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**Is Australian primary care practice equipped to provide
multimorbidity care?**

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Abstract

Background: Australia's population health profile is characterized by rapidly growing numbers of people living with multiple chronic conditions. The challenges of delivering multimorbidity care are particularly salient for primary care as this is where the majority of chronic disease care is provided. Primary care practice tools that promote consistent evidence-based and patient-centred approaches to patient care are one component of the system-wide change needed to address this complex health systems challenge. Tools such as clinical practice guidelines, care plans and patient decision aids exist to support the management of single chronic diseases but their relevance and usefulness in the management of multiple conditions is unclear.

Objectives: The overall aim of this thesis is to examine whether primary care practice tools developed to support the management of chronic disease in Australian primary care practice are transferable to the management of multiple chronic conditions. In answering this question the thesis considered:

- What is known about living with multiple chronic conditions?
- What is known about managing multimorbidity in primary care?
- What primary care practice tools are currently in use to support chronic disease management?
- What are the strengths and limitations of these primary care practice tools for supporting core components of multimorbidity care?
- What are the implications of these findings for policy and practice?

Design: Key elements of multimorbidity care in primary care practice were identified from the literature. The primary care practice tools themselves were identified through the published literature and in consultation with expert stakeholders to validate the selection of tools for analysis. Three tools identified as currently used or available to general practitioners in Australia were included for detailed review: clinical practice guidelines; care plans; and patient decision aids. Comprehensive searches of published and non-published sources were undertaken to identify existing tools relevant to multimorbidity care in each of these categories. Document analysis, directed by the framework approach, was used to systematically and rigorously assess the tools and to identify their strengths and

shortcomings in relation to multimorbidity care. The Appraisal of Guidelines, Research and Evaluation (AGREE II) instrument was also used to assess the quality of clinical practice guidelines.

Results: The analysis revealed strengths and limitations with each of the identified tools in relation to the management of multiple conditions.

Of the thirteen *clinical practice guidelines* reviewed, twelve included at least one core patient-preference recommendation, but more explicit acknowledgement of these recommendations is required. Although ten guidelines used consumer engagement processes during guideline development, these processes were generally limited. More extensive consumer engagement was generally linked to greater incorporation of patient-preference recommendations.

Care plan templates also demonstrated limitations in their ability to support multimorbidity care. None of the sixteen included care plan templates addressed all of the criteria identified as necessary for care planning in a multimorbidity context, but most addressed one or more to at least some extent. Patient preferences, was the most commonly addressed criterion. Substantially less emphasis was placed on priority setting and the review of individual management goals. None of the care plan templates identified conflicts and synergies. The analysis also revealed the majority of templates are pre-filled and are formatted to consider conditions individually, potentially limiting their ability to contribute to genuine care planning and patient-centred care.

Twenty-one *patient decision aids* were identified and reviewed. Key methods used by patient decision aids to acknowledge multiple conditions included flagging potential complications, prompting discussion between the patient and clinician and identifying how further illness could be prevented. All of the patient decision aids reviewed contributed to shared decision-making processes, but scope exists for more systematic presentation.

Conclusion: Each of the three tools reviewed captures some elements of what is required to provide multimorbidity care but none was found to comprehensively incorporate the key components identified as integral to effective multimorbidity care. Adaptations are needed to improve the ability of each to contribute to patient-centred multimorbidity care.

Furthermore, the thesis proposes how these primary care practice tools could be integrated to enhance shared decision-making and the incorporation of patient preferences.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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Contributions by others to the thesis

Dr Allyson Mutch and Associate Professor Fran Boyle (PhD advisors) provided extensive input into the concept and content of this Thesis. They reviewed and provided considerable feedback at all stages of the thesis.

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List of Abbreviations used in the thesis

AGS	American Geriatrics Society
AGREE	Appraisal of Guidelines, Research and Evaluation
AHRQ	Agency for Healthcare Research and Quality
AIHW	Australian Institute of Health and Welfare
CDM	Chronic Disease Management
CKD	Chronic Kidney Disease
COPD	Chronic Obstructive Pulmonary Disease
COPD-X	Chronic obstructive pulmonary disease and exacerbations
CVC	Coordinated Veterans Care
EPC	Enhanced Primary Care
GP	General practitioner
GPMP	General Practitioner Management Plan
IPDAS	International Patient Decision Aid Standards
NICE	National Institute of Health and Clinical Excellence
NHMRC	National Health and Medical Research Council
OHRI	Ottawa Hospital Research Institute
PDA	Patient decision aid
PHCAG	Primary Health Care Advisory Group
QOL	Quality of Life
RACGP	Royal Australian College of General Practitioners
SDMC	Shared decision-making components
TCA	Team Care Arrangements

UK United Kingdom
USA United States of America

Chapter 1 Introduction

Traditionally centred on the treatment of acute and infectious diseases, Australia's health system has made adaptations to address the longevity, severity and uncertainty of chronic disease. The health system has made significant shifts towards the care of patients with a chronic condition (1). The introduction of policies such as the National Chronic Disease Strategy (2), and the Enhanced Primary Care (EPC) strategy have been instrumental in this process (3,4), but there is increasing awareness that single chronic conditions are no longer the core concern. As Fortin and colleagues (5) note, multiple chronic conditions have become the "rule rather than the exception" for patients presenting to primary care, where the majority of chronic disease care is provided (6-11). Multiple long term conditions place a complex set of demands on patients and health practitioners, within a health system that is not designed to respond to such demands (12,13).

In Australia, the bulk of clinical care for multiple long-term conditions takes place in primary care, with the majority of that care provided by general practitioners (GPs) (6,8,9,13-16). Yet, major challenges that limit the delivery of effective multimorbidity care are known to exist (12,17-28), and to some extent, reflect the challenges clinicians and policy makers have faced in shifting care from acute to chronic disease management. Problems commonly observed in routine primary care practice call for solutions that can be implemented on a wider scale (29,30). These solutions, or what Grol and Grimshaw, (30) refer to as "innovations" take a wide variety of forms ranging from macro-level policy, to professional-led clinical practice guidelines for best practice, to specific practice-level changes to improve processes of care. Evidence-based clinical practice guidelines and care planning are two critical drivers of improved primary care for patients with chronic illness. Wagner et al. (31,32), argues for the importance of providing evidence-based medical care in a consistent and systematised manner, and that this can best be achieved through the use of "interventions" and "protocols" that act as effective behaviour change agents for clinicians. Operating "by protocol", rather than relying on clinicians', "rugged individualism", aims to minimise variations in practice and maximise adherence to best practice guidelines for chronic illness care (32). The Royal Australian College of

General Practitioners (RACGP), in its position statement outlining the leadership role general practice must play in the management of multimorbidity (33) support this position arguing: “GPs need guidelines, tools and patient resources to assist them to better assess and manage patients with multimorbidity” (33). This highlights the need for investment in the development of tools that are relevant to the care of patients with multiple conditions (33).

This thesis is concerned with primary care practice tools developed to support the management of chronic disease in Australian primary practice and their transferability to the management of multiple chronic conditions. Common to all such primary care practice tools is recognition of the need for standardisation of processes and procedures to improve consistency of care (30,31,34,35). Primary care practice tools can become a part of normal care provision and routine practice (34). Their ultimate goal is to improve patient care, with other desirable goals including increasing cost effectiveness, reducing inefficiencies, and assisting clinicians delivering care (30-32,34,35). The development and implementation of new routines and improvements in patient care come as a result of emerging evidence and/or the reality that current care processes are not functioning well (34)

In examining primary care practice tools, the thesis is not concerned with GPs’ actual use of the tools but rather their applicability. While understanding how primary care practice tools are used in the management of multiple chronic conditions is important, this understanding would seem superfluous without first establishing whether the tools themselves are fit for purpose. To this end, the thesis presents a detailed analysis of the primary care practice tools using a multimorbidity lens. By examining this issue, the thesis will contribute to an understanding of whether Australia’s primary care system is well positioned to manage multiple chronic conditions.

In considering primary care practice tools, the thesis has sought to conduct an analysis embedded within Lindblom’s theory of incrementalism, which provides a conceptual framework for understanding change within health policy and practice (36-38). Incrementalism posits that since major structural reform is generally difficult and costly to achieve, most health system reform occurs through incremental changes to existing practice that may then culminate in broader system change (39,40). As such,

incremental changes to primary care practice tools, which have previously contributed to broader change for those managing single chronic conditions (4,41,42), may contribute to shifting Australia's primary care system towards a more multimorbidity approach.

In line with incrementalism, the thesis recognises that primary care practice tools are but one component of the wider context in which multimorbidity care takes place and that a combination of system-wide interventions are required to make meaningful and sustainable change (12,32). As Grol states: "it is unrealistic to expect that one approach can solve all the problems in healthcare delivery" (29). Rather the central proposition of the thesis is that good primary care practice tools, as one component of the implementation of new approaches to care, offer a potential catalyst for wider change by promoting consistent practice that is both evidence-based and patient-centred.

The thesis is firmly based in a patient-centred approach to care that values consumer perspectives and the lived experiences of health system users, including people living with multiple conditions. Capturing and incorporating consumer perspectives is increasingly recognised as essential at all levels of the health system – from health services and systems planning and development through to the delivery of individual care (34,43-45). For patients and clinicians to be truly supported in the management of multiple long term conditions, consideration of these issues needs to occur at a policy/system level to ensure meaningful change and engagement at the individual clinic level.

This chapter provides the context of the study and the rationale for the research undertaken. Australia's primary care system is described, key terms are defined and the significance of the research is established. The research questions are presented, along with a brief outline of the thesis structure.

1.1 Primary care

Primary care has long been considered the heart of a strong health care system (46,47). The Institute of Medicine as defines primary care as:

the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community (48)

In short, primary care reflects the core objectives of a health system through the provision of responsive, comprehensive and equitable care (49). There is an important distinction to be made between primary care and primary health care. Although often used interchangeably these terms have quite different, and often contested, meanings. Primary care is best understood as care, predominantly medical, delivered to individuals. In Australia the vast amount of primary care is delivered by fee-for-service general practitioners. Primary health care, in contrast, is a much broader concept. Originating from the World Health Organization's Declaration of Alma-Ata (50) it encompasses an approach to improving the health of populations. The focus of this thesis is on primary care which can be considered one component of a comprehensive primary health care approach.

Starfield (47) identifies four main features of primary care: first-contact access for each health need; long-term person (not disease) focused care; comprehensive care for most health needs; and coordination of care when input from other health professionals is required. In her work, comparing the distribution and provision of primary health care across eleven industrialised countries, Starfield (51) identified that countries with strong primary care, among them Australia, report:

- *Lower overall costs* - attributed to: prevention and early management of health problems; reduced escalation and unnecessary hospitalisations; and corresponding reductions in the burden placed on the secondary and tertiary sectors (46,47,51).
- *Healthier populations* - attributed to greater access to primary care clinicians (46,47,51). Countries (51), and populations within those countries (47), which had greater access to primary care clinicians tended to have better health outcomes.

In Australia, primary care is generally a patient's "first point of contact" with the health system (52). Primary care is made up of over 32, 000 general practitioners (GPs), who operate as private providers working in solo or group practices in the community (23,24,52,53). In 2014-15, approximately 85% of the Australian population visited a GP (53) to access direct care or obtain a referral to other health and medical providers (23,52). Other health professionals providing primary care include allied health professionals (e.g., physiotherapist and optometrists), dentists, pharmacists and Indigenous health (23,52). Primary care clinicians in Australia work on a fee-for-service basis, with costs covered by patients and/or Medicare: Australia's universal health insurance scheme (23,24,52). The appropriateness of this payment method in supporting the management of multiple chronic conditions has been questioned (23,24,39,54,55), as fee-for-service payments encourage short consultation times and an "additive sequential" (21) approach to illness management, in which conditions are considered sequentially and in isolation.

As the core setting of care for multiple chronic conditions (6,8,9,13-16), this thesis focuses on the relationship between primary care clinicians and their patients. The terms 'primary care clinician' or 'general practitioner' are used interchangeably throughout this thesis to acknowledge the medical specialty most frequently identified at the centre of the primary medical care system (51). Patients with multiple conditions will often visit numerous disease-specific specialists and allied health professionals (56,57), but in the current Australian system, general practice is generally considered the main point of coordination and the area of medicine most equipped to oversee and provide holistic care (13,58,59). Primary care clinicians are also known for building long term relationships with their patients, acting as advocates and gatekeepers, and coordinating other health professionals around the patient's health care needs (13,51).

Primary care clinicians operate within a health system and policy context that can support or limit their capacity to deliver effective multimorbidity care. A number of key barriers relevant to the management of multiple conditions have been identified including limited system support for managing multiple chronic conditions. Australia's health system, designed to address acute care needs, has been working to shift focus and acknowledge the increasing chronic disease profile of the population. Existing structures (e.g., fee-for-service and standard consultation times) policy (e.g., the

National Chronic Disease Strategies), and primary care practice tools (e.g., clinical practice guidelines) are directed towards the management of acute and single chronic conditions (17-22,54,60,61). However, the challenge has now become how to manage multiple chronic diseases (12,25), particularly given that current efforts which attempt to combine numerous single condition approaches can result in overly complex and potentially harmful care (62).

1.2 Multimorbidity and comorbidity

The terms 'multimorbidity' and 'comorbidity' are frequently used interchangeably to describe someone presenting with two or more conditions, but closer consideration reveals some key differences that have implications for approaching patient care. Comorbidity was first defined by Alvan Feinstein in 1970 as: "any distinct additional clinical entity that has existed or that may occur during the clinical course of a patient who has the index disease under study" (63).

Feinstein defined the index condition as the focus or priority for clinical care (12,63). This aligns closely with the biomedical model, which focuses on a disease occurring within a body system isolated from other systems (64,65). In acknowledging the "additional clinical entity" Feinstein (63) recognises the presence of other conditions, but as illustrated in Figure 1.1, this is secondary to the principal or index condition which is the focus of clinical concern (12,66). Frequently applied in both research and policy the biomedical model has seen patients with complex comorbidities excluded from research studies, and the development of clinical practice guidelines and care plans which focus predominantly on single conditions (60,67,68). When comorbidities are acknowledged they are typically 'concordant' conditions that is, chronic conditions which share similar risk factors and management strategies to the index condition (69-71). For example, hypertension, and peripheral vascular disease would be concordant to the index condition diabetes. In contrast 'discordant' conditions, share few risk factors or management strategies with the index condition and are rarely acknowledged (69-71). Asthma would be an example of a condition discordant from diabetes. In essence, a comorbidity approach is disease focused, with limited consideration of the cumulative burden and complexity faced by patients and clinicians managing multiple conditions (12,66).

Multimorbidity is defined as the presence of two or more conditions, without any condition necessarily being identified as more or less central as (see Figure 1.1) (12,72). Valderas et al. (66) claim the term multimorbidity emerged as “a modern alternative to comorbidity” that better reflects the reality of managing multiple conditions. Adopting a multimorbidity care approach requires clinicians to acknowledge that patients with multiple conditions rarely experience conditions in isolation; rather, each patient’s overall illness experience is a unique product of their conditions, preferences, beliefs, attitudes, symptoms, medications, functional capacity, and self-care activities (18,21,73). As such, the term aspires to a more patient-centred view, by attempting to capture the whole person not just the individual diseases they have, and acknowledging the importance of structuring care to meet the needs, values and preferences of patients. Like comorbidity, concordant and discordant conditions are also identified in a multimorbidity context; however similarities and differences in risk factors and management plans are identified across all conditions not just the index condition, capturing a more representative or holistic view of the patient (12,69,70,72).

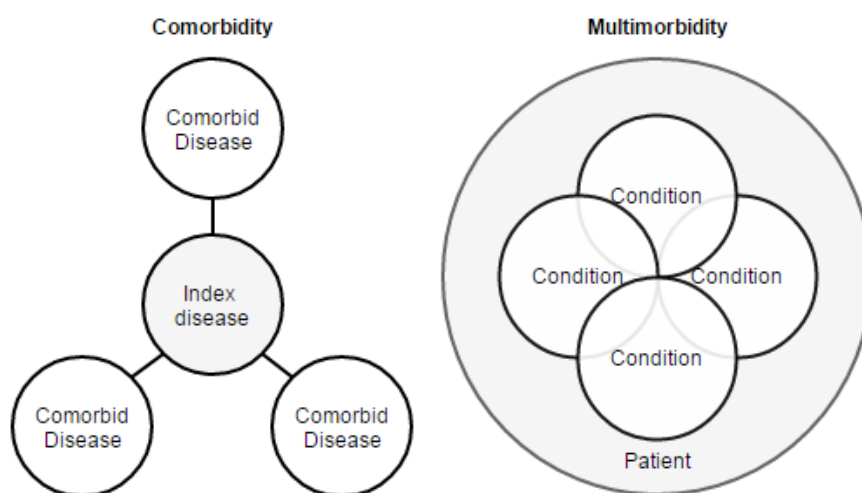


Figure 1.1 - Depiction of comorbidity and multimorbidity – adapted from Boyd and Fortin (12).

The distinction between the terms comorbidity and multimorbidity has important implications for approaches to management and treatment (12,74). Recognising the importance of this distinction, throughout this thesis the terms multiple conditions and multimorbidity care are used. The term ‘multiple conditions’ refers to the presence of multiple chronic conditions or diseases in one individual. ‘Multimorbidity care’ describes an approach to managing multiple conditions, which focuses on viewing the

whole patient and respecting and incorporating their values and preferences for care. In essence, it is synonymous with patient-centred care as it acknowledges the importance of the patient experience and their role in managing care.

1.3 Research issue

For many years, Australia's health care system has been under immense pressure from the demands of managing chronic disease. The Australian Institute of Health and Welfare (AIHW) (52) labels chronic disease: "Australia's biggest health challenge", as the leading contributor to mortality, morbidity and health system costs. Chronic disease can produce adverse consequences such as functional impairment and disability, and requires effective management to minimise further complications (41,52,75). Magnifying the impact of chronic disease is the high prevalence of multiple conditions.

Prevalence and impact

Determining the prevalence of patients with multiple long term conditions across both national and international literature is difficult, as varying methods, population samples, and morbidities are used (5,12,74,76-79). A review comparing the prevalence of multiple conditions in primary care from three different studies, found the prevalence rates differed by as much as 61% (80). Despite this, it is widely agreed the number of conditions co-occurring in an individual generally increases with age (5,76,79,81-87). In Australia, growth in the ageing population has and will continue to have a profound impact on the health system (85), but the presence of multiple conditions is not limited to the elderly. A Canadian population survey on self-reported multimorbidity among 5,010 adults aged 18 years and over found one in five people (936) reported the presence of two or more chronic conditions, and of these 70% (657) were under 65 years of age (81). Similarly, an Australian cohort study found 42% of participants with multiple conditions were under 60 years of age (88).

Patients presenting in primary care practice with only one chronic disease are increasingly rare, leading Tinetti and colleagues (25) to describe multimorbidity as: "the most common chronic condition experienced by adults". Multiple long term conditions are associated with a wide range of adverse outcomes for individuals and

the health system. These included: increased health service use (14,56,79,89-92), polypharmacy (56,90,93-96), hospital admissions (14,79,89,90,97,98), out-of-pocket expenses (99-103), and psychological distress (79,93,104-106), along with reductions in physical functioning (79,107-112), quality-of-life (14,79,113-117), employability (118-120), and continuity of care (56,93,121,122).

Policy level

Formulating an effective response to multimorbidity has presented a significant challenge to health policy makers in Australia and elsewhere in the world (8,12,60,61). A limited evidence-base informing the management of multiple conditions adds to this challenge (16,62,79,123). Steps to reform chronic illness care in Australia are being taken, a report released by the Primary Health Care Advisory Group (PHCAG) (54) late last year (2015) titled: “The Better outcomes for people with chronic and complex health conditions”, is set to “revolutionise” the way chronic disease and multiple conditions are managed in Australia (124). Central to the report recommendations, and underlining the importance of this thesis, is patient-centred care and shared decision-making in primary care settings. The report recommends changes to current health management and funding models, placing greater emphasis on patient-centred care and shared decision-making in primary care settings (54). In the May 2016 federal budget, the Australian Government announced they would commit \$21 million to trial the recommended changes outlined in the report (124). Further contributing to this agenda is the new National Strategic Framework for Chronic Conditions, to be finalised and released later this year (2016). This Framework, unlike its previous iterations, is expected to address multiple conditions (125). The release of these policies is timely, reinforcing the importance of addressing multimorbidity care in primary care settings.

Practice level

Leading researchers, along with other key stakeholders including the PHCAG and the RACGP, argue the complexities of providing multimorbidity care requires a focus on patient-centred care that emphasises patients’ priorities and preferences for care (13,25,54,59,126-129). Patient-centred care is a philosophy of care that has long been

a cornerstone of family medicine but is difficult both to operationalise and measure (125). Challenges in practice arise as clinicians and patients move beyond the traditional biomedical paradigm, to negotiate the different preferences and goals for care that each bring to the consultation (21,28,130,131). Care based on the traditional biomedical model, which focuses on single body systems and diseases, can lead to tensions between clinicians' and patients' preferences and goals for care (21,131,132). While clinicians may focus on the physical or biological aspects of disease, patients' preferences for care, are informed by their lived experience and centre on improving their quality of life and maintaining normalcy (21,28,131,133). A cross-sectional study investigating self-rated health among 3,189 primary care patients with multiple conditions, found the restrictions on patients' ability to participate in normal activities had a stronger association with poor self-rated health than the diagnosis (134). Kleinman (64) in making his classic distinction between illness and disease argues this is because people experience and respond to illness rather than disease. Illness encompasses how people feel, think, or behave based on their perceptions of a condition, whereas disease is the physiological issue clinicians' treat or manage (64).

Hearing and responding to the patient voice within the clinical encounter, to ensure their priorities and preferences for care are considered and integrated, appears central to the provision of high quality multimorbidity care (135,136). Acknowledging that patients' goals and preferences may differ from those of their clinicians, possibly leading them to disengage with treatment advice (70,135), Stewart et al. (137) argue effective care requires clinicians and patients to find "common ground" between their respective disease and illness informed perspectives. In order to find common ground (137) clinicians and patients must engage in shared decision-making to work through these tensions; however, with limited evidence and support on how to manage multiple conditions or incorporate patients' preferences (16,62,79,123), clinicians must rely on their medical judgement and draw on existing tools for assistance where possible. These primary care practice tools include clinical practice guidelines, and care plans, but as tools developed to support the management of single chronic conditions their relevance and usefulness in the management of multiple conditions is unclear.

1.4 Research question

The central question addressed in this thesis is: *Are primary care practice tools developed to support the management of chronic disease in Australian primary practice, transferable to the management of multimorbidity care?* In answering this question the thesis considered the following:

- What is known about living with multiple chronic conditions? (Chapter two)
- What is known about providing multimorbidity care in primary care? (Chapter two)
- What primary care practice tools are currently in use to support chronic disease management? (Chapter three and four)
- What are the strengths and limitations of these primary care practice tools for supporting core components of multimorbidity care (Chapters five, six & seven)
- What are the implications of these findings for policy and practice? (Chapter eight)

1.5 Contribution of the research

Enhancing methods of health care delivery for people with multiple long-term conditions is a priority for most health systems around the world (10,12,13,16,138). There is an urgent need for new innovations and approaches to appropriately respond to the rising numbers of people presenting with multiple chronic conditions in primary care (12,15,16,139). Researchers argue that such approaches should be patient- not disease-centred (10,12,13,59,138-141), embedded in primary care settings (10,12,13,59,138-140), and where possible work within existing resources (34,54,142).

