.6)	20 (64.5)	9 (37.5)	5 (20.8)	10 (41.7)
<b>Follow up and coordination domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	2.66, 1.02			2.52, 1.09			2.62, 1.04			2.63, 1.16			3.34, 0.89			2.59, 1.05		
<b>PACIC total summary score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	3.33, 0.82			2.95, 0.96			3.19, 0.95			2.94, 1.14			4.04, 0.54			2.84, 0.94		

Note. Scale values for PACIC: Min = 1 (Almost never), Max = 5 (Almost always).

Note. During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

**Table S4. Categorical data for Patient Assessment of Chronic Illness Care (PACIC) Measure results. Presented for manual therapy professions (chiropractic, massage therapy, osteopathy) and conventional medicine providers consulted by the same respondents.**

PACIC domain Items	Consulted a chiropractor						Consulted a massage therapist						Consulted an osteopath					
	Chiropractor (n=25)			Medical doctor (n=16)			Massage therapist (n=29)			Medical doctor (n=13)			Osteopath (n=38)			Medical doctor (n=22)		
	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always	Almost never/ Generally not	Sometimes	Most of the time/ Almost always
<i>Over the past 6 months, when receiving medical care for my chronic condition, I was:</i>																		
<b>Patient activation</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Asked for my ideas when we made a treatment plan (n=146)</i>	5 (20.0)	7 (28.0)	13 (52.0)	7 (43.8)	7 (43.8)	2 (12.5)	4 (13.8)	9 (31.0)	16 (55.2)	2 (15.4)	5 (38.5)	6 (46.2)	6 (15.8)	11 (29.0)	21 (55.3)	7 (31.8)	7 (31.8)	8 (36.4)
<i>Given choices about treatment to think about (n=145)</i>	4 (16.0)	6 (24.0)	15 (60.0)	3 (18.8)	8 (50.0)	5 (31.3)	6 (20.7)	4 (13.8)	19 (65.5)	0 (0.0)	3 (23.1)	10 (76.9)	9 (23.7)	9 (23.7)	20 (52.6)	4 (18.2)	7 (31.8)	11 (50.0)
<i>Asked to talk about any problems with my medicines/treatments of their effects (n=142)</i>	4 (16.0)	7 (28.0)	14 (56.0)	6 (37.5)	3 (18.8)	7 (43.8)	9 (31.0)	5 (17.2)	15 (51.7)	2 (15.4)	1 (7.7)	10 (76.9)	9 (25.0)	7 (19.4)	20 (55.6)	4 (18.2)	6 (27.3)	12 (54.6)
<b>Patient activation domain score</b>	Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD		
	3.65, 1.01			3.02, 1.04			3.76, 1.03			3.92, 0.81			3.57, 1.01			3.55, 1.14		
<b>Delivery and practice</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Given a written list of things I should do to improve my health (n=143)</i>	14 (58.3)	6 (25.0)	4 (16.7)	9 (56.3)	3 (18.8)	4 (25.0)	16 (55.2)	8 (27.6)	5 (17.2)	7 (53.9)	2 (15.4)	4 (30.8)	16 (42.1)	10 (26.3)	12 (31.6)	12 (54.6)	8 (36.4)	2 (9.1)
<i>Satisfied that my care was well organised (n=146)</i>	1 (4.0)	4 (16.0)	20 (80.0)	2 (12.5)	4 (25.0)	10 (62.5)	0 (0.0)	3 (10.3)	26 (89.7)	0 (0.0)	4 (30.8)	9 (69.2)	1 (2.6)	2 (5.3)	35 (92.1)	1 (4.6)	5 (22.7)	16 (72.7)
<i>Shown how what I did to take care of my illness influenced by condition (n=141)</i>	4 (16.7)	4 (16.7)	16 (66.7)	4 (25.0)	6 (37.5)	6 (37.5)	4 (14.3)	8 (28.6)	16 (57.1)	3 (25.0)	3 (25.0)	6 (50.0)	2 (5.4)	10 (27.0)	25 (67.6)	8 (36.4)	6 (27.3)	8 (36.4)
<b>Delivery and practice domain score</b>	Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD			Mean, SD		
	3.6, 0.78			3.13, 0.91			3.62, 0.61			3.45, 0.86			3.81, 0.71			3.26, 0.79		
<b>Goal setting and tailoring</b>	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>Asked to talk about my goals in caring for my illness (n=143)</i>	10 (40.0)	1 (4.0)	14 (56.0)	8 (50.0)	2 (12.5)	6 (37.5)	7 (25.0)	8 (28.6)	13 (46.4)	2 (15.4)	5 (38.5)	6 (46.2)	8 (21.1)	13 (34.2)	17 (44.7)	10 (45.5)	6 (27.3)	6 (27.3)
<i>Helped to set specific goals to improve my eating or exercise (n=142)</i>	6 (24.0)	12 (48.0)	7 (28.0)	7 (43.8)	4 (25.0)	5 (31.3)	13 (46.4)	5 (17.9)	10 (35.7)	5 (38.5)	5 (38.5)	3 (23.1)	11 (29.0)	12 (31.6)	15 (39.5)	11 (50.0)	6 (27.3)	5 (22.7)
<i>Given a copy of my treatment plan (n=142)</i>	18 (72.0)	1 (4.0)	6 (24.0)	8 (50.0)	3 (18.8)	5 (31.3)	19 (73.1)	3 (11.5)	4 (15.4)	8 (66.7)	1 (8.3)	3 (25.0)	24 (63.2)	5 (13.2)	9 (23.7)	11 (52.4)	5 (23.8)	5 (23.8)