Effective multimorbidity care requires more than the actions of individual clinicians. Systematic attention is required across primary care (12,61,139,140). Primary care practice tools have previously contributed to practice wide change for those managing single chronic conditions (41,42) and therefore may contribute to shifting Australia's primary care system towards a more multimorbidity approach. This thesis examines the transferability of primary care practice tools to support the provision of

multimorbidity care. In doing so, the contribution of this research is to determine whether Australia's primary care practice tools, developed to address chronic disease in the clinical consultation, are well positioned to contribute to multimorbidity care.

1.6 Thesis structure

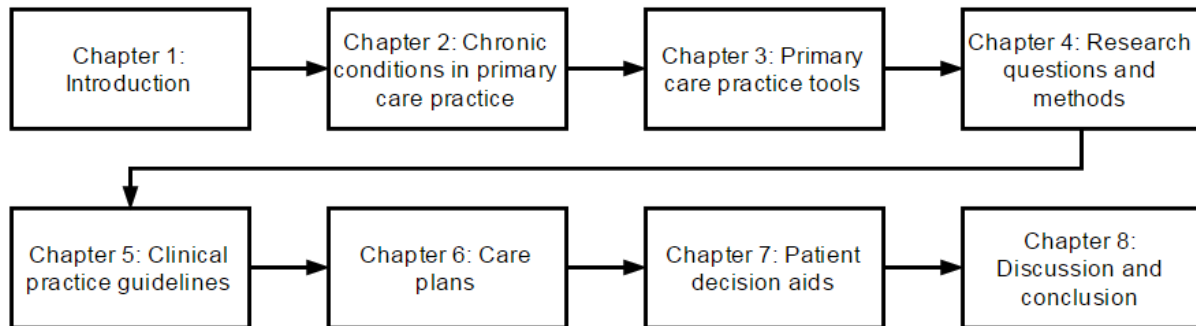


Figure 1.2 - Overview of thesis structure

Chapter two provides a foundational understanding of the challenges patients and clinicians face when managing multiple conditions. The chapter starts with a reflection on the distinction between the concepts of disease and illness. Building on this discussion the chapter then explores chronic illness from the patients' perspective. Having explored the patient perspective, the chapter turns to examine the clinicians' perspective. A critical argument arising from this chapter is the need to involve patients in decisions and reach a shared understanding between patients and clinicians perspectives. The chapter looks to shared decision-making, as one way of facilitating this for those managing multiple conditions.

Chapter three describes the processes used to identify relevant primary care practice tools that aid clinicians and patients in the management of chronic disease. These primary care practice tools are then described, laying the foundation for an examination of the applicability of these tools to the provision of shared decision-making and multimorbidity care.

Chapter four outlines the thesis research question and methods. A three-stage document analysis methodology was applied to the three tools identified for review: clinical practice guidelines, care plans and patient decision aids (PDAs). The three stages were: 1) the identification of relevant documents; 2) collection of the data; and

3) analysis of the data. The framework approach (143) was used to direct data analysis in step three.

Chapters five, six and seven present the evaluation of clinical practice guidelines, care plans, and PDAs respectively. Each chapter is a self-contained piece of research that includes an introduction, methods, results and discussion section. As a similar method of analysis was used for evaluating each of the three tools, there is some inevitable repetition of content across the three chapters.

Chapter eight presents and integrates the findings of the three studies presented in chapters five, six and seven. Implications of the study are discussed, focusing on how the strengths of current primary care practice tools might be drawn together to support multimorbidity care and facilitate shared decision-making. The strengths and limitations of the study are also discussed together with implications for future research, policy and practice.

Chapter 2 Chronic conditions in primary care practice

2.1 Introduction

The following chapter provides a foundational understanding of multiple chronic conditions from the perspective of patient and clinician and seeks to consider the unique challenges posed by their management. In unpacking this broad aim, the chapter is presented in four sections. Section one starts with a consideration of the notions of “disease” and “illness” (64). The distinction between disease and illness emerged in the 1970s through the seminal work of Kleinman and colleagues (64) who sought to illustrate the different points of reference that underlie the perspectives of patients and clinicians.

Drawing from this work, the second section moves to explore patients’ experiences and perspectives of chronic illness. Beginning with an understanding of the “illness trajectory” and the common stages a person moves through as they adapt to a changing health profile and engage in “illness work” (144). The discussion then moves to consider the added “treatment burden” faced by patients managing multiple conditions, and the subsequent need to set and re-set priorities (95). A central finding to emerge from this discussion is the importance of involving patients in the process of identifying and setting priorities that guide their care.

Having explored the patient perspective, the third section turns to examine the clinicians’ perspective of managing multiple chronic diseases. In considering this perspective, recognition is given to professional, practice and health systems level factors that enhance and inhibit clinicians’ ability to provide effective multimorbidity care.

The final section of the chapter seeks to identify the foundations upon which “common ground” between patients’ and clinicians’ can be found (137). In navigating this pathway the chapter explores the notion of patient-centred care, as the foundation for multimorbidity care. Acknowledging that the application of patient-centred care may be difficult to achieve in practice, the chapter argues for shared decision-making as a means of operationalising patient-centred care in primary care practice.

2.2 Disease and Illness

Arthur Kleinman, a psychiatrist and anthropologist, is widely credited with drawing a distinction between the concepts of disease and illness (64). His seminal article: "Culture, illness and care: Clinical lessons from anthropologic and cross-cultural research" (64), compiled with Eisenberg and Good, delineates illness, identified as the patient's lived experience, from disease: the physical or mental malfunction health professionals treat.

The notion of disease, synonymous with the biomedical model, and more recently evidence-based medicine, emerged as the dominant approach to medical care in the 19th century following the work of leading scientists, including Louis Pasteur and Robert Koch, who identified the relationship between germs and disease, which validated germ theory (145). This ground-breaking work emerged at a time when acute and infectious diseases were most prevalent (65,145,146). The biomedical model, underpinned by reductionism, stems from the belief that complex phenomena originate from a single source (65,147). This allows diseases to be considered in isolation, as separate entities, which are thought to appear and progress in the same way, regardless of the context or circumstances of the afflicted individual (64,132,147). The personal, cultural and/or social context of the individual is generally not used to inform diagnosis, treatment or management of the disease (64,65,132,148).

Illness, according to Kleinman, Eisenberg and Good (64), is an individual's reaction to disease, in short, their lived experience. The physiological symptoms and impact of disease generally affects people in similar ways, but the experience of illness, including the behaviours, attitudes, and beliefs that emerge as a result of the experience may differ substantially across individuals, populations and cultures (64,149-151). A person's illness experience will inform the decisions they make regarding their health and health care (64,132,152-154). Individuals will respond, assign meaning, or make sense of their illness, within the context of an "illness narrative": a term Kleinman coined in 1988 (155) to describe the individual's story of illness. These narratives are generally culturally and socially bound, and are used by individuals, communities and populations to comprehend, assign meaning and make sense of the illness experience (146,155).

In examining the notions of illness and disease, this section has not only illustrated the divergence of clinical and lay perspectives it also establishes a baseline from which to examine the consequences of this distinction for care. The following sections move to consider the notions illness and disease within the context of chronic conditions. It begins with key definitional aspects, again reflecting on the distinction between illness and disease, it then moves to examine the broad body of literature investigating the patient's experience of chronic illness and the clinician's experience of managing chronic disease.

2.3 Defining Chronic Conditions

Kleinman (155) was again an early contributor to understandings of chronic illness through his work on illness narratives. Within the context of his investigations he described chronic illnesses as those: "that never entirely disappear" (155). In line with Kleinman's focus, the Chronic Illness Alliance (156), which supports individuals living with chronic illness and the organisations that represent them, developed a definition of chronic illness to reflect the ways in which they dominate the person's life:

... an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life (156).

In contrast to this approach, more frequently cited definitions include those that identify the causes, longevity and incurable nature of chronic disease, as the following from the Australian Institute of Health and Welfare (AIHW) (157) illustrates:

Chronic diseases are caused by multiple factors, including a person's genetic make-up lifestyle and environment. They are long-term conditions and cannot be directly spread from one person to another (157).

Under the umbrella of chronic conditions sit a collection of conditions with varying impacts ranging from mild through to life-threatening (144,158). Advances in medical care and technologies have also seen conditions that were once associated with short-term survival become conditions with which people may live for many years (e.g., HIV) (52).

In Australia, priority chronic condition areas, based on prevalence and impact, have been identified in the National Chronic Disease Strategy (2). These priority areas include: asthma; cancer; diabetes; heart, stroke and vascular disease; and osteoarthritis, rheumatoid arthritis and osteoporosis (2). The National Strategic Framework for Chronic Conditions set to be released in late 2016 will provide a national approach to guide planning, design and delivery of policies, strategies, actions and services to reduce the impact of chronic conditions in Australia (125). The Framework will supersede the National Chronic Disease Strategy 2005 which has provided national policy direction through its recognition of the synergies across the prevention and management of many chronic conditions (125).

2.4 Chronic Illness: The patient experience

The following section provides a broad overview of the research investigating the patient's experience of chronic illness. It steps through the seminal works of Strauss and Corbin, particularly their notions of illness trajectory and illness work. The discussion then moves to consider the individual's experience of multiple chronic conditions: "the most common chronic condition" (25) and the treatment burden that arises from the complex interplay of multiple conditions. The final phase of this section draws from this discussion to explore how individuals work through complexity by establishing different processes of priority setting.

Illness trajectory

The longevity and variable nature of chronic conditions have significant implications for patients' lives (159). Anselm Strauss, a medical sociologist, pioneered much of today's understanding of people's experiences of chronic illness. In the ground breaking book, "Chronic Illness and the Quality of Life" (160), Strauss provided accounts of living with chronic illness placing the focus squarely on subjective experience. The work was among the first to identify chronic disease as a health policy challenge, arguing that while disease may present in similar ways physiologically, an individual's illness experience can vary substantially (160). In later works Corbin and Strauss (160) introduced the concept of the 'illness trajectory' to describe this experience:

... not only to the physiological unfolding of a patient's disease but the total organisation of work done over the course of illness and the impact on those involved with that work and its organisation (160)

For acute conditions, the patient's illness trajectory is relatively linear and predictable, but in the context of chronic illness, the longevity, uncertainty and unending management means patients experience a more complex illness trajectory (144,151,161-172). In acknowledging the unique nature of the patient's experience, Corbin and Strauss (144) documented a number of common phases that occur over the course of illness including: "trajectory onset", "stable", "unstable", "acute", "crisis", and "dying". Subsequent studies have observed similar phases (151,161,163-176).

Trajectory onset begins with the person noticing symptoms, seeking medical assistance and, depending on the timing and manner of their illness, receiving a diagnosis (144). For some, diagnosis can provide relief legitimising the illness experience (144,169), but for many receiving a diagnosis is associated with a sense of losing control in the face of an unknown condition (144,164,172,177). This experience is most clearly illustrated by a participant in Whitemore and Dixon's (177) United Kingdom (UK) study of the ways people integrate their chronic illness experience:

I realised that I am not in the driver's seat of my life anymore and that the diseases are and they control me. You know, I don't control my life. You lose control and that is the biggest issue that I find (177)

As individuals move through the trajectory onset phase they enter the *stable* phase and begin to gain some sense of stability and control (144). During this phase new strategies are adopted to maintain 'normalcy' and overcome the limitations imposed by the condition (144,172). The 'work' of individuals adapting to and managing chronic illness was first described by Corbin and Strauss (178,179) and has had a lasting influence on the field as illustrating the investment required by the individual. Corbin and Strauss (178) identified three types of work: "illness work", "everyday life work" and "biographical work" (see Table 2.1)

Table 2.1 - Types of work

Work type	Description
Illness work	Managing symptoms, handling complex medication regimens, attending medical appointments, and avoiding and working through acute or crisis points (178). Illness work enables some patients to become experts (178) who operate in partnership with their clinician (173). This is not the experience of all as cultural, social, economic and generational factors impact a person's ability to participate (180).
Everyday life work	Day-to-day activities, such as eating, going to work, maintaining relationships, looking after the children or cleaning the house (178), all of which may be impacted by the person's condition (161,168,181,182).
Biographical work	Adaption or reconstruction of the individual's life in accordance with the limitations imposed by the conditions (178). Adaption centres on achieving and maintaining normalcy in the context of the social and physical limitations imposed by illness (161,163,181,183-185). Through this work people may view themselves as two people - their past self (pre-diagnosis) and present self (post diagnosis) (186). The two can be difficult to reconcile as (163,167,171,181,184,186) the following quote, drawn from a participant in Asbring's study of women with chronic fatigue and fibromyalgia (187), illustrates: <i>Having lived a little over 2 years with a 'me' that is no longer the 'real me', because it is a completely new person. As time passes I can find certain things that I recognize from before but the rest is actually new and it's not me and I don't recognise myself. And still, I must socialize with this person (187).</i>

Overall, Corbin and Strauss' (144) notion of work provides insight into the illness experience and clarifies the effort required across all aspects of life to achieve normalcy. Through work, the individual may be able to maintain themselves in the stable phase for some time, but at different points they may also experience an *unstable phase* (144).

Periods of instability stem from negative reactions to medication, natural progressions in the condition, diagnosis of additional conditions, or changes in social context (144,188). To regain stability re-adjustments to medications, lifestyle or social activities may be required (144,172). The clinician can play a substantial role in the person's responses and adaptations during this phase (135,188,189) by reducing complexity (e.g., eliminating unnecessary medications or identifying synergies between conditions) and ensuring the prescribed treatment is feasible and fits within the patients' context (190). Without assistance the person's health may deteriorate causing them to enter an 'acute' or 'crisis' phase.

In more severe instances of instability, people can experience *acute* or *crisis* episodes (144). Acute periods can arise from exacerbations of illness symptoms, or complications associated with condition progression (144). During these periods hospitalisation may be required to stabilise the condition. Until the patient has recovered, their biographical and everyday work may be reduced or cease (144). In more extreme situations or periods of crisis, the person may experience a life-threatening event necessitating emergency treatment and the discontinuation of illness work (144). Following hospitalisation or rest the person must again re-engage in work. This will often involve a significant investment as they come to terms with a new way of life and adapt to limitations manifested by their illness (144).

Entering the later stages of the illness trajectory, the individual's health will start to deteriorate as symptoms become more difficult to control and disability increases (144,172). Engagement in everyday activities may be significantly reduced, requiring further investment in biographical work. Finally, the patient enters the *dying* phase, as the body begins to shut down and the person is unable to participate in illness, every day and biographical work (144,172).

In summary, research investigating illness trajectories and the experiences and challenges individuals face as they adapt and re-adapt, serve to reinforce the importance of understanding the person's illness experiences (144). Moreover, Corbin and Strauss' (178) notion of work highlights the investment individuals make, as daily managers of their health, and provides an understanding of why individuals are uniquely situated to recognise issues or gaps in prescribed care and identify the resources required to manage their health.

Multiple conditions: the patient experience

As the previous discussion has outlined, individuals must make substantial investments in the day-to-day management of a chronic illness, but for those with multiple conditions the challenges of living with chronic illness are amplified (16,111,191-194). Multimorbidity, "the most common chronic condition experienced by adults", places significant demands on individuals, clinicians and the health system (25). Individuals must navigate an illness trajectory complicated by processes of

adaption and re-adaption linked to each subsequent diagnosis (135,182,194). Illness work in this context involves the management of conflicts and interactions between multiple conditions and their associated medications and treatments (25). As Sells et al. (182) argue, the experience of being diagnosed and living with multiple conditions becomes a “cascade of crises” where individuals are constantly challenged physically, psychologically and socially.

Research investigating the experience of managing multiple chronic conditions has grown in prominence in recent years, as an increasing number of largely qualitative studies have examined the challenges people face (133,135,195-198). Much of this research has highlighted the additional work and investment associated with multiple conditions (25), but extending on this Gallacher and colleagues (199) argue work is not only generated by the day-to-day but also through the treatment decisions made by health practitioners. In line with this, they emphasize the notion of ‘treatment burden’ which incorporates:

the ‘workload’ of health care that patients must perform in response to the requirements of their healthcare providers as well as the ‘impact’ that these practices have on patient functioning and well-being (200).

Treatment burden arises from the need to learn about treatments, attend medical appointments, undergo tests or examinations, and adhere to complex medication and self-care regimens (95,199,201,202). For those managing multiple chronic conditions these demands are amplified in the face of unwanted complications and complexity (73,95,202,203). Investigating the time individuals spend on health related activities (e.g., travelling to health services; participating in support groups; and taking medications) Jowsey et al.’s (204) study of over 2500 individuals with multiple conditions found that the time spent increased with each condition. On average, people with two-four conditions spent 11.1 hours on health related activities (excluding exercise) per month, increasing to two-three hours per day for those with five or more conditions (200).

Through investigations of the impact of treatment burden, researchers have identified a number of different types of burden (see Table 2.2). For example, a large scale Australian study involving participants with one or more chronic conditions, identified

financial burden as the most significant burden experienced by participants, followed by lifestyle, social, administrative and medication burden (205). Not surprisingly, researchers have also identified that as care becomes more complex, the level of burden also increases (205,206). This increasing burden is clearly illustrated by the findings of an Australian study involving elderly people with three or more conditions (56). Roughead et al. (56) found that most participants consulted their GP 12 times a year on average; interacted with seven or eight medical professionals; received more than 80 health services; visited a pharmacist approximately every ten days, and were dispensed around 60 prescriptions per year.

Table 2.2 - Types of treatment burden

Burden type	Description
Financial Burden	The costs of medications, consultations and tests which can rise substantially as care becomes more complex (56,93,102,111,205-207).
Administrative Burden	Time spent scheduling appointments, travelling to and attending appointments and undergoing tests (205,206). This burden is compounded by lack of collaboration and coordination between providers, and provision of contradictory or incomplete advice (93,205,207-209). Care may be fragmented and incomplete as patients transition from one clinician to another (13,20,93,111,121,207-210).
Medication Burden	Arises from managing various medications, their side effects, and the associated stigma (205,206). The coordination of medications and the interactions between them is commonly flagged as a core burden (56,93,129,195,197,205,206,211). Multiple medications (Noel et al. (93) identified that some patients take up to 27 medications) are associated with confusion, a sense of being overwhelmed (93,111,129,195,209,211), or a feeling of “resentfulness” at the level of dependence (93).
Lifestyle Change Burden	The demands associated with learning about the conditions and adapting and adhering to new lifestyle practices (e.g., diet and meal planning, exercise) (205). Such changes are often difficult to implement as individuals with multiple chronic conditions, experience greater disability and physical impairment than is generally associated with one condition (73,79,93,111-113,192,193,212).
Social Life Burden	The impact on social relationships, including interactions with children, needing assistance with housework, or having to take medication in front of people (205). This burden has been linked with psychosocial distress, feelings of powerlessness, stigma, loneliness, humiliation, anger, despair (73,93,106,193,213), elevated rates of depression (93,105), and reduced quality of life (79,214-216).

In summary, patients with multiple chronic conditions experience added treatment burden embedded in the management of their complex and diverse health care needs.

Looking to simplify the complexity of managing multiple chronic conditions and the resulting treatment burdens, patients must frequently prioritise conditions, goals, medications and/or outcomes (28,73,93,133,135,189,196,206,217-223).

Prioritising

A critical challenge to emerge from the multimorbidity literature is the need to acknowledge and incorporate patient preferences for care, particularly in relation to determining treatment and management priorities (28,73,93,133,135,189,196,217-223). Individuals with multiple conditions are tasked with managing complex treatment regimens, complicated by conflicting conditions, medications, treatments and outcomes (201). To reduce treatment complexity and minimise negative interactions individuals must set priorities (211,221). Bratzke et al.'s (221) narrative review of thirteen studies investigating priority setting and decision-making among patients with multiple conditions, found priorities were set based on the person's beliefs and attitudes, with one condition often taking priority over others. Priorities were general established in accordance with four main factors: the predictability of the condition; whether the condition could be controlled by medication; whether the condition disrupted others; and the perceived severity of the condition and its impact on daily life (221). However, Bratzke and colleagues (221) also noted variability across the reviewed studies in how patients' perceived or determined condition severity and impact on daily life. This perception was linked to: how 'worrisome' the condition was perceived to be; the physical symptoms; or the person's ability to achieve 'global' rather than disease-specific outcomes (e.g., maintenance of physical function, symptom relief and quality of life) (221).

Bratzke et al.'s (221) review illustrates that the establishment of priorities is not fixed; they change in accordance with the individual's social and life circumstances or following the diagnosis of an additional condition. Providing further clarification of the reasons why priorities change, Morris and colleagues' (135) found that individuals re-prioritise at "pivotal points". Pivotal points generally coincide with the diagnosis of an additional condition, which disrupts or aggravates the person's other conditions and requires the acquisition of new skills or the rearrangement of old ones (135). Morris et al. (135) found that individuals who were diagnosed with a new concordant condition

were generally able to transfer existing self-management practices across conditions, whereas those diagnosed with a discordant condition often reached a “tipping point” as they struggled to accommodate changes in lifestyle, medication management and/or develop of new skills (135). At these points, patients will often seek additional support from clinicians to assist with the re-prioritising process, with the success of these interactions largely determining whether patients can easily accommodate the new condition or are overwhelmed and reach a tipping point (135). In support of these findings, Kerr et al.’s (189) study of nearly 2000 people with diabetes and a range of comorbidities, found that those with discordant conditions needed greater support or assistance when setting priorities than those with concordant conditions.

Overall, research investigating priority setting illustrates the range of factors influencing how and why patients prioritise and highlights the points at which the individual may need to work with a clinician to establish priorities. However, discussion and negotiation of priorities is clearly not always straightforward as patients’ priorities may differ from their clinician (21,70,135,219,220), who’s focus often centres on individual conditions at the expense of interactions between conditions (21). To investigate these issues further, the following section examines the clinician’s experience of managing chronic disease and the way in which their perspective, grounded within a disease model and informed by an evidence-based approach, often drives a different priority setting agenda that may conflict with the patient’s illness based perspective.

2.5 Chronic disease: the clinician experience

The bulk of clinical care for multiple long-term conditions takes place in the primary practice setting (6,8,9,13-15). Yet, numerous studies highlight the challenges facing GPs who provide care for this growing disease profile (18,19,21,224). These challenges arise at the professional, practice and health system levels.

At the professional and practice level, the notion of disease is a central driver informing the clinician’s approach to the management of chronic disease (132,155). As the preceding discussion of disease highlighted, clinicians’ training, practice and broader workforce culture is grounded within the biomedical model (132,155). More recently,

the biomedical model has been underpinned by evidence-based medicine which has emerged as the dominant paradigm directing medical decision-making. Evidence-based medicine refers to:

The conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research (225).

As Sackett et al.'s (225) definition illustrates, the focus of evidence-based medicine is on making the best clinical decisions for the patient, but in practice evidence-based medicine has been criticised for its strong disease focus; rigid application of treatment and management protocols matched to individual diseases; and its inability to inform the care of 'deviant cases' who are often actively excluded from the research trials that generate evidence (130,226-228). Notably these deviant cases often include those experiencing multiple conditions (227,228).

Thus despite the prominence of evidence-based medicine, its inability to accommodate those with multiple conditions in the process of generating evidence has resulted in a dearth of best practice methods to guide treatment (15,16). As a result, clinicians, like their patients, experience high levels of uncertainty in the presence of multiple conditions due to limited evidence on how conditions, medications and other treatments will interact or conflict (19,73,79,123,211,224,229,230). Consequently, clinicians are left with two options: apply multiple single-condition based interventions and risk prescribing harmful and/or conflicting treatment regimens that further magnify the patient's treatment burden (62); or abandon evidence-based medicine and rely on their judgement to develop care decisions and treatment priorities (226,231-233). The latter option is supported by those clinicians who argue they are most able to develop care arrangements for their patients (226,231-233); however this option may also fall short if it is dominated by a disease model. Illustrating this concern, Bower and colleagues' (21) examination of clinical priority setting found GPs prioritised individual diseases to ensure pressing medical concerns were addressed before the consultation ended; any remaining health concerns, which may have arisen from the interaction of conditions, were put

off until the next consultation. Overall, both options are limited in practice and their ability to provide optimum care is not without question, but the barriers posed by the health system appear to create further challenges that clinicians must also navigate.

At the health system level, primary care clinicians operate within a system and policy context that can support or undermine their capacity to deliver effective multimorbidity care. Many of the key barriers GPs face including: time constraints (17-21); restrictions imposed by fee for service arrangements (23,24,54,157); and fragmented rather than coordinated care (19,20,224) are most visible in the clinical setting, but stem from health system arrangements designed to support acute and single long-term conditions, rather than the complex management of multiple conditions (19,61,211,224). As Loeb et al. (234) argue, reliance on professional or personal strategies do not overcome the system barriers that prevent GPs from delivering optimal care.

In summary, the preceding sections of this chapter have endeavoured to navigate the experience of patients and clinicians living with and managing multiple chronic conditions. The discussion has identified that patients and GPs experience numerous barriers associated with the management of multiple chronic conditions, but at the patient level, the process of prioritising and re-prioritising emerges as a potential response to address some of these barriers. As the gatekeepers of care, GPs appear best placed to work with patients to set priorities, but the goals and priorities established through the clinical consultation may not always align (21,70,135,219,220): a challenge that has potentially significant consequences for management. Patients whose priorities and goals align with their clinician report greater satisfaction with their health care (137,235-237), but those who do not report higher levels of non-adherence and adverse outcomes (132,137,179). Acknowledging and incorporating patient priorities and preferences and navigating “common ground” (137) between clinical and lay perspectives clearly warrants further investigation to ensure the aims of multimorbidity care can be achieved.

2.6 Reaching common ground and developing shared understanding

Understanding the distinction between disease and illness has important implications for approaches to management and treatment as clinicians and patients seek to explain poor health; identify what is important; determine how they will behave or act; and construct responses (64,132,152-154). From a clinical perspective, emphasis is placed on diagnosing and treating disease (64,65). To do this, the clinician may draw on a range of sources of information including: clinical tests, published evidence, medical records and their knowledge of the condition to inform management as Figure 2.1 illustrates (137). However, the clinical determination of disease and its management may differ from, or even conflict with, the patient's perspective. As Kleinman et al. (64), and others argue (64,149,150,193), it is not the physiological aspects of the disease, but the broader social and emotional experience of illness that is central to the patient. As Figure 2.1 highlights, the person's social and cultural context, experiences, preferences, and feelings are fundamental to their understanding of disease and how it must be managed (137).

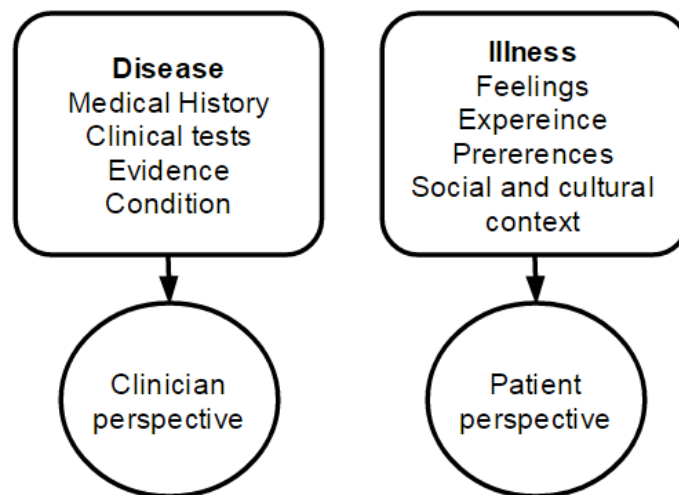


Figure 2.1- Factors informing the clinical and patient perspectives

In reflecting on the contributions of the clinician and patient, it is clear that both explanatory models are legitimate: neither should be given primacy nor considered in isolation as the implications for management and care are potentially detrimental (132,137,179). A substantial body of empirical research, conducted over the last forty

years, particularly within primary care settings, has found that care focused solely on single body systems and diseases can lead to tensions between clinicians' and patients' preferences and goals for care (21,64,65,131,132). At heart of the challenge then, is the need for patients and clinicians to find, what Stewart and colleagues (137), identified as "common ground". Stewart et al. (137) proposed that effective care requires clinicians and patients to find common ground and develop a *shared understanding* between their respective disease and illness informed perspectives (see Figure 2.2).

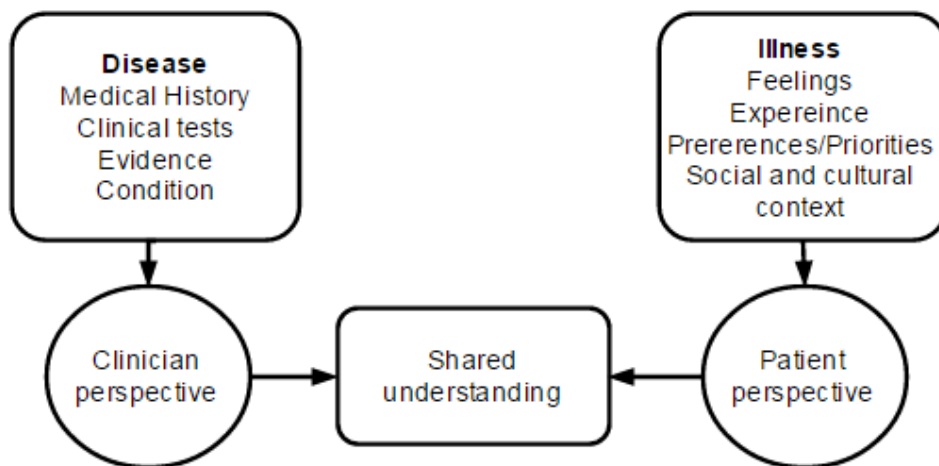


Figure 2.2 - Reaching a shared understanding between clinician and patients perspectives

Understanding patients' illness experiences is particularly important for primary care clinicians as they are generally responsible for managing a person's health over long periods of time and act as advocates and care coordinators for their patients. As such, there is a strong imperative for primary care clinicians' to treat or manage the disease with due consideration of the unique illness perspectives of individual patients (64,65,132,137). Disagreements or conflicts arising from differing perspectives need to be identified and discussed to reach agreement (137). Without this common or shared understanding, care may be compromised, patients may not adhere to the prescribed treatment or feel their voice has not been heard, fostering a negative clinician-patient relationship (132,137,179). Patients are more likely to benefit if they are engaged in care decisions to reach a shared understanding with their clinician (137,235-237). At the centre of this approach is the notion of patient-centred care.

2.7 Patient-centred care

Patient-centred care has been defined as:

Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care (238)

In essence, patient-centred care aligns closely with the notion of illness but seeks to actively engage the patients' voice in the delivery of care, particularly for those experiencing multiple long-term conditions.

The Picker Institute, an international non-profit organisation devoted to furthering the study and application of patient-centred care, outlines eight dimensions of patient-centred care (239). The "Picker Principles", acknowledge the breadth of engagement required to establish the patient voice, and were developed from a comprehensive review of the literature and focus groups with patients, family and carers, clinicians and non-clinician hospital staff (239,240) (see Box 2.1).

1. Involvement of patients in health care decisions and respect for their values and preferences for care
2. Provision of coordinated, effective and integrated care
3. Clear communication and provision of information to patients to support self-management
4. Acknowledgement of the patients' physical and environmental needs
5. Support and respect for patients' emotional needs
6. Involvement of the patients' family and/or carer
7. Support continuity of care and patients' transition between providers and settings
8. Ensure patients' have access to fast and reliable healthcare

Box 2.1 - The Picker Principles: Dimensions of Patient-Centred Care (239)

In principle there is active support for the notion of patient-centred care and the overarching ideals have been widely embraced (130,137,241,242); however as with evidence-based medicine the application of these ideals in clinical practice are less straight forward and have drawn criticism (130,241,242). In particular, patient-centred care appears to represent a less structured approach, which requires additional time

and has no clear methods for measuring effectiveness (242). Notably it also involves a redistribution of power within the clinical consult, which may be considered a threat by some clinicians who have established a predominant role in their relationship with the patient (242). The most prominent critique relates to a widely held view that patient-centred care is something of a “fuzzy concept” (130). In line with this Stewart suggests it is: “most commonly understood for what it is not—technology centred, doctor centred, hospital centred, disease centred” (243).

In acknowledging the inherent difficulties associated with operationalising patient-centred care in the clinical setting some have argued, shared decision-making may provide an active patient-centred method to engage patients and clinicians in care (244). In line with this, Barry and Edgeman-Levitan (244) argue shared decision-making may provide the practical steps clinicians and patients need to develop a shared understanding between their distinct perspectives (see Figure 2.3).

In line with this, shared decision-making will be used throughout this thesis as a proxy for the broader concept of patient-centred care. The following discussion provides an overview of the literature describing and investigating the evidence informing the use of shared decision-making.

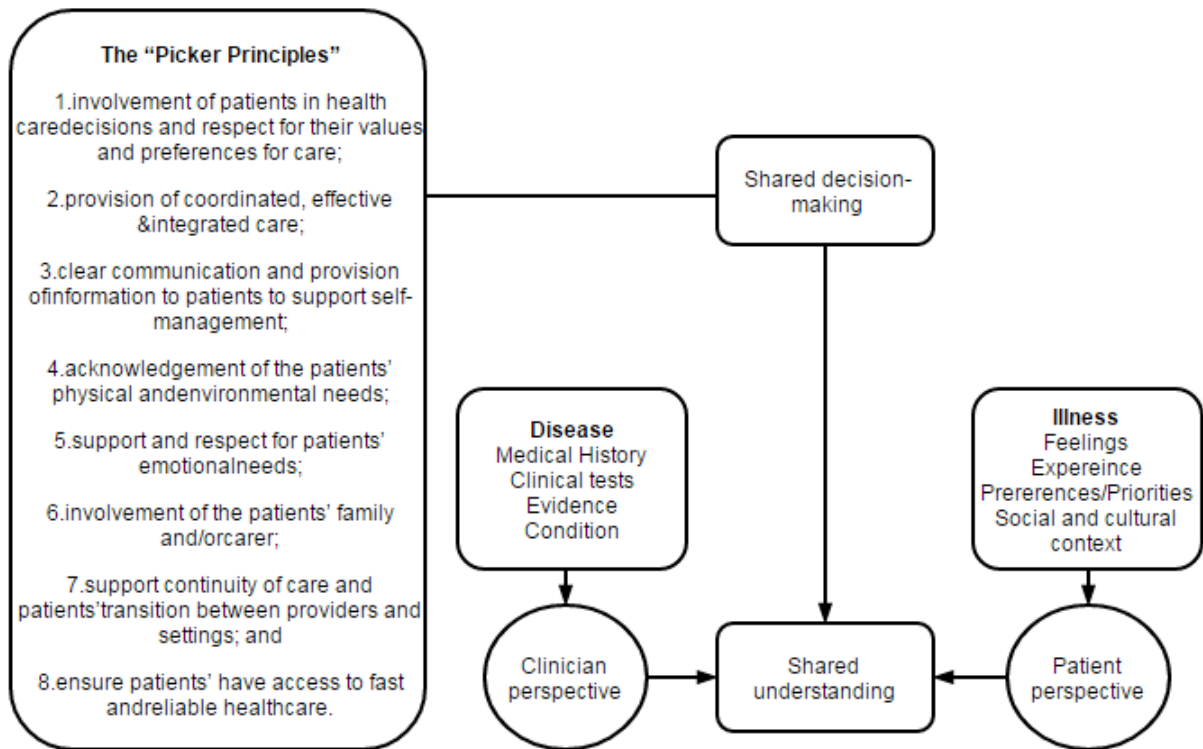


Figure 2.3 - Role of patient-centred care and shared decision-making on clinician-patient relationship

Shared decision-making

Shared decision-making is defined as:

a consultation process where a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances (245)

As a central component of patient-centred care (137), shared decision-making assumes even greater salience in multimorbidity care because there is often not a single correct treatment option (244,246). Often when faced with a decision, patients and clinicians may discuss two or more available options (140, 209). In some instances, one option may far outweigh the others, while others might be preference-sensitive (244,246). Preference-sensitive decisions, are those for which there is limited evidence informing the options; the benefits and harms of the provided options are similar; or the evidence does not favour one option over another (141,247-252). In these situations the preferences and priorities of the patient need to be considered, as

the value placed on the expected benefits, harms and/or outcomes may differ across clinicians and patients, across patients faced with the same decision, and within patients over time (244,246,251,253).

Charles et al. (246,254) argue that for shared decision-making to occur, both participants (i.e., the primary care clinician and the patient) must work through three components (see Table 2.4).

Table 2.3 - Shared decision-making components

Component	Description
Information exchange	Involves both participants sharing and exchanging information (140, 218). At this stage clinicians would present the treatment or management options, for which a decision needs to be made. Knowledge of disease progression, known risks and benefits, along with their preferences or perspectives on the various options is also shared (140, 218). In response, patients may share information regarding their lifestyle, social context, beliefs or fears regarding their disease(s) or treatment options. At this point patients should be encouraged to share their preferences and goals for care, along with any information or prior knowledge regarding the presented options (140, 218).
Deliberation	Involves both participants deliberating and discussing the exchanged information (140, 218). Patients and clinicians preferences for care can differ. For example, clinicians may view the benefit of a particular option as outweighing the potential risks or side effects whereas patients may place greater importance on avoiding the side effect. These differences, if not addressed, can foster a negative clinician-patient relationship (97, 100, 111). This process is about working through the information exchanged and exploring both the patients' and clinicians' preferences for care, to reach a shared understanding (140, 218).
Deciding on treatment to implement	Involves the clinician and patient reaching an agreement and deciding on a particular option (140, 218). After having shared the relevant information and deliberated around it, the final decision should reflect both participants' agreement based on their shared knowledge and preferences for care (140, 218).

Subsequent authors (141,247,248,255) have identified similar components or steps, but central to all of these works is the focus on engaging and involving patients in decision-making processes. Of note is the emphasis on sharing information in order to achieve shared decision-making. While it is often assumed these steps occur symbiotically, this is not always the case (256). For shared decision-making to occur, participating persons must share their relevant knowledge and preferences. This process of sharing information, before jointly deliberating and agreeing on a decision is what differentiates the shared decision-making model from other approaches such

as the *paternalistic model*, which places the patient in a passive role alongside dominant clinician, and the *informed model*, which locates the patient in a dominant position while the clinician functions in the more passive role of information provider (246,256).

Shared decision-making seeks to find a balance between these approaches through emphasising the importance of both parties sharing information in order to participate in shared decision-making. Clinicians need to share their knowledge on the patients' diseases and the evidence informing treatment or management and patients' need to share their preferences, priorities and expectations regarding care. In line with this, Charles et al. (246) suggests:

shared decision-making is seen as a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their wellbeing.

Shared decision-making is increasingly considered an "ethical imperative" (257), and a characteristic of good clinical care (245,258). Despite, the increasing emphasis on shared decision-making, its benefits have not been extensively examined (259,260). Most literature examining the benefits of shared decision-making centres on patient decision aids (PDAs) (245). The most recent of a series of systematic reviews, concluded the use of PDAs results in patients having an increased knowledge of options, improved risk perceptions, lower decisional conflict, and selection of options more in line with their preferences (251). In addition, a longitudinal study into medical decision-making for 203 women with breast cancer, found those who were more engaged in choosing their treatment had significantly higher overall quality of life than those who were passively involved (236).

In Australia, share decision-making is encouraged in clinical practice guidelines, policy documents and by consumer health organisations (44,258). However, there is no clear strategy for implementing shared decision-making in primary care practice (44,245,258), although, this may change with the newly released 'Better outcomes for people with chronic and complex health conditions' report (54) and the soon to be released National Strategic Framework for Chronic Conditions (125). Presently, the

tools and infrastructure needed to support shared decision-making are lacking (44,245,258). According to Hoffman et al. (245),

Australia is drastically lagging behind many other countries in all aspects of shared decision-making — policies, lobbying, advocacy, research funding, training, resources and implementation (245)

Consequently, they call for greater system support of shared decision-making in primary care practice (245).

A systematic review of 38 studies investigating health professional's perceptions of shared decision-making identified three core facilitators to uptake of shared decision-making by clinicians (261). These included: clinician motivation; the belief that shared decision-making would lead to improve patient outcomes; and the belief that shared decision-making would lead to improved clinical processes (261). This suggests primary care clinicians recognise the importance of participating in shared decision-making (261), but encounter challenges in practice. Known barriers include: short consultation times; limited training for clinicians on how to participate in shared decision-making; threat to power relationships; and limited availability of resources or tools to support shared decision-making (262,263). Consequently, clinicians (40, 192, 195), along with the RACGP (33) and the PHCAG (54) have called for methods to support shared decision-making and work through potential differences in priorities.

Working through the shared decision-making components, outlined by Charles et al. (246), is one way clinicians and patients could achieve shared decision-making and support multimorbidity care within the clinical encounter. To support this work, the tools informing primary practice should also assist clinicians and patients to meet these steps. In Australia primary care practitioners draw on a range of tools, but it is unclear to what extent these tools enhance or limit clinicians' ability to participate in shared decision-making for patients with multiple conditions. This thesis seeks to address this question but first the tools supporting clinical care need to be identified.

2.8 Conclusion

The aim of this chapter was to contextualise lay and clinical perspectives, as they map with the notions of illness and disease, to inform an understanding of the management of chronic conditions. Building on this discussion the chapter explored the experience of living with multiple chronic conditions and the many challenges patients and clinicians experience when managing these conditions. A critical argument arising from this discussion was the need to engage patients in care decisions to ensure they are supported in priority setting processes and are able to participate in the development of a shared understanding with clinicians. The chapter proposes shared decision-making, a central component of patient-centred care, as one way of facilitating this process. On the basis of this discussion, the following chapter seeks to identify and describe the current primary care practice tools that could be used to assist patients and clinicians to achieve shared decision-making.

Chapter 3 Primary care practice tools

3.1 Introduction

Chapter two provided a foundational understanding of chronic illness and disease from the perspectives of patients and clinicians. Arising from this discussion was the need to ‘reach a shared understanding’ between patients and clinicians whose perspectives may differ. Shared decision-making was argued as one approach to facilitate this process and achieve multimorbidity care. However, as noted in Chapter two, shared decision-making is not consistently practised across primary care settings. Identified barriers include: short consultation times; inadequate training of clinicians in practising shared decision-making; and limited availability of resources or tools to support shared decision-making (262,263). Clinicians (19,224,230), along with the RACGP (33) and the PHCAG (54), have called for tools to support shared decision-making in primary care, particularly when managing multiple conditions.

Building on this discussion, the purpose of the present chapter is to identify and consider current primary care practice tools and their ability to contribute to shared decision-making and multimorbidity care. As such, the chapter is comprised of three sections. The first section briefly revisits the discussion, presented in Chapter one, describing what is meant by the term ‘primary care practice tool’ and why they are the focus of this thesis.

Having reiterated the importance of these tools, the second section outlines the methods used to identify the three primary care practice tools which are the focus of this thesis. Clinical practice guidelines and care plans emerged as two tools, instrumental in providing chronic disease care in Australian primary care practice. These tools were validated by expert stakeholders, who also identified an additional tool - PDAs. Extending on this discussion the final section of this chapter provides a brief description of each of the three tools, including their purpose, benefits in a single disease context, and relevance for patients with multiple conditions.

3.2 Primary care practice tools

Primary care clinicians draw on a range of tools to support care provision, from diagnostic tests, to evidence-based clinical practice guidelines, to care plans (32). For the purposes of this thesis, primary care practice tools are those that support the clinical consultation between primary care clinicians and patients through the standardisation of information or processes. Development of such tools typically springs from the need to support practice wide change, or establish uniformity in care provision, due to clinician need, gaps in care provision, new research or policy debates (30,32). Regardless, of their individual purpose, all of these resources and tools inform and influence the way clinicians choose to provide care (4,30,32,264). As such, some can and have been used as mechanisms to influence system wide change in care provision (30,32,41,42). Recognising this role, this thesis chose to focus on primary care practice tools rather than on the practice or actions of individual clinicians. This research takes the viewpoint that primary care practice tools have previously contributed to practice wide change (30,32,41,42) and therefore could support a shift towards better care for those with multiple chronic conditions. In taking this viewpoint the thesis applies the theory of incrementalism to data analysis and interpretation (37).

The theory of incrementalism advocates “an evolutionary rather than revolutionary process” (140) to policy decision-making. This contrasts most prominently with rational-comprehensive theory, which espouses a process of policy decision-making whereby decisions are made following a comprehensive examination of all choices and their impacts (36-38). Although considered the ‘ideal’ the rational-comprehensive approach is rarely achieved in practice, as policy makers are seldom able to identify or reach a consensus with all stakeholders on the core objectives to be achieved and/or the methods to attain them, due to limitations in time, evidence and resources (36-38). Consequently, Lindblom (37) proposed the theory of incrementalism as a more realistic and achievable approach to real-world policy decision-making. Although numerous other theories exist, incrementalism features prominently in Australian public policy and numerous examples demonstrate that this is what drives change in health policy and practice (39,40,265-268).

Within the context of this research incrementalism offers a framework for considering how policy relating to primary care for chronic disease had been developed in Australia and how changes might be made in the future. Specifically, applying incrementalism led the thesis to be framed around the question of what changes, if any, to existing primary practice tools are required to support a shift toward multimorbidity care rather than a question focused on large-scale comprehensive system reform.

Clinical practice guidelines and care plans are two examples of primary care practice tools used extensively in Australia to drive care provision.

- Guidelines, as mentioned earlier, are considered the epitome of evidence-based medicine, and as such are viewed not only as a means of guiding the provision of quality care but also as a means of evaluating it (264,269). Clinical practice guidelines, were identified in both the chronic illness literature and policy discussions as core tools directing care provision in primary practice and the health system more broadly (2,30,32,33,54,233,270).
- Care plans facilitate coordinated multidisciplinary care, which actively involves the patient and is structured to their individual needs (4,39,271-273). Care plans have been a core part of primary care practice in Australia for almost two decades (4,39,271-273). They are widely supported in the chronic illness literature, health policy, clinical practice guidelines and care models as a means of individualising chronic disease care (33,54,136,159,272-276).

Given their significance as core tools aiding and informing chronic disease management in primary care settings, both clinical practice guidelines and care plans were included for analysis in this research. To validate the importance of these tools and to ensure no other relevant tools had been missed, leading primary care researchers were identified.

3.3 Expert stakeholder consultation

A purposive sample of primary care clinicians, with expert knowledge regarding primary care practice tools currently available to support the management of chronic conditions, was identified and questioned. Purposive sampling involves deliberately

selecting participants based on certain qualities and experiences the participants possess, which might be overlooked when using a convenience or random sample (277,278). The study sought participants with expert knowledge in health systems and policy aspects of primary care.

Ten primary care clinicians were identified through 'Research Profiles' a searchable online platform. The platform was developed in 2003, by the Primary Health Care Research and Information Service (PCHRIS), and allows those involved in primary care research to share their achievements, research ideas, research outcomes and ongoing or future research projects (279). Emails were sent to ten primary care clinicians informing them of the current study and inviting them to participate in a short (approximately 5 minute) survey (appendix 1). The difficulties of engaging GPs in face-to-face interviews are well documented, therefore a short online survey was considered more appropriate given the survey's purpose, and the increased likelihood of a higher response rate (280,281). Considerable effort was placed on the format and content of the questions to ensure they would not exceed five minutes, as research suggests primary care clinicians are less likely to participate in studies which require more of their time (280,282). An information sheet (appendix 2) was included in the text of the email and potential participants were advised that clicking on the link to answer the questions via 'Survey monkey' would indicate consent to participate in the study. The University of Queensland's School of Population Health Research Ethics Committee approved the study (appendix 3).