<i>Encouraged to go to a specific group or class to help me cope with my chronic illness (n=138)</i>	17 (68.0)	4 (16.0)	4 (16.0)	8 (53.3)	3 (20.0)	4 (26.7)	14 (51.9)	7 (25.9)	6 (22.2)	6 (50.0)	3 (25.0)	3 (25.0)	20 (54.1)	4 (10.8)	13 (35.1)	15 (68.2)	3 (13.6)	4 (18.2)
<i>Asked questions, either directly or on a survey, about my health habits (n=144)</i>	8 (32.0)	5 (20.0)	12 (48.0)	4 (25.0)	6 (37.5)	6 (37.5)	6 (20.7)	8 (27.6)	15 (51.7)	3 (25.0)	3 (25.0)	6 (50.0)	18 (47.4)	5 (13.2)	15 (39.5)	10 (45.5)	3 (13.6)	9 (40.9)
<b>Goal setting and tailoring domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	2.79, 0.79			2.87, 1.09			2.99, 0.92			2.97, 0.92			2.96, 0.97			2.73, 1.05		
<b>Problem-solving and contextual counselling</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<i>Sure that my practitioner/doctor thought about my values and my traditions when they recommended treatments to me (n=144)</i>	5 (20.0)	3 (12.0)	17 (68.0)	7 (43.8)	3 (18.8)	6 (37.5)	3 (10.3)	5 (17.2)	21 (72.4)	3 (23.1)	1 (7.7)	9 (69.2)	6 (15.8)	4 (10.5)	28 (73.7)	3 (13.6)	5 (22.7)	14 (63.6)
<i>Helped to make a treatment plan that I could do in my daily life (n=143)</i>	5 (20.0)	5 (20.0)	15 (60.0)	5 (31.3)	6 (37.5)	5 (31.3)	9 (32.1)	5 (17.9)	14 (50.0)	3 (25.0)	3 (25.0)	6 (50.0)	6 (16.2)	10 (27.0)	21 (56.8)	10 (45.5)	3 (13.6)	9 (40.9)
<i>Helped to plan ahead so I could take care of my illness even in hard times (n=140)</i>	6 (24.0)	6 (24.0)	13 (52.0)	6 (37.5)	5 (31.3)	5 (31.3)	9 (31.0)	6 (20.7)	14 (48.3)	1 (8.3)	6 (50.0)	5 (41.7)	5 (13.5)	13 (35.1)	19 (51.4)	8 (36.4)	5 (22.7)	9 (40.9)
<i>Asked how my chronic illness affects my life (n=141)</i>	6 (24.0)	6 (24.0)	13 (52.0)	6 (37.5)	3 (18.8)	7 (43.8)	3 (10.3)	8 (27.6)	18 (62.1)	0 (0.0)	2 (16.7)	10 (83.3)	7 (18.9)	8 (21.6)	22 (59.5)	7 (31.8)	7 (31.8)	8 (36.4)
<b>Problem-solving and contextual counselling domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	3.57, 0.91			3.05, 1.08			3.74, 0.86			3.77, 0.76			3.66, 0.96			3.30, 1.13		
<b>Follow-up and coordination</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<i>Contacted after a visit to see how things were going (n=140)</i>	14 (56.0)	6 (24.0)	5 (20.0)	11 (68.8)	3 (18.8)	2 (12.5)	15 (53.6)	7 (25.0)	6 (21.4)	9 (75.0)	3 (25.0)	0 (0.0)	27 (73.0)	3 (8.1)	7 (18.9)	18 (81.8)	1 (4.6)	3 (13.6)
<i>Encouraged to attend programs in the community that could help me (n=137)</i>	18 (72.0)	3 (12.0)	4 (16.0)	10 (62.5)	3 (18.8)	3 (18.8)	14 (50.0)	8 (28.6)	6 (21.4)	7 (58.3)	3 (25.0)	2 (16.7)	19 (51.4)	7 (18.9)	11 (29.7)	16 (72.7)	2 (9.1)	4 (18.2)
<i>Referred to a dietician, health educator, or counsellor (n=137)</i>	20 (80.0)	5 (20.0)	0 (0.0)	9 (56.3)	1 (6.3)	6 (37.5)	20 (71.4)	6 (21.4)	2 (7.1)	7 (58.3)	1 (8.3)	4 (33.3)	25 (68.4)	7 (19.4)	4 (11.1)	14 (63.6)	4 (18.2)	4 (18.2)
<i>Told how my visits with other types of practitioners/doctors helped my treatment (n=138)</i>	12 (48.0)	5 (20.0)	8 (32.0)	9 (56.3)	3 (18.8)	4 (25.0)	12 (42.9)	10 (35.7)	6 (21.4)	2 (16.7)	6 (50.0)	4 (33.3)	23 (63.9)	5 (13.9)	8 (22.2)	12 (54.6)	4 (18.2)	6 (27.3)
<i>Asked how my visits with other doctors/practitioners were going (n=142)</i>	12 (48.0)	5 (20.0)	8 (32.0)	9 (56.3)	3 (18.8)	4 (25.0)	7 (24.1)	5 (17.2)	17 (58.6)	3 (25.0)	6 (50.0)	3 (25.0)	20 (55.6)	4 (11.1)	12 (33.3)	9 (42.9)	4 (19.1)	8 (38.1)
<b>Follow up and coordination domain score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	2.34, 0.95			2.44, 1.27			2.67, 0.90			2.67, 0.84			2.37, 1.02			2.35, 1.15		
<b>PACIC total summary score</b>	<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>			<b>Mean, SD</b>		
	3.06, 0.72			2.86, 1.00			3.23, 0.69			3.27, 0.73			3.14, 0.80			2.95, 0.96		

Note. Scale values for PACIC: Min = 1 (Almost never), Max = 5 (Almost always).

Note. During calculation of PACIC domain scores and summary scores, observations with more than one missing value per domain were excluded; these observations were included in single item calculations.

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