The questions asked of the expert stakeholders are shown in Figure 3.1 below. The questions related directly to the professionals opinions and did not ask for information on specific patients, as research suggests clinicians are often reluctant to participate in studies which disrespect their patient's confidentiality (282).

Management of multiple long term conditions

1. Based on your experience how would you rate the following tools for use in the management of multiple long term conditions in primary care? Please rate on a scale of 1 (not useful) to 5 (very useful).

	1	2	3	4	5
Care Plans	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical practice guidelines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Particular strengths or weaknesses

Care plans

Clinical practice guidelines

3. What additional tools, relevant to the Australian setting, would you add to this list?

4. What do you believe are the essential features of a tool designed to support GPs in the management of multiple long term conditions in primary care?

5. What do you think is most needed to assist GPs in the management of multiple long term conditions? (Please list what you see as the 3 main priorities).


Powered by

 See how easy it is to [create a survey](#).

Figure 3.1 - Screenshot of the 'Survey Monkey' survey sent to expert stakeholders

Six GPs responded to the survey. All the responses to free-text questions were ordered and the process of thematic analysis was used to guide analysis (283,284).

Clinical practice guidelines and care plans were confirmed as core tools used in the management of multiple chronic conditions in primary practice. Clinical practice guidelines received an average rating of 3.2 out of 5 for their usefulness in the management of multiple conditions, and care plans received a rating of 3.8 out of 5. Two additional tools were identified: prevention guidelines, and PDAs. As this thesis aimed to investigate primary care practice tools which assist with the management, not prevention, of multiple conditions prevention guidelines were excluded. PDAs were included for analysis.

In summary, three primary care practice tools: clinical practice guidelines, care plans, and PDAs were identified and validated through consultation with expert stakeholders.

The following section provides a brief description of each of these tools starting with clinical practice guidelines.

3.4 Clinical practice guidelines

In the 1990s, the Institute of Medicine released a series of reports on clinical practice guidelines, which they defined as a “systematically developed statement to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (285). Since this time the development and use of clinical practice guidelines has continued to rise, with guidelines now being considered a core component of quality care translating evidence into practice (227,269,286,287). Wolff (269) attributes the growing interest in clinical practice guidelines to three major factors: rising health care costs; variations in clinical practice; and the provision of inappropriate care. Clinical practice guidelines are viewed as a means of overcoming these issues by drawing clinicians’ attention to ineffective, wasteful and potentially harmful practices, thereby improving consistency of care (288). Although, initially developed based on consensus among experts in the field, clinical practice guidelines have shifted to being based on systematic research evidence in line with the evidence-based medicine movement (227). As a result they are generally created for the ‘average patient’ from population based trials with narrow inclusion criteria (227). In essence, clinical practice guidelines provide health care providers and patients with evidence-based recommendations on the best methods for treating and managing certain health concerns (108,289,290).

Clinical practice guidelines have demonstrated their effectiveness in guiding the management of single chronic conditions, by improving the consistency of care and drawing clinicians’ attention to ineffective and potentially harmful practices (288,291-294). A systematic review of 59 studies investigating the effect of clinical practice guidelines found all but four reported improved adherence to the recommended procedures. Of the 11 studies that examined the outcomes of the recommended care, nine showed statistically significant improvements (291). Similarly, a systematic review of 20 studies examining the use of Dutch guidelines found their use significantly improved the structure of care in 17 of the 19 studies examining this outcome (293).

In addition, of the nine studies which look at patient health outcomes, six showed significant improvements as a result of guideline use (293).

Relevance in a multimorbidity context

In considering the relevance of clinical practice guidelines to support multiple chronic conditions, a number of limitations have been observed including: the quality of guidelines; their consideration of multiple conditions; and their accessibility. Each of these is considered in more detail below, starting with guideline quality.

Guideline quality

For guidelines to improve health care, they need to be of sufficient quality (295). Tools such as the Appraisal of Guidelines, Research and Evaluation (AGREE II) instrument have been developed to evaluate the quality of guidelines (296). The AGREE instrument uses twenty-three items across six domains (see Box 3.1), to assess the method of guideline development and how well these methods were reported (296).

Domain 1. Scope and Purpose is concerned with the overall aim of the guideline, the specific health questions, and the target population (items 1-3).

Domain 2. Stakeholder Involvement focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users (items 4-6).

Domain 3. Rigour of Development relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them (items 7-14).

Domain 4. Clarity of Presentation deals with the language, structure, and format of the guideline (items 15-17).

Domain 5. Applicability pertains to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline (items 18-21).

Domain 6. Editorial Independence is concerned with the formulation of recommendations not being unduly biased with competing interests (items 22-23).

Box 3.1 - The six domains of the Appraisal of Guidelines, Research and Evaluation (AGREE II) instrument (297).

Currently there is no ‘gold standard’ process for developing guidelines and as a result, methodologies can differ. Many organisations have attempted to standardise guideline development by creating handbooks, which require guideline developers to meet certain methodological standards (295,296,298,299). In Australia, to receive approval from the National Health and Medical Research Council (NHMRC), guideline developers must meet the standards set out in the “NHMRC procedures and

requirements for meeting the 2011 NHMRC standard for clinical practice guidelines” (286). However, organisations are free to develop and disseminate guidelines without meeting quality standards and as a result clinicians are exposed to numerous, often conflicting guidelines of varying quality (295).

An Australian study investigating the quality of guidelines for older people with comorbidities, assessed using the AGREE instrument¹, found the quality of guidelines varied widely (295). Guidelines that did not receive approval from the NHMRC generally had poor descriptions of the methods used for collating evidence and creating recommendations, in comparison to those guidelines that had received NHMRC approval (295). Without a clear account of the methods used to develop guideline recommendations, clinicians are unable to determine the strength and quality of the recommendations and their applicability to patients (295).

Consideration of multiple conditions

A common criticism of guidelines is that they focus too much on single chronic conditions (12,27,62,295,300,301). While, this mirrors the way evidence is collected, it does not reflect the realities of primary care practice where the number of patients presenting with multiple conditions is increasing (301).

An Australian review of guidelines and their significance to older patients with multiple conditions found current guidelines have little relevance to this population group (139,295). Of the 17 guidelines reviewed, nine provided guidance for patients with one comorbid condition, two for patients with multiple conditions, and only one for elderly patients with multiple conditions (139,295). Similarly, a Canadian systematic review of guidelines addressing comorbidity, found their applicability to patients with multiple conditions was limited. Of the 20 guidelines identified only 14 gave specific recommendations for the treatment of comorbidities, with a mean of three comorbidity related recommendations per guideline (71). The majority of these recommendations addressed concordant conditions (46 recommendations) rather than discordant conditions (8 recommendations) (71). None of the recommendations provided

¹ The AGREE instrument was updated in 2010, subsequent to the article's publication, and renamed the AGREE II.

guidance for patients with more than one co-existing condition (71). Hughes, McMurdo and Guthrie (302) examined the extent to which patient comorbidity was address in guidelines developed by the National Institute of Health and Clinical Excellence (NICE), the central guideline development organisation in the United Kingdom. They observed considerable variation in the consideration of comorbidity across the guidelines, with some discussing comorbidity extensively and others not at all. This suggests further guidance is need on how to address or consider multiple conditions in guidelines.

Due to the lack of applicable guidelines addressing the management of multiple conditions, clinicians often resort to using disease specific guidelines. This may be detrimental to patient care, as the clinicians can apply any number of different guidelines to one individual, with limited consideration of their interaction (12,189,303,304). This is best illustrated by Boyd et al.'s (12) study of the feasibility of applying multiple treatment recommendations drawn from guidelines, for the management of a hypothetical 79 year old with five chronic conditions (12). The result was an overly complex, harmful regimen that included multiple conflicts in prescribed treatments (12).

Accessibility of guidelines

Clinicians appear to have positive attitudes towards clinical practice guidelines (71,290). In a survey of 79 Australian GPs, guidelines were considered by the vast majority to support decision-making (94%) and medical education (92%)(305). Similarly, in a systematic review of 30 studies examining clinicians' perceptions, clinical practice guidelines were perceived by the majority of respondents as a helpful source of advice, good educational tool and intended to improve quality (290). Likewise, a survey of 264 primary care clinicians in the Netherlands found 97% of clinicians believed guidelines were a useful source of advice, 94% thought they were based on sound and sufficient evidence and 89% believed guidelines would result in improved patient care (306).

Despite these positive attitudes, research suggests guideline uptake varies as clinicians identify a number of barriers with their implementation. These barriers can

be classified into three common themes: guideline characteristics, environmental characteristics and practitioner characteristics.

Guideline characteristics: Clinicians perceive guideline characteristics relating to quality, length, and complexity and compatibility as barriers to their use. Issues of guideline quality were discussed above and are not repeated here.

- *Length* - Studies suggest clinicians are more likely to adhere to guidelines, which are short and simple (226,231-233,305,307). Use of 2-3 page summaries, flowcharts, and/or single page checklists are supported by clinicians as methods for simplifying guideline content, making them more accessible at the point of care (305). However, this conflicts with the importance clinicians may place on understanding the methods used by the guideline developers to generate the recommendations.
- *Complexity and compatibility* - Less complex guidelines and those which require fewer changes to the clinician's existing practices were more likely to be followed (226,233,305).

Environmental characteristics including lack of time and resources may also reduce guideline uptake.

- *Lack of time* - Clinicians report lack of time as a major barrier to the use of guidelines (226,231-233). Finding appropriate guidelines can be timely as not all countries, including Australia, have a central organisation responsible for developing and disseminating guidelines. As a result clinicians can spend considerable time locating relevant guidelines (226,231). In addition, some guidelines are in the order of 200 pages in length and reading these documents can place an added burden on already time-poor clinicians (226,231).
- *Lack of resources* - Lack of resources referred primarily to organisational restrictions such as limited information management systems, referral pathways and funding and resources to be able to carry out the guideline recommendations (226,231).

Practitioner characteristics include age, location, awareness, confidence and applicability.

- *Age* - Older GPs are generally less likely than their younger counterparts to use guidelines (233,270). This may be because older clinicians have more experience and therefore believe they do not need guidelines or alternatively are reluctant to change their existing practices (233,270).
- *Location* - Clinicians located in rural areas are less likely to adhere to guidelines compared to those in urban areas (233). This could be because clinicians in urban areas have greater access to resources and professional peers than those in rural areas.
- *Awareness* - With an increasing number of guidelines developed and disseminated, somewhat paradoxically, clinicians report lack of awareness of the existence of guidelines (231,232,270).
- *Confidence* - Lack of confidence in their ability to carry out recommendations was another barrier identified by a number of clinicians (231-233,270). Doubt or disagreement about the expected outcome of the guideline recommendation has also contributed to non-adherence among clinicians (226,231-233). If the clinician felt the guideline recommendation would not result in the expected outcome for their patient then they would not follow it (226,231-233).
- *Applicability* – The applicability of guidelines was another major concern identified by clinicians (226,231-233). Clinicians were cautious of applying guidelines based on evidence drawn from population based trials with narrow inclusion criteria as they felt their patients did not fit the average or ideal patient for whom the guideline recommendations were designed, but rather had more complex problems (71,226,231-233,290,306). As such, clinicians believed using guidelines would conflict with their patient’s individual circumstances and preferences for care (71,226,231-233,290,306). This problem was emphasised for patients with multiple long-term conditions (71,226,231-233,290,306).

Issues such as these point to potential shortcomings in guideline development, including inadequate involvement of consumers and end user clinicians for whom the guidelines are designed. Research suggests a patient-driven approach centred on addressing the person's preferences and overall health goals would be more appropriate for patients with multiple conditions (67,250,308,309).

Incorporating patient preferences

The notion of 'preferences' refers to "the desirability of a health-related outcome, process or treatment choice" (250). Krahn and Naglie (250) argue that the identification and incorporation of patient preferences in guideline development and implementation may improve the patient-centredness of clinical practice guidelines. They suggest that obtaining consumer input during guideline development may provide the foundation for greater systematic attention to patient preferences and support for patient decision-making in clinical consultations (250,310,311). Encouraging consumer participation in the guideline development process became popular from the early 1990s (312). Strategies to engage consumers include involving consumers in guideline-development groups, providing drafts for feedback, conducting surveys of consumers or running consumer focus groups or workshops parallel to the clinical guideline development groups (308,313-315). Some of these approaches have been criticised for being 'passive' or 'tokenistic' (314,315). Broader evidence assessing the impact of these approaches on guideline development is limited, with the exception of a recent study by Tong et al. (311). Tong et al. (311) found active consumer engagement led to the identification of additional patient-centred recommendations which had not been flagged by health professionals.

Involvement of consumers in guideline development should not replace, nor is intended to replace, the discussion of patient preferences in the clinical consult. Rather consumer input should assist to identify recommendations which might be considered preference-sensitive. Flagging preference-sensitive recommendations and incorporating the preferences of individual patients is particularly important in the presence of competing health outcomes (217). There may be few competing health outcomes for patients with one long-term condition as treatment is focused on obtaining a particular disease-specific outcome, such as maintaining a healthy blood

glucose level for those with diabetes (217). In contrast, research suggests patients with multiple conditions, change from disease-specific to 'global' cross-disease health outcomes such as maintenance of physical function, symptom relief and quality of life (217,316). Guidelines should encourage clinicians to discuss patients' individual preferences when recommendations are labelled as preference-sensitive (250,316,317). However, research suggests guidelines do not frequently provide this information (317) and it is unclear whether clinicians in fact use guidelines in this way for patients with multiple conditions.

In summary, clinical practice guidelines are core drivers of evidence-based medicine in primary care practice. However, their quality and relevance in a multimorbidity context has been questioned. GPs argue clinical practice guidelines are made for the 'average patient' and do not consider the needs and preferences of individual patients, particularly those with multiple conditions. Use of consumer engagement processes, during guideline development could assist in making guidelines more patient-centred by identifying preference-sensitive recommendations for further discussion in the clinical consultation. Having briefly examined clinical practice guidelines, this section now turns to consider the second primary care tool - care plans.

3.5 Care plans

Care plans have long been part of the primary care landscape (32,318). They emerged in response to the rise in chronic illness, which subsequently required changes in the approach and organisation of care (273). As outlined in chapter two, the longevity and complexity of chronic conditions often necessitates patients to visit numerous health care providers and self-manage their care on a day-to-day basis (159,319,320). Care plans, a written articulation of clinician and patients' combined strategy for managing a chronic condition, arose as a means of assisting both clinicians and patients to coordinate care according to the needs of the individual (321-323). Ideally, patients' GPs will use care planning discussions, and the resulting care plan, to coordinate other health care providers around the patient and their individual needs. This ensures care continuity and responsiveness. Care plans are also intended to support patients to self-manage by outlining their individual health care needs, management goals and

the resources required to achieve them (235,271,321,324,325). The care planning process typically involves a number of key features.

- First, health problem(s) are jointly defined by the clinician and patient, wherein the patient's health concern(s) are acknowledged along with the clinician's diagnosis of medical condition(s) (235,321,325).
- Second, the patient's goals and objectives regarding their condition(s) are identified. A care plan outlining the actions to be taken by the patient and care providers to obtain these goals and objectives is developed, in line with the patient's context and preferences (235,321,325). A copy of the care plan is given to the patient.
- Third, clinicians ensure patients have access to the necessary self-management resources, such as other health professionals, training seminars, consumer health organisations, and support services (235,321,325).
- Finally, the clinician would organise for regular check-ups or follow ups to ensure the patient was still managing well, check on potential complications and if required, update the care plan (235,321,325).

In Australia, care plans have been a part of primary care practice for almost 20 years. Introduced in 1999, as part of the 'Enhanced Primary Care' (EPC) Package, the care plans aimed to encourage and support a multidisciplinary approach to chronic disease management (326). For the first time GPs and allied health professionals could receive reimbursement from Medicare for time spent developing multidisciplinary care plans for patients with chronic and complex care needs (4,39,271). The EPC package was modified in 2005 to cover two types of care plans: Team Care Arrangements (TCA) developed by clinicians in collaboration with allied health professionals for patients with multidisciplinary care needs; and General Practice Management Plans (GPMP) developed by primary care clinicians for patients with chronic disease (271).

Care plans have demonstrated success in improving clinicians' adherence to recommended guideline for treatment. Adaji et al. (4) investigated whether having a GPMP or TCA improved clinicians adherence to recommended treatments outlined in

guidelines for patients with type I and II diabetes. They found a strong association between care planning and increased testing of processes recommended by diabetes guidelines in contrast to those without a GPMP or TCA (4). Similarly, a study examining the care of patients with type 2 diabetes before and after the use of a TCA plan found that following the development of a TCA patients' received care more closely aligned with care recommended by diabetes guidelines. Care plans have also shown to improve patients' knowledge of symptoms, reducing exacerbations and increasing adherence to self-management regimes (271,327-329). In addition, Lewis and colleagues (330) reported that patient participation in care planning led to improved identification of health needs and services to meet those needs. Patients felt they received better quality of care and had an enhanced understanding of their condition (330). Likewise, a UK study of care plans and care planning for patients with long-term conditions found most patients reported some benefit from participating in care planning discussions (321). Similarly, Shortus et al. (331) found that patients who obtained a care plan were more satisfied with the care coordination they received. However, an Australian study of 2296 people with long-term conditions, investigating the use of care plans and patients' engagement in their development, found the degree to which patients contribute to the formation of their care plans remains low (275).

Relevance in a multimorbidity context

Care plans are intended to be individualised and patient-centred, incorporating the patient's emotional, physical, financial and social circumstances (332). As a result, patients may be more likely to self-manage effectively, achieve their health goals and adhere to their care plans (235,328,332-334). A recent Cochrane review of personalised care planning for adults with chronic conditions called for research to investigate care planning for patients with multiple conditions, after they were unable to identify any studies explicitly examining this issue (335). Despite the limited literature informing this area, researchers have argued for the potential of care plans to address some of the gaps in care for people with multiple conditions (12,21,62,139,335).

One notable and highly relevant exception is a recent Australian trial of a multiple condition care plan template conducted by Morgan et al. (136). The care plan template

was developed for patients with depression, diabetes, and/or coronary heart disease, as part of the TrueBlue study. Clinical practice guidelines were used to inform the care plan template, with prompts for health professionals being included to ensure guideline-recommended checks (e.g., eye check) were performed (136). The template also requested the patient's goals and preferences be listed and reviewed every three months, along with any barriers or enablers to achieving these goals. Practice nurses, funded by Medicare, were primarily responsible for the development of care plans with the patient (136). Patients were scheduled for 45 minute consultations with the practice nurse, during which time the nurse would document the patient's clinical information (e.g., pathology results, risk factors, medications), arrange referrals, and work with the patient to identify their priorities and goals for care. The study found guideline-recommended checks were more frequently performed by health professionals using the TrueBlue care plan. In addition, patient lifestyle goals were set by 96% of the 142 intervention patients (136). Based on their findings Morgan et al. (136) identified a number of factors that contributed to successful care planning for the management of multiple conditions, including the integration of multiple guidelines, tracking clinical concerns and needs across conditions, monitoring multidisciplinary referral processes, identifying patients' goals and priorities and establishing systems to ensure their regular review. This study provides some evidence of how care plans may be part of a renewed approach.

With an increasing number of patients presenting with multiple chronic conditions in primary practice (5), it is time to take stock and consider whether care plans meet the needs of patients and clinicians managing multiple conditions.

3.6 Patient decision aids

PDAs are not currently well used within Australian primary care practice (245,336). As such, it was somewhat surprising that this tool was identified through consultation with expert stakeholders. PDAs are advocated as a means of facilitating or operationalising shared decision-making (245,337). Their emergence in the last two decades coincides with increasing attention to engaging patients in care decisions (244,257,338).

PDA's are "tools designed to help people participate in decision-making about health care options" (339). They do this by providing information on the benefits and harms of the various options and assisting patients to determine the value they place on the provided benefits and harms (339). The term 'decision aid' was first used in an article by O'Connor and colleagues (340) in 1998, to describe an intervention designed to assist women considering hormone replacement therapy after menopause. Since then the development and implementation of PDA's has continued to expand (251,341). Elwyn et al. (342), who have made substantial contributions to the field, identify three categories of PDA's:

1. *Those intended for use by clinicians and patients in the clinical consultation*, such as "balance sheets" or "option grids". These PDA's generally use short statements or graphics to present information on the various options (342). They do not provide extensive information, as their purpose is to prompt further conversation between clinicians' and patients' on the various options (342).
2. *Those that can be used by patients independently of the clinical encounter*. These PDA's are more common (342). They provide extensive information on the various treatments options, and while they can be used independently they are intended to augment rather than replace discussion with clinicians in the consultation (342). Typically, PDA's are provided after a consultation to be discussed further at the next consultation or prior to a consultation so patients come prepared to engage in decision-making (342).
3. *Those mediated by other social encounters*. These PDA's are used outside of the clinical encounter, and are facilitated through mediums such as telephones, Twitter, or Facebook interactions. Unlike the first two categories of PDA's, PDA's mediated by other social encounters typically occur between patients and persons other than their primary care clinician.

Use of PDA's which are more detailed, provide clear probabilities and processes to assist with clarifying the value patients place on the benefits and harms, result in improved knowledge, more accurate risk perceptions and choosing of options more in

line with their values (251). Despite this there is ongoing debate as to whether the use of these detailed decision aids facilitates genuine shared decision-making within the clinical consultation (341). Early findings from Elwyn and colleagues (343) the use of option grids (“a brief summary of options organised in tabular format, limited to one side of standard size paper”), suggest the use of shorter PDAs, while not providing extensive information, may facilitate greater shared decision-making or “decision talk” between clinicians and their patients (343).

PDAs have emerged as a means of facilitating or operationalising shared decision-making in the clinical consultation, particularly for those facing preference-sensitive decisions (337,344,345). Cochrane reviews have compared (346-348) the use of PDAs to usual care for people facing treatment or screening decisions. The most recent (251) included 115 randomised control trials and concluded there was strong evidence that use of PDAs results in increased patient knowledge of options and feelings of being informed and clear on the issue of importance to them (251). There was moderate evidence indicating patients using PDAs had improved risk perceptions, were more likely to participate in decision-making and select options more in line with their preferences (251). Although, they have proven effective in supporting patients and clinicians managing single conditions, the ability of PDAs to support shared decision-making for patients with multiple conditions remains untested.

Despite the evidence for benefits, routine use of PDAs is low (263). Known barriers include: short consultation times; limited training for clinicians on how to use PDAs to facilitate shared decision-making; concern that use of PDAs might cause distress to patients; perceived threats to existing patient-clinician relationships; limited availability of PDAs; and concerns about PDA quality (262). Although, a number of minimum standards or criteria have been put forward (337,349,350), primarily for assessing quality, a consensus has yet to be reached on what “active components” (349) PDAs should include. For instance the use of patient stories, short descriptions of other patients’ experiences when making the same treatment choice, is highly debated, with many arguing that more research is needed to confirm their benefits (52, 54, 55).

Relevance in a multimorbidity context

Attributes of PDAs, such as helping patients to understand the risks and benefits of treatment options, assisting patients to clarify the value they place on these benefits and harms and participate in shared decision-making (344), suggest potential in terms of supporting multimorbidity care. Nevertheless, PDAs have not yet been examined in a multimorbidity context.

In summary, three primary care practice tools were identified as relevant to the aims of this thesis: clinical practice guidelines; care plans; and PDAs. Each was identified as having a particular purpose: guidelines to support evidence-based medicine; care plans to facilitate multidisciplinary and patient-centred care; and PDAs to operationalise shared decision-making. All three were shown to have positively influenced or informed care for the management of single chronic conditions, but questions arose regarding their suitability within a multimorbidity context. For guidelines, specific issues that arise are whether they are of sufficient quality, include patient preference recommendations, and involve consumers in guideline development. For care plans, questions relate to whether they are applicable in a multimorbidity context or how well care plans accommodate the different care needs of patients with multiple and often complex needs and how readily these are considered when constructing a care plan. For PDAs, there are wider questions about their applicability to the multimorbidity context and how might they be better integrated into Australian primary care practice.

3.7 Conclusion

The aim of this chapter was to examine primary care practice tools currently available to assist in the management of chronic disease. Consequently, the chapter has outlined how the three tools chosen for analysis in this thesis (clinical practice guidelines, care plans and PDAs) were identified and presented a brief description of each. This description highlighted that while all of these tools inform and influence decision-making in primary care their conceptual underpinnings and intended purpose differ. The benefits of each tool were explored in relation to the management of single chronic conditions, but in so doing questions were raised regarding their applicability

in a multimorbidity context. Building on this discussion the next section outlines the thesis research question and methods used.

Chapter 4 Research question and methods

4.1 Introduction

Chapter three provided a brief description of three primary practice tools currently available to support chronic disease management. Each demonstrated benefits in the management of patients with a single chronic condition, but questions arose regarding their suitability or transferability to the management of patients with multiple chronic conditions. Expanding on this discussion this chapter now turns to outline the thesis research question and the methodology used to answer it. To avoid excessive repetition this chapter provides only a brief outline of the methods used, as detail will be provided in subsequent chapters.

4.2 Research question and aims

The central question addressed in this thesis is: *Are primary care practice tools developed to support the management of chronic disease in Australian primary practice, transferable to the management of multimorbidity care?* In answering this question the thesis considered the following:

- What is known about living with multiple chronic conditions? (Chapter two)
- What is known about providing multimorbidity care in primary care? (Chapter two)
- What primary care practice tools are currently in use to support chronic disease management? (Chapter three)
- What are the strengths and limitations of these primary care practice tools for supporting core components of multimorbidity care (Chapters five, six & seven)
- What are the implications of these findings for policy and practice? (Chapter eight)

4.3 Methods

This thesis, used an applied policy research methodology to address the research question and drive analysis. Applied policy research differs from other theoretical research in that it aims to address specific information requirements, which result in clear recommendations or actionable outcomes (143,351,352). Although most applied policy research is quantitative, a consequence of policy-makers initially desiring empirical 'facts' to inform policy, the contributions of applied qualitative policy research is increasingly recognised (352,353).

Applied qualitative policy research adheres to the aims of applied research, to answer clear informational needs and produce actionable outcomes, while also having the benefit of being able to provide a rich description or comprehensive understanding of the issue under examination (143,352). In using an applied qualitative policy research methodology the thesis incorporates features of interpretivist and pragmatist epistemologies (353). Aspects of interpretivism are demonstrated in the need to understand the context of the item or person under study (353). In developing this understanding, researchers aim to align their interpretations as closely as possible to participants accounts, but also recognise "that deeper insights can be obtained by synthesising, interlocking and comparing the accounts of a number of respondents" (353). Consequently, the researchers interpretations are synthesised and placed or situated within a broader context to assist understanding (353). Applied qualitative policy research also aligns with pragmatism, as choosing the most appropriate research methods for the research question under investigation is valued more than adhering to a particular epistemological position (353).

The research involved two key phases: the identification of primary care practice tools currently used in primary care practice and the search for and subsequent analysis of these tools using a three-stage document analysis process, including data analysis using the Framework approach. Figure 4.1 depicts the two stages outlined in more detail below. Framework analysis is specifically designed for applied qualitative research (143,351,352). Consequently, the analysis is targeted at providing 'answers', in that it creates greater understanding of the issues under investigation (143,351,352).

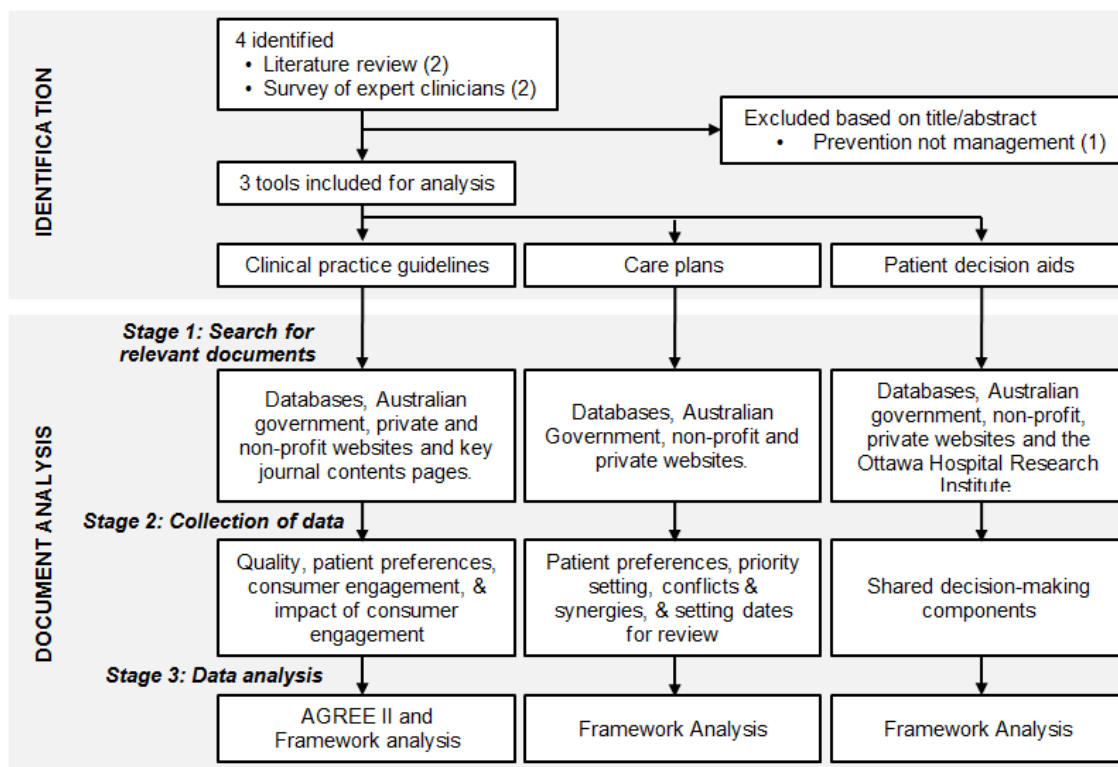


Figure 4.1 - Thesis methods

4.4 Identification

Three primary care practice tools were identified and included for analysis: clinical practice guidelines, care plans and PDAs. The processes used to identify these primary care practice tools were described in Chapter three. In summary, clinical practice guidelines and care plans emerged during a review of the literature and their importance confirmed by a survey of expert primary care clinicians. The expert primary care clinicians also identified PDAs as an additional tool warranting evaluation.

4.5 Document analysis

Document analysis was the methodology chosen for this thesis. Document analysis is a “systematic procedure for reviewing or evaluating documents – both print and electronic (computer-based and internet-transmitted) material” (354).

Documents can include but are not limited to diaries, catalogues, newspapers, guidelines, and reports (355). As with other qualitative analytical methods, document analysis seeks to provide meaning or greater understanding on the chosen topic (355,356). There are a number of advantages of using document analysis including:

- *Less costly and time consuming* than other qualitative research methods, as it does not require the information within the documents to be collected. Rather it requires the selection and analysis of data or documents (354).
- *Documents are generally in the public domain* making them easier to access as researchers rarely have to obtain authors' permission or seek ethical clearance (354,357).
- *A more stable and unobtrusive* research method as the documents do not change or react as a result of the researcher's presence as can happen with other qualitative research processes (354).

There are also some limitations with using document analysis such as: insufficient detail, when the data contained in the documents is not sufficient to answer the research question (354); and irretrievability, when some documents are unable to be collected (357,358). However, these were not perceived as outweighing the abovementioned benefits given the research questions in this thesis. Moreover, the benefit was that this method, which effectively involves secondary analysis, enabled a more comprehensive and detailed analysis of a large set of materials to be undertaken. Accordingly, document analysis was considered appropriate, given the aim of the thesis was to assess primary care practice tools, which are documentary sources. The document analysis process outlined by Sarantakos (359) was used for this thesis. The process involved three stages: 1) search for relevant documents; 2) collection of the data; and 3) analysis of the data.

Stage 1: Search for relevant documents

A separate bibliographic database search was conducted for each of the three primary care practice tools as shown in Table 4.1. Additional searches were conducted by hand searching key journals and published articles. Unpublished or grey literature searches were also conducted using relevant websites and online sources.

Initially, Australian primary care practice tools developed to support patients with multiple conditions were sought, but when this produced little to no results, the search was broadened. The modified search strategy examined tools developed to support those with single chronic conditions, but which acknowledged comorbid conditions

(i.e., medical conditions additional to the index condition (12)). For example, if a clinical practice guideline for diabetes also discussed depression it was included. By focusing on primary care practice tools for single chronic conditions, but which included comorbidities, a balance was achieved between too few documents (i.e., including only those addressing multiple conditions) and too many documents (i.e., including all those which addressed single chronic conditions). To be included the primary care practice tools had to address one of the chronic conditions classified under Australia's National Health Priority areas (360) including: cardiovascular health; stroke; cancer (colorectal, lung, breast and prostate); diabetes; depression; chronic kidney disease; asthma and chronic obstructive pulmonary disease; and arthritis and musculoskeletal conditions. Additional criteria included primary care practice tools relevant to a primary care setting; and applied to people aged 18 years and over.

This thesis focused on Australian primary care practice tools and as such, all of the identified tools were sought from Australian sources, with the exception of PDAs. None of the included PDAs were identified through Australian sources. Therefore an additional search was conducted through the 'Ottawa Hospital Research Institute' an international inventory of PDAs.

Table 4.1 - Stage 1 of the document analysis process

Stage	Primary care practice tools		
	Clinical practice guidelines	Care plans	Patient decision aids
Identification of relevant documents	Databases, Government, private & non-profit websites & key journals	Databases, Government and non-profit websites	Databases, Government, private & non-profit websites. Ottawa Institute

Stage 2: Collection of data

Copies of all relevant documents, 13 clinical practice guidelines, 16 care plan templates, and 21 patient decision aids were collected. All of the documents were available in the public domain and therefore ethics approval was not required to conduct the study. Although each of the tools were analysed to inform the broader research question, it was evident from the literature review and the initial scan of the documents that the primary care practice tools could not be assessed in the same way or using the same research question. Each primary care practice tool is designed for

a different purpose and therefore the way they contribute to chronic disease care differs. As a result, the research questions posed and the specific purpose of the document analysis was different for each of the three tools (see Table 4.2).

- The document analysis of *clinical practice guidelines* assessed the extent to which they: incorporate patient-preference recommendations; use consumer-engagement processes during development (and, if so, how and with what outcomes); and meet standard quality criteria for guidelines.
- The document analysis of *care plans* assessed whether care plans meet the needs of patients and clinicians managing multiple conditions. Drawing on key themes from the literature the study examined whether care plan templates support: the identification of patients’ preferences; priority setting; the identification of conflicts and synergies in care; and the review of patients’ goals and priorities.
- The document analysis of *patient decision aids* investigated the ways they acknowledge or consider multiple conditions in decision-making and their ability to contribute to or support the shared decision-making components outlined by Charles et al. (246).

Table 4.2 - Stage 2 of the document analysis process

Stage	Primary care practice tool		
	Clinical practice guidelines	Care plans	Patient decision aids
Collection of data and research question	13 Clinical practice guidelines Quality; incorporate patient-preference recommendations; use consumer-engagement processes; do these consumer engagement processes produce more patient-preference recommendations	16 Care plan templates Address/support the following processes: identifying patients’ preferences; setting priorities; identifying conflicts & synergies; & setting dates for care plan review	21 Patient decision aids How do they acknowledge multiple conditions and contribute to the shared decision-making components

Stage 3: Data analysis

Quality – AGREE II

The analysis of guideline quality was assessed using the AGREE II instrument (295,298,361,362). The AGREE II is a validated tool that assesses guideline quality according to 23 items listed under six domains: scope and purpose; stakeholder involvement; rigour of development; clarity of presentation; applicability; and editorial independence. For each domain, items are scored on a 7-point scale from seven (strongly agree) to one (strongly disagree). An overall domain score is calculated from the sum of individual items standardised as a percentage for each domain. There are currently no standardised instruments for assessing the quality of care plans and PDAs. Although a number of minimum standards or criteria have been proposed for PDAs, such as the International Patient Decision Aid Standards (IPDAS), a consensus has yet to be reached on what should be included (349).

Framework Approach

The qualitative data analysis was directed by the framework approach (143). The framework approach includes five steps: familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation (143).

1. *Familiarisation*. First the researcher becomes familiar with the documents to “get a feel of the data” as a whole, while simultaneously taking notes on key points or repeating themes (143,351,352).
2. *Identifying a thematic framework*. The notes taken during the familiarisation stage are used to develop an index thematic framework by which the data can be examined and referenced (143,351,352).
3. *Indexing*. The index framework is systematically applied to all the collected data. This is done by annotating the data with numerical codes from the index for future recovery and comparison (143,351,352).
4. *Charting*. The annotated data is extracted and placed in charts according to the appropriate part of the thematic framework to which they relate (143,351,352).

Therefore, charts are developed for each key theme with entries from various data sets (143,351,352).

5. *Mapping and interpretation.* Interpretation of findings involves using the charts to define concepts, map the range and nature of various phenomena and find associations between themes with a view to providing explanations for the findings (143,351,352). The process of mapping and interpretation is influenced by the research objectives as well as by the themes, which emerge from the data.

Framework analysis is specifically designed for applied qualitative research in which the objectives of the research are clearly established and shaped by specific information requirements (143,351,352). Although the process starts rather deductively, with pre-determined questions and objectives asked of the data, but still uses a grounded or inductive approach, as new themes or categories are continuously added to the thematic framework to reflect the data (351). The framework approach tends to be more structured than other qualitative methods, with the indexing and charting of themes allows for easy retrieval and comparison of data (143,351). The framework approach is most frequently used in health care settings, to investigate a range of research questions and document types (143,363). Of particular interest to this thesis, was a study by Hegarty and colleagues (298), who used the framework approach to investigate how depression guidelines could be made more relevant and applicable to primary care.

Table 4.3 - Stage 3 of the document analysis process

Stage	Primary care practice tools		
	Clinical practice guidelines	Care plans	Patient decision aids
Data analysis	AGREE II instrument & Framework analysis	Framework analysis	Framework analysis

4.6 Conclusion

This chapter outlined the aims of this thesis and the research methods used. The aim of this thesis was to evaluate the ability of primary care practice tools, developed to address chronic disease, to contribute to effective patient-centred multimorbidity care.

This chapter described the two-phase process used to address this aim: 1) the identification of primary care practice tools currently being used in primary care practice and 2) the search and analysis of these tools using a three-stage document analysis process. The three stages of the document analysis process were outlined, including a brief overview and rationale for use of the framework approach. The next chapter presents the first part of the thesis results in the form of a published research paper examining the first tool: clinical practice guidelines.

Chapter 5 Clinical practice guidelines

The previous chapter provided an overview of the methods used to find and analyse clinical practice guidelines, care plans, and PDAs. This chapter examines the first tool: clinical practice guidelines. The chapter presents a paper I co-authored during my thesis, titled “Incorporating patient preferences in the management of multiple long-term conditions: is this a role for clinical practice guidelines?” The paper was published in the Journal of Comorbidity. In line with the University of Queensland’s requirements, the article has been reproduced in standard formatting. In addition, the referencing has been changed to ensure consistency throughout the thesis and all references are now presented at the end of the thesis.

5.1 Abstract

Background: Clinical practice guidelines provide an evidence-based approach to managing single chronic conditions, but their applicability to multiple conditions has been actively debated. Incorporating patient-preference recommendations and involving consumers in guideline development may enhance their applicability, but further understanding is needed. **Objectives:** To assess guidelines that include recommendations for comorbid conditions to determine the extent to which they incorporate patient-preference recommendations; use consumer-engagement processes during development, and, if so, whether these processes produce more patient-preference recommendations; and meet standard quality criteria, particularly in relation to stakeholder involvement. **Design:** A review of Australian guidelines published from 2006 to 2014 that incorporated recommendations for managing comorbid conditions in primary care. Document analysis of guidelines examined the presence of patient-preference recommendations and the consumer-engagement processes used. The Appraisal of Guidelines for Research and Evaluation instrument was used to assess guideline quality. **Results:** Thirteen guidelines were reviewed. Twelve included at least one core patient-preference recommendation. Ten used consumer-engagement processes, including participation in development groups (seven guidelines) and reviewing drafts (ten guidelines). More extensive consumer engagement was generally linked to greater incorporation of patient-preference

recommendations. Overall quality of guidelines was mixed, particularly in relation to stakeholder involvement. **Conclusions:** Guidelines do incorporate some patient-preference recommendations, but more explicit acknowledgement is required. Consumer-engagement processes used during guideline development have the potential to assist in identifying patient preferences, but further research is needed. Clarification of the consumer role and investment in consumer training may strengthen these processes.

Key words: multimorbidity, comorbidity, primary care, patient preference, consumer participation, clinical practice guidelines

5.2 Introduction

Clinical practice guidelines targeting specific long-term conditions provide an evidence-based approach to treatment and management and can lead to improved patient care (364). However, the ability of guidelines to support complex care regimes for patients with multiple long-term conditions is the subject of some debate (27,62,295,301,303). The use of multiple disease-specific guidelines for individual patients is impractical and potentially hazardous (27,62,301,303).

Alternative approaches to addressing multiple conditions using clinical practice guidelines have been proposed and considered (301,365). These include the development of meta-guidelines, which address common clusters of co-occurring conditions (365) and greater cross-referencing between guidelines that are available electronically (301). Some single-condition-specific guidelines include recommendations addressing comorbid conditions (27); but the extent to which these guidelines also consider patient preferences is unclear.

While the debate about the adaption of clinical guidelines continues, a strong theme in the literature is the need to foster a patient-centred approach to the management of multimorbidities and take greater account of what patients want and value (67,250,308,309). Patient preferences – “the desirability of a health-related outcome, process or treatment choice” (250)– are considered important for the management of multiple and competing health conditions as the patient’s focus is shifted from disease-specific goals to more global cross-disease outcomes, such as maintenance of

physical function, symptom relief and quality of life (217,366). In essence, some recommendations may be acceptable to most patients, but others may be “preference-sensitive” and dependent on the patient’s views about outcome, process or choice (250). Researchers argue that incorporating patient preferences may mitigate the common criticism that guidelines developed to address single conditions are created for the “average patient” and do not acknowledge the complexity of individuals’ circumstances and preferences (67,367).

Krahn and Naglie (250) argue that the identification and incorporation of patient preferences in guideline development and implementation may improve the patient-centredness of clinical practice guidelines. They suggest that obtaining consumer input during guideline development may provide the foundation for greater systematic attention to patient preferences and support for patient decision-making in clinical consultations (250,310,311). Strategies to engage consumers in guideline development include providing drafts for feedback, involving consumers in guideline-development groups, conducting surveys of consumers or running consumer focus groups or workshops parallel to the clinical guideline development groups (308,313-315). Some of these approaches have been criticised for being passive or “tokenistic” (314,315), but broader evidence assessing their impact on guideline development is limited, with the exception of a recent study by Tong et al. (311), which found that active consumer engagement led to the identification of patient-centred recommendations not flagged by health professionals.

The widely used Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument (368) acknowledges the importance of consumer input by way of an item assessing whether the views and preferences of the target population (patients, public, etc.) have been sought. In Australia, for clinical practice guidelines to receive approval from the National Health and Medical Research Council (NHMRC) (286), they must “be developed by a multidisciplinary group that includes relevant experts, end users and consumers affected by the clinical practice guideline”.

While consumer engagement is strongly advocated, it is unclear how such engagement takes place or whether it leads to greater inclusion of patient-preference recommendations in clinical guidelines. More broadly, the extent to which clinical

practice guidelines encourage patient-centred care through the inclusion of patient preferences also requires further investigation.

5.3 Objectives

The objectives of this study were to review clinical practice guidelines that include recommendations for comorbid conditions to determine the extent to which they: (1) incorporate patient-preference recommendations; (2) use consumer-engagement processes in their development phase; and (3) meet standard criteria for guideline quality, particularly in relation to the stakeholder-involvement processes; and to consider whether consumer-engagement processes in guideline development result in greater integration of patient-preference recommendations.

5.4 Methods

Inclusion criteria

The study examined Australian clinical practice guidelines developed to support single chronic conditions, but which included recommendations for comorbid conditions (i.e., medical conditions additional to the index condition (12)).

All guidelines developed to support the National Health Priority areas were included: cardiovascular health; stroke; cancer (colorectal, lung, breast and prostate); diabetes; depression; chronic kidney disease; asthma and chronic obstructive pulmonary disease; and arthritis and musculoskeletal conditions (360). Additional selection criteria included: application in primary care settings; and applied to people aged 18 years and over. Guidelines are updated approximately every 6 years; therefore, the search, which began in 2012, focused on guidelines published between 2006 and 2012. The search was later extended to include publications up to January 2014.

Search strategy

Ovid MEDLINE, Web of Science (ISI), Embase, Cinahl, PsycINFO, Cochrane and PubMed, were searched using the terms: “guideline”, “Australia”, and “primary care”. Additional searches were conducted on Australian websites, including the Department of Health, NHMRC, National Institute of Clinical Studies, Royal Australian College of

General Practitioners and relevant non-profit organisation websites. The Medical Journal of Australia and the Internal Medicine Journal, key journals publishing clinical guidelines, were also searched.

Study selection

Figure 5.1 summarises the guideline selection process. In all, 4,866 citations were identified: 4,835 of these were excluded, based on title and summary. The full text of 31 guidelines was reviewed. Eighteen were excluded because they: did not provide recommendations for comorbid conditions; focused on prevention and detection; addressed out-of-scope conditions; targeted young people; were not applicable to primary care; or were outdated versions of an included guideline. Clinical updates or addenda were assessed in conjunction with the original guideline. Thirteen guidelines were included in the final analysis.

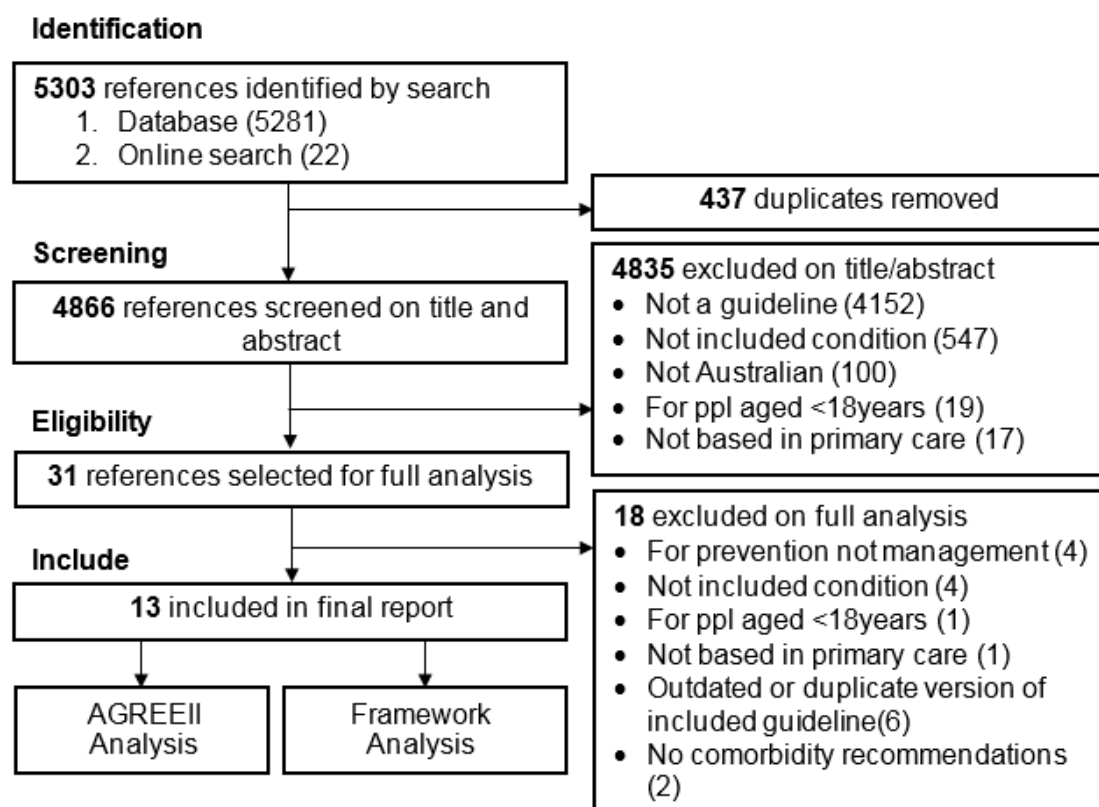


Figure 5.1 - Search strategy. AGREE, Appraisal of Guidelines for Research and Evaluation

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Data analysis

Data analysis was conducted in three stages in accordance with the three main aims of the study. Stages 1 and 2 involved document analysis and Stage 3 involved a quality assessment using AGREE II. Ethics approval was not required as all data were drawn from published materials available in the public domain.

Stage 1

Document analysis of the guidelines was conducted to identify recommendations that incorporated patient preferences. Clinical practice guidelines vary in complexity and size, ranging in length from ten to several hundred pages and frequently provide a list of core recommendations or essential points, which are then further explained throughout the document by “supporting evidence statements”. The core recommendations and supporting evidence statements were analysed to identify recommendations that focused on patient preferences.

Analysis was directed by the framework approach (352), which involved five steps (familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation). Detailed review of the guidelines ensured familiarity with content and enabled the identification of key themes that aligned with the notion of patient preferences. An index framework that defined key themes including and consistent with patient preferences (e.g., “actively involved” recommended patients be engaged, involved or given the opportunity to participate in the decision-making process) was developed and used to code content. Relevant passages from each guideline were extracted in accordance with the themes and placed in charts to assist with mapping and interpreting the data.

Three guidelines provided recommendations and evidence statements for both children and adults (369-371). Recommendations and evidence statements that focused only on children were excluded from the analysis.

Stage 2

Document analysis using the framework approach was also conducted to assess the consumer-engagement processes used during guideline development. Explanation of

guideline-development processes, including consumer engagement, was typically described at the beginning or end of the guideline, or occasionally in a separate report. All of this material was reviewed. A thematic framework was developed from key themes identified in the document analysis and from the literature (e.g., “training and education”). This framework was used to code guideline content.

Stage 3

An assessment of guideline quality was conducted using the AGREE II instrument (368). AGREE II is a validated tool that assesses guideline quality according to 23 items listed under six domains: scope and purpose; stakeholder involvement; rigour of development; clarity of presentation; applicability; and editorial independence (27,368). For each domain, questions are scored on a 7-point scale from seven (strongly agree) to one (strongly disagree). An overall domain score was calculated from the sum of individual items standardised as a percentage for each domain (368). Guidelines were assessed as “good quality” (27) if they scored above 60% on all of the AGREE II domains. Two reviewers (C.E.Y. and K.S.B.) independently scored each guideline. The AGREE II concordance calculator (372) confirmed an acceptable level of agreement between the reviewers.

In line with the study aims to examine consumer-engagement processes, particular attention was paid to the stakeholder domain in the AGREE II, which includes three items: 1) guideline development includes individuals from all relevant professional groups; 2) the views and preferences of the target population (e.g., patients, public) have been sought; and 3) the target users of the guideline are clearly defined (368).

5.5 Results

Thirteen guidelines met the inclusion criteria: four guidelines for cardiovascular health (373-376); one guideline for stroke (377); one guideline for prostate cancer (378); two guidelines for diabetes mellitus (369,370); two guidelines for musculoskeletal health (379,380); two guidelines for respiratory conditions (371,381); and one guideline targeted multiple chronic conditions focusing on the prevention and management of chronic kidney disease for people with type 2 diabetes (382). Eleven guidelines were developed by non-profit organisations (369-371,373-378,381,382)

and two guidelines by the Royal Australian College of General Practitioners (379,380). Five guidelines were approved by the NHMRC (369,377,379,380,382). The guidelines ranged in length from 19 to 288 pages.

Incorporating patient preferences

Across the 13 guidelines, a total of 1,076 core recommendations were reviewed, of which 49 (4.5%) were identified as patient-preference-related recommendations (see Table 5.1). The number of total core recommendations ranged from 18 to 335 for individual guidelines and the number of core patient-preference-related recommendations ranged from 0 to 16 (0–12.2 % of the total core recommendations). A further 108 statements, directing clinicians to consider patient preferences, were identified in the supporting evidence statements (range 0–25).

Examination of both the guideline recommendations and supporting evidence statements revealed four key themes: patient preferences; care plans; actively involved; and risks and benefits (Table 5.1). General introductory comments or “blanket statements” (67) emphasising the need to consider individuals’ views were also identified.

Twelve guidelines explicitly asked for patient preferences to be considered by the clinician in relation to treatment, interventions, or outcomes (369-371,373-381). For example, the guideline on type 1 diabetes stated, “Choice of device should be made on the basis of ease of use, patient preference/suitability and overall cost” (369).

Care plans, also referred to as management, action and treatment plans, were highlighted by all but two guidelines (376,382) as a means of working collaboratively with patients to identify their preferences and goals for care. Care plans were the most frequently flagged core patient-preference-related recommendations (range 0–13) and were also commonly discussed in the supporting evidence statements (range 2–6) (see Table 5.1). For example, the guideline for rheumatoid arthritis stated the following: “general practitioners should aim to engage patients with RA [rheumatoid arthritis] in individualized care plans that include treatment goals and objective measures of disease” (379).

Seven guidelines (369-371,376,377,379,381) called for patients to be actively involved or engaged in decision-making and as a member of the healthcare team, as illustrated by this example from the guideline for type 2 diabetes, “Encourage patients to participate and take an active role in the management of their diabetes” (370).

Five guidelines (371,375,377,378,380) suggested outlining the risks and benefits of recommended treatments to enable patients to make an informed decision based on their treatment preferences, as demonstrated by the guideline for prostate cancer:

Toxicities should be considered in the context of what is important to each individual patient, as for some patients impairment of sexual function may have a significant impact on their quality of life and overall adjustment, as well as affecting adversely those close to them (378).

Eleven guidelines provided blanket statements (369-371,374-380,382). These were statements provided at the beginning of the document, instructing clinicians that all recommendations should be individualised to consider the needs, preferences and context of each patient. For example, the chronic kidney disease in type 2 diabetes guideline, the only guideline that did not include any core patient-preference-related recommendations, began with the following overarching statement:

This document is a general guide to appropriate practice, to be followed subject to the clinician’s judgement and the patient’s preference in each individual case. The guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of development (382).

Table 5.1 - Appraisal of the included guidelines according to the patient-preference framework.

Guideline	Total core recommendations	PPR (% total)	PPR (ES)			
			Patient preferences	Care plans	Actively involved	Risks and benefits
Acute coronary syndromes (374)	44	2 (4.5)	1 (1)	1 (2)	0 (0)	0 (0)
Asthma (371)	158	3 (1.9)	0 (7)	3 (13)	0 (3)	0 (2)
Chronic heart failure (376)	80	1 (1.2)	1 (3)	0 (0)	0 (3)	0 (0)
Chronic kidney disease in type 2 diabetes* (382)	18	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Chronic obstructive pulmonary disease (381)	34	2 (5.9)	0 (4)	1 (6)	1 (0)	0 (0)
Coronary heart disease (375)	44	1 (2.3)	1 (0)	0 (3)	0 (0)	0 (1)
Early rheumatoid arthritis* (379)	30	2 (6.7)	0 (3)	1 (4)	1 (1)	0 (0)
Hip and knee osteoarthritis* (380)	34	2 (5.9)	0 (1)	2 (2)	0 (0)	0 (1)
Hypertension (373)	25	3 (12.0)	0 (2)	3 (5)	0 (0)	0 (0)
Locally advanced and metastatic prostate cancer (378)	57	7 (12.2)	2 (2)	0 (2)	0 (0)	5 (3)
Stroke* (377)	335	16 (4.8)	1 (3)	13 (6)	0 (6)	2 (4)
Type 1 diabetes* (369)	132	8 (6.0)	2 (3)	4 (3)	2 (0)	0 (0)
Type 2 diabetes (370)	85	2 (2.4)	0 (2)	1 (5)	1 (2)	0 (0)
Total	1,076	49 (4.5)	8 (31)	29 (51)	5 (15)	7 (11)

*Received National Health and Medical Research Council (NHMRC) approval. ES, evidence statements; PPR, patient-preference-related recommendations.

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Guideline quality

The AGREE II domain scores for each guideline are presented in Table 5.2. Across all guidelines, the applicability domain (i.e., “the guideline outlined potential barriers and facilitators to its implementation in practice, strategies to improve uptake, and resource implications”) received the lowest domain scores, while clarity of presentation (i.e., “are the recommendations specific and easily identifiable, and are the various options clearly presented”) received the highest domain scores (368). Clarity of presentation was the only domain for which all guidelines scored above 60 %. The five guidelines approved by the NHMRC consistently scored higher across all domains (369,377,379,380,382). Within this group, the guideline for stroke was the only guideline to score above 60 % in all domains (377). Of particular interest was the stakeholder involvement domain. Six guidelines scored above 60 % for this domain (369,377-380,382). Closer examination of the individual items within this domain revealed that 11 guidelines scored better (average between the two reviewers above 4.2 (60 %) on a 7-point rating scale) for the first item: “included individuals from all relevant professional groups in the development group” (369,371,373,374,376-382); and the third item: “clearly defined target users” (369-371,374-380,382). In contrast, only four guidelines scored above 60 % (369,377,378,382) on the second item “the views and preferences of the target population (patients, public, etc.) have been sought”. To score highly on this item, guideline developers needed to outline the strategies used to gain consumer perspectives, report the outcomes of this process and describe how this was used to inform the guideline.

Table 5.2 - Individual standardised Appraisal of Guidelines for Research and Evaluation (AGREE) II domain scores for the guidelines studied.

Guideline	Year	Scope and purpose (%)	Stakeholder involvement (%)	Rigour of development (%)	Clarity of presentation (%)	Applicability (%)	Editorial independence (%)
Acute coronary syndromes (374)	2006	67	58	19	69	25	33
Asthma (371)	2006	44	50	20	67	29	0
Chronic heart failure (376)	2011	53	50	14	72	13	79
Chronic kidney disease in type 2 diabetes* (382)	2009	89	86	75	72	42	38
Chronic obstructive pulmonary disease (381)	2011	53	50	17	75	27	4
Coronary heart disease (375)	2012	31	39	11	69	27	63
Early rheumatoid arthritis* (379)	2009	86	78	72	83	31	25
Hip and knee osteoarthritis* (380)	2009	81	78	68	81	21	46
Hypertension (373)	2010	0	25	5	86	23	38
Locally advanced and metastatic prostate cancer (378)	2010	64	81	78	83	23	54
Stroke* (377)	2010	83	86	74	78	71	88
Type 1 diabetes* (369)	2011	92	81	76	78	54	46
Type 2 diabetes (370)	2012	53	47	8	72	40	0

%, overall score of the two reviewers calculated according to the AGREE II scoring system. Maximum AGREE II score 100%; COPD-X, chronic obstructive pulmonary disease and exacerbations. *Received National Health and Medical Research Council (NHMRC) approval.

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Consumer-engagement processes

The thematic framework developed for this phase of the analysis covered four key themes: consumer involvement in the development group; clarification of this role; provision of drafts for public review; and training and education. Across the guidelines, only two methods of engagement were reported: involving consumer representative(s) in guideline-development groups; and providing drafts for public review. Seven guidelines used both methods (369,377-382), three provided drafts for public review only (373,375,376), and three did not report their methods of engagement (370,371,374) (see Table 5.3).

Most guideline-development groups included one or two consumer representatives recruited from relevant non-profit organisations, with the exception of the guideline for stroke (377), which included three consumers, and the guideline for chronic kidney disease in type 2 diabetes (382), which included five consumers, one for each of the five smaller expert advisory groups forming the guideline-development group (see Table 5.3). None of the guidelines reported training and education of consumers. Seven guidelines reported the broad role of the development group (369,377-382); only one provided a specific explanation of the consumer's role (382).

Consumer representatives were selected and appointed by Diabetes Australia for each EAG [Expert Advisory Group] to ensure the consideration of people with type 2 diabetes with respect to their acceptability of the proposed guideline recommendations (382).

Ten guidelines provided drafts for public review (369,373,375-382), but the extent to which this engaged consumers was not always possible to ascertain. Four guidelines provided an explanation of the results of the public-review processes, outlining how comments were incorporated or changes made (369,377,378,382). The comments addressed a range of issues including guideline structure, chapter size, editing, and clarification of recommendations and supporting evidence statements. Six guidelines did not clarify the extent or nature of the feedback process (373,375,376,379-381). For example, the guideline on osteoarthritis stated, "Feedback collected from the survey and independent submissions were collated and addressed by the Working Group" (380).

The study also considered whether consumer-engagement processes in guideline development resulted in greater integration of patient preferences. There was some suggestion that more extensive use of consumer-engagement processes (i.e., both provision of drafts for public review and inclusion of consumers in the development group) was associated with greater incorporation of patient-preference recommendations. Six of the seven guidelines that produced the greatest proportion of core patient-preference recommendations (as shown in Table 5.3) used both consumer-engagement (369,377-381). However, the guideline that reported the most comprehensive consumer-engagement processes (i.e., provided a specific explanation of the consumers role, included five consumers in the development group, and stated how the public review feedback was incorporated) (382) did not explicitly include recommendations targeting patient preferences. Rather a blanket statement was provided at the beginning of the document calling for patient preferences to be considered when applying the guideline to individual patients.

Table 5.3 - Appraisal of the included guidelines according to the consumer-engagement framework.

Guideline	Consumers included in development group (n)	Role description	Provision of drafts for public review	Training and education
Acute coronary syndromes (374)	NR	NR	NR	NR
Asthma (371)	NR	NR	NR	NR
Chronic heart failure (376)	NI	NR	Yes	NR
Chronic kidney disease in type 2 diabetes* (382)	5	Broad group and consumer specific	Yes	NR
Chronic obstructive pulmonary disease (381)	1	Broad group description	Yes	NR
Coronary heart disease (375)	NI	NR	Yes	NR
Early rheumatoid arthritis* (379)	1	Broad group description	Yes	NR
Hip and knee osteoarthritis* (380)	1	Broad group description	Yes	NR
Hypertension (373)	NI	NR	Yes	NR
Locally advanced and metastatic prostate cancer (378)	3	Broad group description	Yes	NR
Stroke* (377)	2	Broad group description	Yes	NR
Type 1 diabetes* (369)	2	Broad group description	Yes	NR
Type 2 diabetes (370)	NR	NR	NR	NR

*Received National Health and Medical Research Council (NHMRC) approval. NI, not included; NR, not reported.

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5.6 Discussion

All 13 of the reviewed guidelines acknowledged patient preferences, either explicitly or indirectly through related themes, but their location and prominence varied, appearing as core recommendations, supporting evidence statements and/or blanket statements. Ten guidelines reported some form of consumer engagement during their development. The guidelines that employed the most extensive consumer-engagement processes (e.g., both provision of drafts for public review and inclusion of consumers in the development group) were among those with the greatest proportion of patient-preference recommendations. Overall, the quality of guidelines was mixed; the lack of evidence of strategies to incorporate the views and preferences of consumers saw many fall short on stakeholder involvement.

Quantifying the extent to which guidelines incorporate patient preferences was not always straightforward, as some recommendations and supporting evidence statements were less explicit in their request that patient preferences be considered. Similarly, patient preferences were more frequently presented in supporting evidence statements than in core recommendations. Presenting patient preference information in supporting evidence statements may undermine the potential of guidelines to support a more systematic discussion of patient preferences in primary care as it risks this information being overlooked by time-poor clinicians. In practice, clinicians and patients frequently identify differences in their preferences, priorities and goals for care when managing multiple conditions; if not discussed and worked through, these differences can lead patients to disengage from clinical advice (135). Clearer and more frequent flagging of patient-preference-related recommendations in guidelines is needed to draw attention to patient preferences in clinical consultations. Consistently identifying these recommendations and facilitating their discussion is one way in which guidelines might support a more systematic approach to patient-centred care (250,311).

Overall, more extensive use of consumer-engagement processes in guideline development was linked to a greater proportion of core patient-preference recommendations; however, closer consideration of the consumer-engagement processes used across the guidelines highlights shortfalls in practice. Ten guidelines engaged consumers in public-review processes. These typically passive methods have been criticised for limiting consumers'

ability to actively engage and provide valuable input (311,314,383). Seven guidelines engaged consumers in development groups, but there was little evidence of the provision of training or specific role descriptions for consumers.

Research suggests that unless guideline developers provide consumers participating in development groups with education and training, a clear explanation of their role, and sufficient support (e.g., more than one consumer representative), their involvement is likely to be tokenistic and relatively ineffective (313-315). In support, Tong et al. (311) found that, when adequately assisted and engaged, consumers were able to contribute meaningfully to guideline development by identifying topics and outcomes (e.g., day-to-day management and overall illness experience) not identified by health professionals. This experiential input is the cornerstone of consumer engagement: it extends the clinicians' focus from disease to incorporate the patients' social context, experiences, and feelings (384). In short, without effectively engaging consumers, guideline developers risk producing guidelines that may not fully address the topics and outcomes of importance to patients, particularly those experiencing multiple conditions (311,314,384).

Our findings, like those of Vitry and Zhang (295), demonstrate the role of NHMRC standards in contributing to the development of higher quality guidelines in Australia. Currently, the inclusion of a consumer representative in guideline development groups is a NHMRC standard (286), but our findings are consistent with other research suggesting this approach may be of limited value when used in isolation and without proper support of consumers (314,315). Further clarification of consumer-engagement processes and their purpose could be driven by a revision of the NHMRC standards for clinical practice guidelines (286).

The limitations of this study need to be acknowledged. An extensive search was conducted, but it is possible that eligible guidelines were missed as, unlike other countries, such as the UK (385), there is no centralised guideline-development organisation in Australia. The analysis conducted for this study was based on all publicly available information including published guidelines and their supporting documents. It is possible that more extensive consumer-engagement processes were conducted, but not reported. Since standardised quality-assessment practices, such as AGREE II, rely on published materials, there is a clear need for guideline developers to provide full information that accurately reports all elements of the development process.

5.7 Conclusion

Clinical practice guidelines appear to be taking important steps towards supporting clinicians and patients through the incorporation of patient-preference recommendations, but there is scope for more explicit acknowledgement. Consumer-engagement processes used to develop guidelines have the potential to contribute to the identification of patient preferences, but further research is needed to investigate the contribution and impacts of these processes. Clarification of the consumer role and investment in consumer training may help to strengthen these processes and further support a systems-based approach to patient-centred care for people with multiple chronic conditions.

Conflicts of interest

The authors declare that they have no competing interests.

Funding

This study was not funded.

Chapter 6 Care plans

The previous chapter presented a research paper examining the first primary care practice tool: clinical practice guidelines. This chapter will present research examining the second primary care practice tool: care plans. The chapter presents a paper I co-authored during my thesis, titled “Are care plans suitable for the management of multiple long-term conditions?” The paper has been submitted to the Journal of Comorbidity and is currently under review. In line with The University of Queensland’s requirements, the article has been reproduced in standard formatting. In addition, the referencing has been changed to ensure consistency throughout the thesis and all references are now presented at the end of the thesis.

6.1 Abstract

Background: Care plans have been part of the primary care landscape in Australia for almost two decades. With an increasing number of patients presenting with multiple chronic conditions, it is timely to consider whether care plans meet the needs of patients and clinicians. **Objectives:** To review and benchmark existing care plan templates that include recommendations for comorbid conditions, against four key criteria: patients’ preferences; setting priorities; identifying conflicts and synergies; and setting dates for review. **Design:** Document analysis of Australian care plan templates published from 2006-2014 that incorporated recommendations for managing comorbid conditions in primary care. **Results:** Sixteen templates were reviewed. All of the care plan templates addressed the patient preference criteria, but this was not done comprehensively. Only three included priority setting processes. None assisted in the identification of conflicts and synergies between conditions. Fifteen required dates for reviewing the plan be provided. **Conclusions:** Care plans are a well-used tool in primary care practice but their current format perpetuates a single-disease approach to care, which works contrary to their intended purpose. Restructuring care plans to incorporate shared decision-making and attention to patient preferences may assist in shifting the focus back to the patient and their care needs.

Key words: multimorbidity, comorbidity, primary care, patient preference, consumer participation, patient care planning

6.2 Introduction

Care plans, widely advocated as mechanism to individualise chronic disease care (335), are intended to engage primary care clinicians and patients in an examination of clinical evidence and a consideration of patients' preferences, needs and values to inform and facilitate care planning and shared decision-making (318,335). Empirical evidence indicates care plans can: enhance self-management practices (386); increase adherence to guideline recommendations (4); improve processes and clinical outcomes (387); and reduce or delay hospitalisation (388). However, the effectiveness of care plans relies on the care planning processes used and the clinician's and patient's desire and ability to participate in these processes (210,276,321).

Care plans in Australia

Care plans have been used across Canada, Germany, the United Kingdom, the United States, and Australia (335). In Australia, the introduction of the Enhanced Primary Care (EPC) package in 1999 signalled a shift to care planning and a significant change in approach to chronic disease management (4,39). For the first time primary care clinicians could be reimbursed by Medicare, Australia's universal health insurance scheme, for time spent developing multidisciplinary care plans for patients with chronic and complex care needs (4,39). In 2005, the EPC was expanded and renamed the Chronic Disease Management (CDM) items, but care plans remained central to the policy (4,39).

Care plan templates designed to meet the minimum requirements set by Medicare (see Box 1) and assist with the development of General Practice Management Plans (GPMP) (i.e., care plans involving GPs) and Team Care Arrangements (TCA) (i.e., care plans led by the GP with involvement from a multidisciplinary team of health professionals) have been developed by governments, non-profit, and professional organisations (389). The use of templates is not mandatory, clinicians can develop their own plan format, but Bolger-Harris et al. (389) found most clinicians prefer templates because they are quick, adaptable, increase the chance of reimbursement by Medicare, and provide prompts and checklists for care.

<i>A General Practice Management Plan (GPMP) must describe:</i>
--

- the patient's health care needs, health problems and relevant conditions;
- management goals with which the patient agrees;
- actions to be taken by the patient;
- treatment and services the patient is likely to need;
- arrangements for providing this treatment and these services; and
- arrangements to review the plan by a date specified in the plan.

A Team Care Arrangements (TCAs) must describe:

- treatment and service goals for the patient; and
- treatment and services that collaborating providers will provide to the patient; and
- actions to be taken by the patient; and
- arrangements to review by a specified date

Box 6.1 - Medicare requirements for General Practitioner Management Plans and Team Care Arrangements (324)

Despite this preference for care plan templates GPs are critical of their ability to “cater for patients with multiple chronic diseases” (389). Adding weight to these concerns, the Royal Australian College of General Practitioners (RACGP) (60) questions the ability of care plans to meet the needs of patients and GPs managing multiple chronic conditions. The RACGP argues the predominant focus on the provision of single-disease care is the most serious gap in Australia's primary health care system, and suggests the chronic disease management items only add to this issue, as the “needs of complex patients with advanced disease or multiple diseases are not acknowledged” (60).

Care plans in a multimorbidity context

Empirical evidence informing the development and application of care planning for patients with multiple conditions is needed (335). A recent Cochrane review of 15 randomised trials examining personalised care planning for adults with chronic conditions, found no studies that explicitly examined whether care plans led to improved physical, psychological, or subjective health, or improved capabilities for self-management for patients with multiple conditions (335). Acknowledging the limited evidence informing multimorbidity care (16,62), researchers have increasingly argued in favour of approaches that move beyond a focus on disease (12,141,248,250,309). These arguments are grounded within a patient-centred approach, but also stem from empirical work identifying the impractical and potentially hazardous outcomes that can arise when disease-centric interventions that target single

conditions (such as clinical practice guidelines) are applied across multiple conditions (62,303). Care plans have been emphasised as a mechanism for enhancing the provision of multimorbidity care by supporting patient-centred care (12,21,62,141,248,335), although in practice patients report diverse experiences and different levels of engagement in care planning processes (275,321,390,391). To achieve greater consistency in care planning and the resultant care plan broader system level interventions are required (136,392).

A recent study by Morgan et al. (136) trialling care planning for patients with depression, diabetes, and/or coronary heart disease, demonstrates the potential utility of care plans in a multimorbidity context. The trial involved significant investment, with multiple system level changes including: merging evidence-based guidelines; training primary care practice staff in goal setting and problem solving; changes to practice based information technology; and automating recall for review (136,392). A multiple condition care plan template, informed by clinical practice guidelines, was developed to support clinicians and patients to record and track changes across clinical data for all their conditions. The template required extensive review of the patient's goals and preferences along with barriers to achievement; the development of multidisciplinary care arrangements; and established prompts for guideline-recommended checks (136). In comparison with usual care, patients achieved significant clinical improvements in depression and cardiovascular disease risk (136). Guideline-recommended checks were also more frequently performed, multidisciplinary care arrangements and communications were well structured and managed, and patients' goals were comprehensively monitored (136).

Morgan et al. (136) concluded that many factors contributed to the success of the trial, but the identification of patients' goals and priorities, and establishing systems to ensure regular review appeared central (136). These findings provide preliminary evidence for a patient-centred approach that draws on care planning to enhance multimorbidity care (12,141,248,393), while also highlighting the level of system level investment required to support such an approach (136). Systems level investment to support the management of multiple conditions is clearly essential, but at a time of fiscal constraint this is a significant challenge. Major health system reform is difficult and costly to achieve, with most reform arising from incremental change to existing practice (39,40). Examining whether current tools that support practice, such as care plan templates, are fit for purpose in the context of multimorbidity care is timely.

Examining the potential of Care plan templates

An examination of care plans and their potential utility for multimorbidity care requires careful consideration of key criteria integral to patient-centred care and shared decision-making. Identifying an empirical evidence base informing appropriate assessment criteria is an obvious challenge, but a number of leading agencies and authors in the field, such as the American Geriatric Society Expert Panel (AGS) (141), Muth et al. (248) and others (190,393,394) have proposed key principles to guide the management of multiple conditions within primary care. These principles, developed through extensive literature reviews and in consultation with expert stakeholders (141,248), emphasise the need for: establishing patients' preferences, setting priorities, identifying conflicts and synergies and establishing review processes. In the absence of a solid evidence base, these components provide a preliminary basis for evaluating whether care plans support the management of multiple chronic conditions.

Patients' Preferences

Understanding the health issues, treatments, and agreed actions of significance to the patient, that is, his or her '*preferences*' (250) acknowledges there is rarely a single correct treatment option when managing multiple conditions (244). Moreover it recognises that in managing multiple conditions a patient's focus often shifts from disease-specific goals to more global cross-disease outcomes, such as maintenance of physical function, symptom relief and quality of life (394). Emphasis on shared decision-making and establishing patients' preferences stems from the need to manage the misalignment that can arise between the preferences and goals of patients and those of their clinician (135,141,219,248,250). This misalignment may lead patients to disengage from clinical advice thereby undermining shared decision-making processes (135). Despite the increasing emphasis on shared decision-making, and taking greater account of what patients want and value (44,54), its benefits have not been extensively examined (260).

Setting priorities or goals

Overly complex management regimens, conflicts between medications and conditions, and excessive treatment burden are key challenges arising from the management of multiple conditions (19,21,224). Patients overwhelmed by the burden of treatment may not adhere

to prescribed treatments (190). In response, The AGS (141) and Muth et al. (248) suggest a patient-centred approach acknowledges that *priorities or goals must be set* in line with the patient's preferences (141,248). In doing so, recognition must also be given to whether patients wish to participate in care decisions (9,395).

The challenges associated with setting priorities are well documented, with clinicians frequently citing limited resources and the narrow evidence base informing the management of multiple conditions as central to this problem (19,394). Clinical practice guidelines, the main drivers of evidence based care in primary practice, do not account for multimorbidity. Therefore the information needed to inform goal setting discussions, such as numbers needed to treat (NNT) and harm (NNH), is often absent or conflicting for patients with multiple conditions (12,62,141,393). Despite this, evidence suggests patients with multiple conditions can still engage in shared priority or goal setting discussions with their clinician, by ranking which broad cross disease goals are of most importance to them (394). Identifying the goals of most importance to the patient is a first step to directing guideline-based disease-specific care (141,248,393).

Conflicts and synergies

The identification of conflicts and synergies is a central part of care planning for patients with multiple conditions designed to help patients accommodate and avoid being overwhelmed by new conditions (135). When managing multiple chronic conditions, clinicians often adopt an "additive-sequential model", in which they examine conditions individually with the most pressing addressed before the consultation ends and the remainder held over until the next consultation (21). This process, perpetuated by current Medicare funding arrangements and clinical practice guidelines, reinforces the centrality of individual diseases rather than consideration of conflicts or congruence between them. This can undermine the clinical management of multiple conditions, as it may fail to support patients who place greater importance on function than disease (122). Opportunities to take a more personalised and holistic view of the patient's care (83) and reduce patient burden through processes such as de-prescribing, may also be lost (396).

Regular review

The AGS (141) and Muth et al. (248) highlight the need for constant review of patients' goals, priorities and preferences. This is in keeping with the view that care plans should be living, dynamic documents that change over time and at pivotal points (such as the diagnosis of a new condition (135)), to reflect and support the needs of patients (54,335). Regular review of patients' goals, priorities and preferences ensures care continues to be targeted at the issues of importance and relevance to patients (136). Review also serves as a means to monitor goals and ensure patients are supported to work through any barriers that undermine progress (136). Setting a date for review of the care plan is a Medicare requirement (see box 1), but the scheduled fee for reviewing a GPMP plan is significantly lower (\$72.05) than that for preparing one (\$144.25) [44].

In summary, recent evidence (136) suggests care plans may have the potential to move beyond the management of single conditions and support the provision of multimorbidity care, but this process must be underpinned by key criteria integral to patient centred care and shared decision-making. The purpose of this study is to review and benchmark existing care plan templates, which include recommendations for comorbid conditions, against these four criteria: patients' preferences, setting priorities, identifying conflicts and synergies and establishing review processes.

6.3 Methods

OvidMedline, Web of science (ISI), Embase, Cinahl, PsycINFO, Cochrane and Pubmed, were searched for care plan templates using the following terms: 'patient care planning', 'case management', 'care plan', and 'Australia'. An extensive search of the grey literature was also conducted using Australian websites including: the Department of Health, Department of Veterans Affairs, Primary Health Networks, Royal Australian College of General Practitioners (RACGP) and relevant non-profit organisations websites.

The study sought disease-specific (i.e., they include prefilled data related to the specified condition) and generic (i.e., they include general headings but no prefilled information) care plan templates. To be included a template needed to acknowledge comorbid conditions (e.g., if a care plan template for diabetes also discussed depression it was included). Templates which acknowledged comorbid conditions were the focus as they were more

likely to recognise and support the needs of patients with multiple conditions. Disease-specific templates were also restricted to those that addressed a chronic condition classified as Australia’s National Health Priority areas (360): cardiovascular health; stroke; cancer (colorectal, lung, breast and prostate); diabetes; depression; chronic kidney disease; asthma and chronic obstructive pulmonary disease; and arthritis and musculoskeletal conditions. Additional criteria included: care plan templates for development in primary care practice settings; and applied to people aged 18 years and over.

Figure one summarises the template identification process. After combining the results of all searches and deleting duplicates, 1757 citations remained. Citations were screened individually based on title and summary; 1720 were excluded at this point. The full text versions of 37 care plan templates were screened for eligibility. Twenty-one were excluded because they did not consider co-occurring conditions or were not designed for use in primary care.

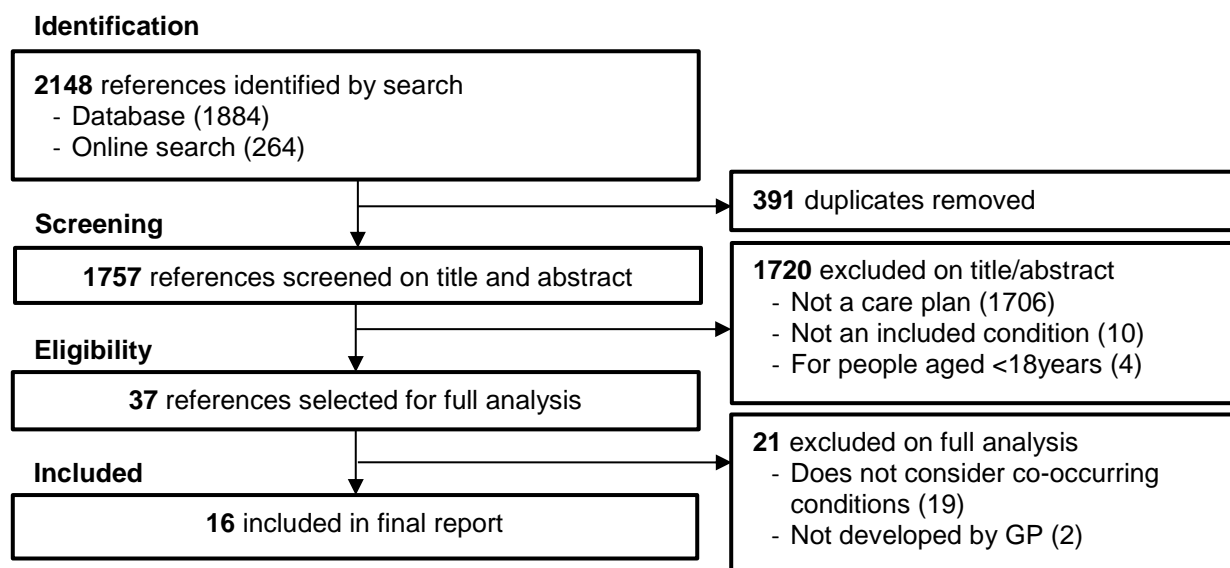


Figure 6.1 – Search strategy care plan

Data analysis

Document analysis guided by the framework approach was used to review the care plan templates. The framework approach, which involves five steps (familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation) (352), was chosen because of its emphasis on applied research that seeks to provide ‘answers’ to clearly established aims (352).

To assess the ability of care plan templates to support the management of multiple chronic conditions, the four criteria relevant to care planning for patients with multiple conditions (patient preferences; priority setting; identification of conflicts and synergies between conditions; and review) were used to construct a data-extraction index or thematic framework (Table 6.1). The thematic framework was used for coding, with relevant passages from each care plan template extracted in accordance with identified themes and placed in charts to assist with mapping and interpreting the data.

Table 6.1 - Care plan framework themes

Theme	Description
Patient preferences	Health issues identified by patients, patients' preferences for management goals, process or treatment choice.
Priority setting	Processes to assist clinicians and patients to prioritise health issues/conditions, management goals, outcomes, treatments, or services.
Identification of conflicts/barriers & synergies/enablers	Identification of: conflicts between conditions, medications and management strategies; barriers to following the care plan; commonalities between conditions, medications and management strategies; and enablers to following the care plan.
Review	A date for reviewing patient goals and priorities.

6.4 Results

Sixteen care plan templates (397-412), thirteen designed for specific diseases (397-403,406,408-412) and three generic ones (404,405,407) developed to cover a range of conditions met the inclusion criteria. Of the thirteen disease-specific templates: four were for cardiovascular health (397,402,408,410); four for musculoskeletal conditions (399-401,403); two for diabetes (411,412); one for depression (398); one for COPD (409); and one for mental health (406). Seven care plan templates were GPMPs (398,400,401,404,406,408,412), four were TCAs (399,403,405,410), four were combined GPMPs and TCAs (397,402,409,411), and one was for the Coordinated Veterans Care (CVC) Program (407). The CVC Program is an initiative of the Department of Veterans' Affairs, which provides reimbursement to primary care clinicians who develop care plans for veterans and eligible relatives with one or more chronic conditions or complex care needs (413). Ten care plan templates were developed by Primary Health Networks (formerly Medicare Locals) (397-403,409-411); three by the Department of Health (404-406); one by

the Department for Veterans Affairs (407); one by the Royal Australian College of General Practitioners (412); and one by the Heart Foundation (408).

All of the disease specific templates (397-403,408-412), with the exception of the GPMP for Mental Health (406), included some pre-filled information (see Table 6.2). This information, drawn from clinical practice guidelines, was provided under each of the care plan headings or components for the specific condition. For example, the GPMP for Depression (398) included pre-filled information on the patient's problems, goals, required treatments and services including patient actions, and arrangements for treatments/services for depression. Pre-filled data on the patient's health issues, corresponding goals, and treatments and agreed actions was organised under similarly labelled subheadings across the disease specific templates: general, lifestyle, biomedical, medication, and psychosocial. The generic templates (404,405,407) did not include pre-filled information, they provided the headings (e.g., health issues, goal, required treatments and agreed actions) under which primary care clinicians and patients can record information (see Table 6.3). The GPMP for Mental Health was the only disease-specific template, which did not include pre-filled data (406). The template includes many of the same headings included in the generic templates (i.e., patient need, goals, treatments), and headings related specifically to mental health (i.e., results of mental state examination, crisis/relapse) (406).

Table 6.2 - Extract from a disease-specific care plan template (398).

GP MANAGEMENT PLAN – MBS ITEM NO. 721 (DEPRESSION / ANXIETY DISORDER)			
Patient problems/needs/relevant conditions	Goals – changes to be achieved (if possible)	Required treatments and services, including patient actions	Arrangements for treatments/services (when, who, and contact details)
1. <i>General</i>			
Patient's understanding of depression/ anxiety	Patient to increase their understanding of depression/anxiety and how it can be managed	Patient education	GP Nurse Allied health professional
Symptoms	Improve mood, sleep, energy, attention, concentration, motivation, sexual function Improve physical symptoms (e.g. fatigue, headache, muscle pains, weight loss) Increase self confidence Identify and address thoughts related to suicide	Medication Consider: – CBT – Counselling – Psychotherapy – Relaxation training	GP Allied health professional Psychiatrist
Causes/stressors and precipitants	Identify stressors and precipitants, such as relationship and family problems, negative thinking, loss and grief, coexisting physical conditions	Counselling consider: – Problem solving – CBT – Interpersonal therapy – Marital/family therapy – Loss/grief counselling	GP Patient Allied health professional Psychiatrist
Maintenance/relapse prevention	Avoid relapse/decrease severity of relapse	Regular review Address stressors and known risk factors for relapse	GP Patient Allied health professional

Increase awareness of stressors/circumstances that could trigger a relapse

Early intervention of a recognized relapse

Psychiatrist

Table 6.3 - Extract from a generic care plan template (404).

PREPARATION OF A GP MANAGEMENT PLAN (ITEM 721)			
Patient's health problems/health needs/relevant conditions	Management goals with which the patient agrees	Treatment and services required, including actions to be taken by the patient	Arrangements for providing treatment/services (when, who, contact details)
<p>Copy of GPMP offered to patient? YES / NO</p> <p>Copy/relevant parts of the GPMP supplied to other providers? YES / NO / NOT REQUIRED</p> <p>GPMP added to the patient's records? YES / NO</p> <p>Review date for this plan: dd / mm / yy</p> <p>The referral form issued by the Department can be found at www.health.gov.au/mbsprimarycareitems or a form can be used that contains all of the components of the Department's form.</p>			

Table 6.4 - Appraisal of the included care plans according to criteria

Care plan template	Patient preferences			Priority setting	Identification of conflicts and synergies between conditions	Review
	Patient identified health issues	Patient identified management goals	Patient agreed treatments and actions			
GPMP; Generic (404)	+	++	+	-	-	+
GPMP Diabetes (412)	+	+	+	-	-	+
GPMP CHD (408)	-	++	++	-	-	+
GPMP Depression (398)	+	+	+	-	-	+
GPMP Osteoarthritis (400)	+	+	+	-	-	+
GPMP Osteoporosis (401)	+	+	+	-	-	+
GPMP mental health; Generic (406)	+	++	+	-	-	+
TCA; Generic (405)	-	-	+	-	-	+
TCA CHD (410)	-	+	+	-	-	+
TCA Osteoporosis (399)	-	+	+	-	-	+
TCA Osteoarthritis (403)	-	+	+	-	-	+
CVC; Generic (407)	+	++	++	++	-	++
GPMP & TCA diabetes (411)	+	+	+	+	-	-
GPMP & TCA COPD (409)	++	+	++	-	-	+
GPMP & TCA Cardiac (397)	++	+	++	-	-	++
GPMP & TCA Hypertension (402)	+	++	+	+	-	+

- does not address criteria; + somewhat addresses criteria; ++ addresses criteria

GPMP = General practitioner management plan. TCA = Team Care Arrangement. CVC = Coordinated Veterans Care.

Data relating to the four criteria relevant to care planning for patients with multiple conditions (patient preferences; priority setting; identification of conflicts and synergies between conditions; and review) are outlined below. Table 6.4 presents a summary of the extent to which each of the assessed templates addressed the four criteria.

Patient preferences

Across the templates, the broad criterion of patient preferences was mapped against three subthemes: a description of the health issue(s); management goals; and treatments and agreed actions. Eleven care plans (397,398,400-402,404,406,407,409,411,412) required the patient's health issues or conditions be recorded. For example, the GPMP template for diabetes included the following heading: "patient's problems/needs/relevant conditions", under which clinicians and patients could respond (412). Two templates (397,409), both combined TCA/GPMPs, extended this request for information by encouraging primary care clinicians and patients to independently record the health issues. Of the five templates (399,403,405,408,410) that did not request information on the health issue(s), four were TCA templates (399,403,405,410), which are not required by Medicare, to record patients' health issue(s).

Fifteen care plan templates (397-404,406-412) provided a heading under which goals for care could be recorded, for example, the TCA template for Osteoarthritis flagged: "goals to be achieved" (403). Six templates (402,404,406-408,411) stipulated patients should agree to the goals for care, as the following example from the generic GPMP template illustrates "management goals with which the patient agrees"(404). The generic TCA template (405) did not record patients' management goals but focused on treatment and service goals.

All of the care plan templates recorded the treatments and/or agreed actions (397-412). For example, the GPMP for Depression flagged: "treatment and services required, including actions to be taken by the patient" (398). Four templates (397,407-409) stipulated that the primary care clinician should agree to these treatments or

actions and patients as the GPMP/TCA template for Chronic Obstructive Pulmonary Disease demonstrates: “agreed action by health professionals and patients” (409).

Setting priorities or goals

The priority-setting theme included processes to assist clinicians and patients to prioritise patient preferences. Only three care plan templates included priority-setting processes (402,407,411). Two templates, the GPMP for Diabetes and the GPMP/TCA for Hypertension, addressed this criteria in a rudimentary way simply recording the “primary diagnosis/main issue” (402,411). The third template, for the CVC program, asked the patient to identify and rate their problems (8 point scale: zero = ‘not at all’ - eight = ‘a lot’) (407). The template also asked patients to identify a goal and rate their progress in achieving the goal (8 point scale: zero = no success, eight = complete success) (407). Notably the template only included space for one problem statement and one goal statement, but additional statements could be added elsewhere (407).

Conflicts and synergies

Processes for identifying conflicts and synergies between conditions were not flagged by any of the care plan templates.

Regular review

In line with the minimum requirements set by Medicare all of the care plan templates (397-410,412), with the exception of the GPMP/TCA for diabetes (411), requested a review date for the care plan, but only two templates requested a review of the patient’s management goals.

6.5 Discussion

Sixteen care plan templates were identified to assess their ability to support shared decision-making and enhance the management of multiple conditions. None of the care plan templates addressed all of the criteria (patient preferences; priority setting; identification of conflicts and synergies; and review), but most addressed one or more

to some extent. Patient preferences, linked to three subthemes (health issue(s); management goals; and treatments and agreed actions) was the most commonly addressed criterion, while substantially less emphasis was placed on priority setting and the review of individual management goals. None of the care plan templates identified conflicts and synergies.

Thirteen of the reviewed care plans were pre-filled disease specific templates. The inclusion of pre-filled data in care plan templates, while important for bringing evidence-based medicine to the point of practice, runs the risk of overshadowing genuine care planning discussions. Care planning is intended to involve both primary care clinicians and patients reflecting on clinical evidence and the patient's preferences, to inform and facilitate shared decision-making, resulting in the development of a joint care plan for managing the person's condition(s) (335). In contrast, the pre-filling of templates can direct care-planning discussions to focus on the issues, goals, treatments and agree actions recommended by disease-specific clinical practice guidelines. In essence, the discussion remains one sided with the emphasis being placed on clinical decision-making and "medical agendas" (391), rather than supporting genuine care planning discussions and consideration of patients' preferences for care. This is particularly concerning for patients with multiple conditions who are known to have contraindications to the treatments recommended in guidelines (62).

In line with the single disease approach for which clinical practice guidelines are often criticised (62,303), the care plan templates guided clinicians to consider co-occurring health issues in a sequential manner. Isolating the management of conditions in this way may not reflect the way patients think or prioritise care (21,135,394). When considering trade-offs between competing conditions, medications and treatments, patients often shift focus from disease-specific outcomes to more global health outcomes such as maintenance of physical function, symptom relief and quality of life (16,394), with some patients preferring not to acknowledge individual conditions (9). Fried et al. (394) suggest having patients identify or prioritise the global health outcomes of importance to them and organise care planning around these outcomes.

Pre-filled information sees the direction and focus of care at least partially pre-determined while “data field” requirements under current GP Medicare funding arrangements may present a further barrier to shared decision-making between clinicians and patients. Swinglehurst et al. (390) and Blakeman et al. (391) made similar observations when examining the use of care plan templates in UK primary care practices. Disease-specific care plan templates directed care-planning discussions towards “medical agendas”, while completing specified “data fields” to meet set quality indicators, impeded the clinician’s ability to engage in genuine care planning processes. These findings in combination with our own suggest care plans have drifted from their intended purpose, of fostering patient-centred care, to driving clinicians to meet policy requirements. Pre-populated care plans have a place in current primary care practice as indicated by the expressed preferences of clinicians (389). However, our findings support calls for pre-populated disease-specific, information to serve as a means of achieving the broader health goals identified by the patient, and not as a goal in itself (248,393,394).

Few of the care plan templates reinforced the need to engage patients in the development of care plans or included processes to assist clinicians and patients to set priorities. Some patients may not wish to participate in care decisions, but this should be an informed rather than an imposed choice (414). When faced with managing numerous potentially conflicting conditions, often with limited time and resources, some patients and clinicians will set priorities but these can differ (135,219). Working through differing priorities can assist to increase patients’ adherence with prescribed care (190), reduce the complexity or treatment burden faced by patients (190) and ensure the care plan addresses the issues of importance to patients (219). Yet seeking “agreement” with patients was not comprehensively encouraged or supported by the templates. Similarly, templates did not seek to reduce the complexity of care management through the identification of conflicts and synergies. Research suggests primary care clinicians rarely initiate priority setting discussions with their patients (415), but it is unclear whether this is due to limited availability of priority setting tools (19,224,262) or the culture of current practice (262). Clinicians have called for methods to support shared decision-making and resolve potential

differences between their priorities and those of their patients with multiple conditions (19,224). By not encouraging priority setting and regular review of patients' priorities and goals for care, care plans are missing a valuable opportunity to assist both clinicians and patients to manage multiple conditions.

Overall, our findings suggest current care plan templates may inadvertently impede, rather than foster shared decision-making, but there is scope for care plans to support the management of multiple conditions. This was demonstrated by the generic CVC template, which addressed the majority of the criteria, and included comprehensive methods for setting priorities. The generic CVC template encouraged patient ownership of the plan using headings such as "Identified issues (including self-management)"; "What I want to achieve?" and "Steps to get there" The template also encouraged the review of individual goals and the documentation of the patients' progress towards that goal, allowing for potential barriers or enabler to care to be identified. The CVC template offers a clear example of how templates might be improved to better facilitate shared decision-making and multimorbidity care. Care plans are but one component of the wider system in which multimorbidity care takes place. To make meaningful and sustainable change, modifications to improve their relevance in a multimorbidity context, must be underpinned by, broader system level interventions. Some of these system level changes are already underway. The recent Primary Health Care Advisory Committee (PHCAG) report recommends changes to Australia's current health management and funding models, placing greater emphasis on patient-centred care and shared decision-making in primary care settings (54). Care plans are explicitly identified as a means of facilitating patient-"work with and support their patients to set shared goals and make shared decisions about the inclusions of their care plan that are aligned and appropriate to their needs, circumstances, preference and context" (54).

The report also cautions against the use of "expressly automated" care plans, targeted more "towards satisfying requirements for payment rather than the needs of the patient" (54). In the May 2016 federal budget, the Australian Government announced

a \$21 million commitment to trial the recommended changes outlined in the report (124).

The limitations of this study need to be acknowledged. An extensive search was conducted, but it is possible eligible Australian care plan templates were missed. No formal or tested criteria currently exist for evaluating care plan templates in a multimorbidity context. The evaluation criteria used in this study were drawn from current evidence, but it is possible that relevant questions or criteria were not considered. In addition, due to the limited evidence base for multimorbidity interventions and management (16,335), we do not know if adopting care plan templates based on the domains suggested will impact patient outcomes. Nonetheless, the findings highlight a number of issues that are potentially important in shaping the management of multiple conditions. This study evaluated care plan templates and not the manner in which they are used by clinicians or patients. It is possible that clinicians engage in priority setting discussions and the identification of conflicts and synergies without these being flagged in current templates. However, current research suggests this is not generally the case. This study focused on care plan templates developed for use in Australian primary care practice and as a result, the care plans assessed were structured towards meeting the requirements set by Medicare and Australian clinical practice guideline recommendations. However, our findings are consistent with those reported by Swinglehurst et al. (390) and Blakeman et al. (391), suggesting they may have broader implications for the design of care plan templates beyond the Australian context.

6.6 Conclusion

Care plans are a well-used tool in primary care practice but their current format perpetuates a single-disease approach to care, which works contrary to their intended purpose. Policy constraints, medical agendas and clinical practice guidelines strongly influence the use of care plans in current practice. Restructuring care plans to incorporate shared decision-making and attention to patient preferences may assist in shifting the focus back to the patient and their care needs.

Conflicts of interest

The authors declare that they have no competing interests.

Funding

This study was not funded.

Chapter 7 Patient Decision Aids

7.1 Introduction

This chapter begins the discussion of how current primary care tools could be used collectively to contribute to multimorbidity care. It brings together the findings of the preceding chapters, in concert with a review of PDAs, to map the ways in which primary care practice tools can be used to facilitate shared decision-making and support multimorbidity care. To address this aim, the chapter is presented in two sections. Section one of the chapter draws on the findings from the expert stakeholder consultation to examine PDAs, a contemporary primary care practice tool not currently in widespread use in Australia. PDAs have been designed to support shared decision-making and provide space for the patient voice; however their contribution to the management of multiple chronic conditions has not previously been examined. This section offers a brief overview of PDAs, before providing a more detailed analysis of PDAs designed to work through disease specific decisions but which acknowledge other conditions within the decision-making process. These PDAs are mapped against the SDMCs, outlined by Charles et al. (246) in chapter two, to identify where they are most suitably able to contribute to shared decision-making and supporting multimorbidity care.

Section two seeks to merge the results of the current review of PDAs and the reviews of clinical practice guidelines and care plans, to outline the contribution these tools make to the SDMCs. This discussion moves beyond the limitations of the current tools, examined in detail in earlier chapters, to identify where their contribution may be most appropriately directed to support a multimorbidity care approach.

Patient decision aids

PDAs are electronic or paper-based tools that facilitate shared decision-making (337,344,345) and are widely used in the United States and the United Kingdom (251,416). They are designed to facilitate shared decision-making by supporting

patients and clinicians to participate in decision-making about health care options (336,337,344,345). Consensus has yet to be reached on the “active components” that PDAs must include (349) but, Trevena et al. (336) have identified a number of common steps decision aids should work through, including: outlining available options; identifying the risks and benefits of options; and ensuring patients’ preferences are elicited and incorporated (336).

PDAs fall under three classifications of use: by clinicians and patients in the clinical consult; by patients independent of the clinical encounter; and decisions mediated through other social encounters (342). Unlike the first two classifications, PDAs mediated by other social encounters typically occur outside the clinical setting and involve participants other health professionals. This research focuses on the first two PDA classifications, given their application to patient-clinician interactions, which is the focus of this thesis.

A number of Cochrane reviews conducted over the last 15 years have compared the use of PDAs to usual care for people facing treatment or screening decisions and demonstrated positive outcomes (251,346-348). The most recent review, involving 115 randomised control trials concluded the use of PDAs results in patients having an increased knowledge of options, improved risk perceptions, lower decisional conflict, and selection of options more in line with their preferences (251).

Despite this evidence-base, the ability of PDAs to support shared decision-making for patients with multimorbidity care remains untested. Attributes of PDAs, such as helping patients to understand treatment options, assisting patients to clarify how they feel about options and facilitating participation in shared decision-making (344), suggest promise in a multimorbidity context. In considering this, the objectives of this research were to investigate: the ways PDAs acknowledge or consider multiple conditions in decision-making; and the ability of PDAs to contribute to or support the SDMCs.

7.2 Review of patient decision aids

OvidMedline, Web of science (ISI), Embase, Cinahl, PsycINFO, Cochrane and Pubmed, were searched using terms including: ‘decision support techniques’, ‘decision support systems, clinical’, ‘decision support systems, patient’, ‘information seeking behaviour’, ‘decision making’, ‘patient participation’ and ‘patient preference’. An extensive search of the grey literature was also conducted using the International Ottawa Hospital Research Institute A to Z Inventory of Decision Aids and Australian websites including the Department of Health, National Health and Medical Research Council, the Australian Commission on Safety and Quality in Health Care, Royal Australian College of General Practitioners and relevant non-profit organisations websites. This was important as PDAs may take the form of “grey resources” rather than appear in traditional published formats. None of the included PDAs were identified through database searches; all were identified by searching the grey literature. Figure 7.1 summarises the search and selection process.

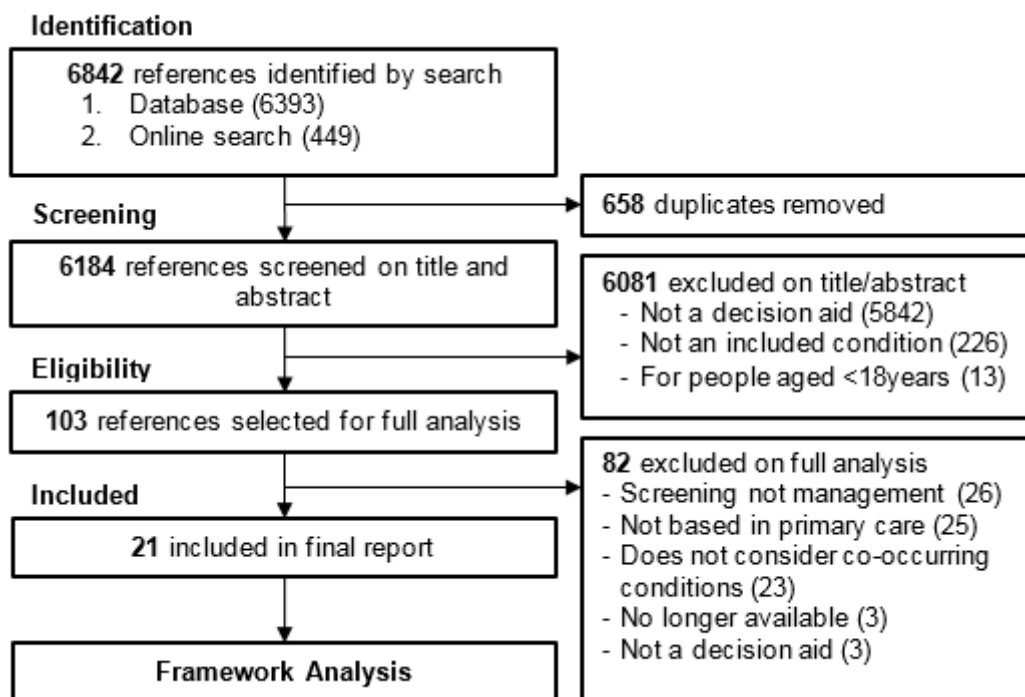


Figure 7.1 - Search strategy patient decision aids

This review targeted PDAs developed to support patients with chronic conditions. Recognising that PDAs typically focus on discrete decisions for particular conditions, the search focused on decision aids that acknowledged other conditions within the decision-making process, along with those classified as 'generic'. Generic PDAs do not include pre-filled information; instead they outline a number of key steps for assisting clinicians and patients to work through decisions and as such they may be particularly useful in supporting the management of multiple conditions.

Disease-specific PDAs were restricted to those that addressed a chronic condition classified as Australia's National Health Priority areas (360): cardiovascular health; stroke; cancer (colorectal, lung, breast and prostate); diabetes; depression; chronic kidney disease; asthma and chronic obstructive pulmonary disease; and arthritis and musculoskeletal conditions. Additional inclusion criteria were: PDAs for use in general practice; and applied to people aged 18 years and over.

Data analysis

Document analysis, directed by the framework approach (352) outlined in chapter four, was conducted in two stages. Stage one investigated the ways comorbid conditions were acknowledged or considered in decision-making; and stage two examined their ability to support shared decision-making. Unlike clinical practice guidelines, there is no quality assessment tool available to examine the quality of PDAs. Minimum standards have been proposed to assess quality (252,349,417), but consensus has not been reached on what format PDAs should take, how much detail they should contain (251), or which "active components" (349) (e.g., best estimate charts or value clarification processes²) should be included. Ethics approval was not required as all data were drawn from published materials available in the public domain.

² Value clarification processes, such as rating exercises or patient stories, are those which aim to assist patients to clarify the value they place on the benefits and harms presented. Rating exercises ask patients to rate on a five point scale (five point scale: zero = not important, five = very important) how important the reasons for or against an option are for them. Patient stories, aim to assist patients to clarify their own feelings about the various options by providing the personal stories of other patients who have faced the same decision. The value of patient stories in support patient decision-

Stage 1

Document analysis of the PDAs was conducted to identify the way PDAs addressed or acknowledge the presence of other conditions during the decision-making process. Detailed review of the PDAs ensured familiarity with content and enabled the identification of key themes relating to other conditions (i.e., those not the focus of the PDA). An index framework (see Table 7.1) that defined key themes including and consistent with other conditions (e.g., “potential complications” flagged when other conditions might cause complications in the decision-making process) was developed and used to code content. Relevant passages from each PDA were extracted in accordance with the themes and placed in charts to assist with mapping and interpreting the data.

Table 7.1 - Multiple conditions framework themes

Theme	Description
Potential complication	The PDA flagged how other conditions might impact the treatment, process or choice. Themes identified include ‘pre-existing conditions’ and ‘ask your doctor’.
Increase risk	The PDA discusses how the treatment might increase a person’s risk of developing comorbid conditions.
Reduce risk	The PDA discusses how the treatment might reduce a person’s risk of developing comorbid conditions.

Stage 2

Document analysis using the framework approach was also conducted to assess the ability of PDAs to support shared decision-making. This was determined by examining their potential to contribute to the three components necessary for achieving shared decision-making, as outlined by Charles et al. (246). The SDMCs were used as criteria against which each PDA was reviewed to determine the extent to which the components were addressed. A thematic framework (see Table 7.2) was developed from key themes identified in the document analysis that aligned with the SDMCs (e.g.,

making is highly debated, with many arguing more research is needed to confirm their benefits and develop a definitive set of standards.

“processes to assist with value clarification”). This framework was used to code PDA content.

Table 7.2 - Patient decision aid framework themes

Theme	Description
SDMC 1: Information exchange	The tool prompts the sharing of information by clinicians and patients. Themes identified include ‘benefits and harms’.
SDMC 2: Deliberation	The tool includes processes to assist the clinician and patient to deliberate regarding the shared information. Themes identified include: ‘processes to assist with value clarification’, ‘talk with your doctor’; ‘ask your clinician’ question prompts and ‘discuss other treatment options with your clinician’.
SDMC 3: Deciding on treatment to implement	The tool prompts the documentation and review of a decision, which has been jointly agreed to by clinicians and patients. Themes identified include: ‘check decision’.

7.3 Findings

Patient decision aid characteristics

Twenty-one PDAs met the inclusion criteria: thirteen for musculoskeletal health (418-430); three for diabetes (431-433); two for depression (434,435); one for chronic kidney disease (436); one for cardiovascular disease (437); and a generic decision aid (438). The PDAs had been developed by Government and non-government organisations in the UK, USA and Canada (see Table 7.3).

Thirteen PDAs (420-430,433) were classified for use by patients and clinicians in face-to-face clinical encounters (see Table 7.3). These PDAs were shorter (i.e., no more than four pages) providing only a brief summary of options which could be quickly examined and used to facilitate further discussion in the clinical consult. One PDA used a small comparison table to present information, which provided a brief tabularised summary of options, and two PDAs presented information as option grids (429,430), which are more detailed stand-alone comparison tables. Nine PDAs used best estimate charts (420-428), which are presented as a simple graphic that illustrates the likelihood of a risk or benefit occurring, per 100 people (see Figure 7.2) (342). One decision aid was generic (see Box 7.1) (438).

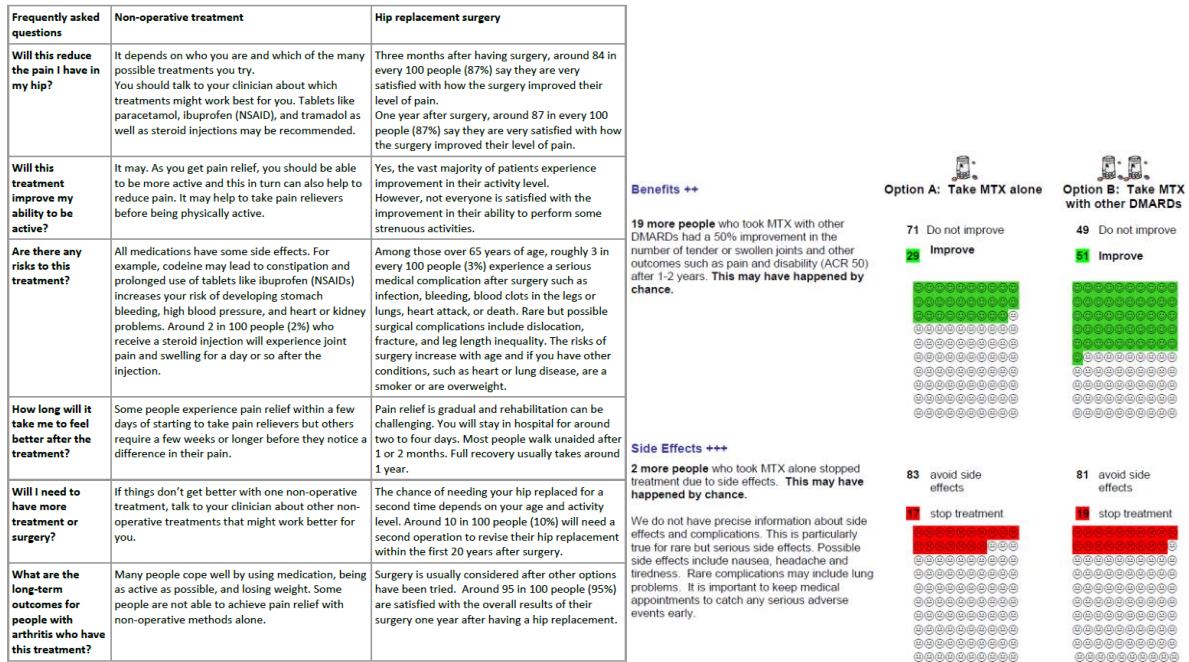


Figure 7.2 - Summary table (left) from a PDA for Osteoarthritis of the hip (430) and a best estimate chart (right) from a PDA for rheumatoid arthritis (423).

Eight PDAs (418,419,431,432,434-437) were categorised for use by patients independent of the clinical encounter (see Table 7.3). These decision aids were longer ranging from 12 to 16 pages. Although these PDAs also used best estimate charts (two PDAs) (434,437) and/or comparison tables (four PDAs) (418,419,431,434) to present information, they also provided a comprehensive explanation of the options, along with background information on the condition being addressed. Three of the PDAs did not include either best estimate charts or comparison tables, presenting information in written format only.

Eight PDAs targeted decisions related to medication initiation (420-426,433), five examined the use of multiple medications (419,431,434,436,437), and three considered medication versus other options (e.g., skin creams or surgery) (418,429,430). Of the remaining decision aids: two gave patients the option of initiating a non-pharmacological treatment (e.g., transcutaneous electrostimulation or ultrasound therapy for osteoarthritis) (427,428); one compared multiple non-pharmacological treatment options (435); one provided information on methods for

measuring blood sugar and taking insulin (432); and one was generic (refer to Box 7.1) (438).

The generic PDAs provided only headings or data fields which guide the intended user(s) through four steps:

Step 1: “Clarify your decision” –the patient must identify the decision which needs to be made; their reasons are for making the decision; when they need to make a decision; and how far along they are with making a decision (438).

Step 2: “Explore your decision” - the patient must consider the benefits and risks of the various options in light of personal preferences (438). The patient is asked to list the available options and the main risks and benefits known. The patient is then asked to rate how much the listed benefits and risks matter to them on a scale from 0 (not at all) to 5 (matters a lot) (438) and then identify which option they prefer (438). They are also asked to list other persons who are involved in the decision-making process and which option they prefer. The decision aid asks how this other person can support the patient and whether the person is pressuring the patient (438). This component concludes by asking the user which role they would prefer in making the choice: share the decision with [name person]; decide myself after hearing the views of [name person]; or someone else decides [name person] (438).

Step 3: “Identify your decision-making needs” - assists patients’ to determine their decision-making needs by considering the following: do you know the benefits and risks of each option (438)? Are you clear about which benefits and risks matter most to you (438)? Do you have enough support and advice to make a choice? Do you feel sure about the best choice for you (438)?

Step 4: “Plan the next step based on your needs” - provides additional components or suggestions for the patient to work through based on earlier responses (438). For instance if a patient is unclear about which benefits and risks mattered most to them, then the PDA suggests the following to assist: review the stars in the balance scale to see what matters to you; find people who know what it is like to experience the benefits and risks; talk to others who have made the decision; read stories of what mattered most to others; and discuss with others what mattered most to you.

Box 7.1 - Description of generic patient decision aid

Table 7.3 - Patient decision aid characteristics

Name of Patient Decision Aid	Disease	Organisation	Classification	Decision	Information presentation format
“ACE Inhibitors” and “ARBs” To Protect Your Heart? (437)	Cardiovascular disease	AHRQ USA	Independent of consult	Multiple medications	Best estimate charts
Medicines for Early Stage Chronic Kidney Disease A Review of the Research for Adults With Kidney Disease and Diabetes or High Blood Pressure (436)	Chronic kidney disease	AHRQ USA	Independent of consult	Multiple medications	Written format
Medicines for Treating Depression: A review of the research for adults (434)	Depression	AHRQ USA	Independent of consult	Multiple medications	Best estimate charts Comparison table
Medicines for Type 2 Diabetes: A review of the research for adults (431)	Diabetes	AHRQ USA	Independent of consult	Multiple medications	Comparison table
Managing Osteoarthritis pain with medicines: A review of the research for adults (418)	Musculoskeletal health	AHRQ USA	Independent of consult	Medication versus other options	Comparison table
Medicines for Psoriatic Arthritis: A review of the research for adults (419)	Musculoskeletal health	AHRQ USA	Independent of consult	Multiple medications	Comparison table
Therapies for Treatment-Resistant Depression: A Review of the Research (435)	Depression	AHRQ USA	Independent of consult	Multiple non-pharmacological treatments	Written format
Methods for Delivering Insulin and Monitoring Blood Sugar (432)	Diabetes	AHRQ USA	Independent of consult	Between methods for testing blood sugar and injecting insulin	Written format
Should I take etanercept (Enbrel) for rheumatoid arthritis? (421)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Should I take tocilizumab (Actemra) for rheumatoid arthritis? (422)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts

Should I take Risedronate (Actonel®) for osteoporosis? (423)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Should I take Etidronate (Didronel®) for osteoporosis? (424)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Should I take abatacept (Orencia®) for rheumatoid arthritis? (425)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Should I take alendronate (Fosamax®) for osteoporosis? (426)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Should I have ultrasound treatment for osteoarthritis (OA) in my knee? (427)	Musculoskeletal health	Cochrane Group	In consult	Non-pharmacological initiation	Best estimate charts
Should I have transcutaneous electrostimulation (TENS) for osteoarthritis (OA) in my knee? (428)	Musculoskeletal health	Cochrane Group	In consult	Non-pharmacological initiation	Best estimate charts
I have never taken medication for rheumatoid arthritis before. Should I take methotrexate (Rheumatrex®) alone or with other disease-modifying anti-rheumatic drugs for rheumatoid arthritis? (420)	Musculoskeletal health	Cochrane Group	In consult	Medication initiation	Best estimate charts
Diabetes, Type 2: Should I Take Insulin? (433)	Diabetes	Healthwise USA	In consult	Medication initiation	Comparison table
Osteoarthritis of the knee (429)	Musculoskeletal health	Option Grid Collaborative	In consult	Medication versus other options	Option Grid
Osteoarthritis of the hip (430)	Musculoskeletal health	Option Grid Collaborative	In consult	Medication versus other options	Option Grid
Ottawa Personal Decision Guide (438)	Generic	OHRI & Uni of Ottawa, Canada	In consult	Generic	Generic

AHRQ, Agency for Healthcare Research and Quality; US, United States, OHRI, Ottawa Hospital Research Institute

Multiple chronic conditions

Analysis of the PDAs revealed three key approaches to acknowledging other conditions in the decision-making process (see Table 7.4). The first, used by seventeen PDAs, involved flagging the potential complications additional conditions may pose in the decision-making process (418-431,433,435). For fourteen PDAs this involved identifying specific pre-existing conditions known to negatively impact the treatment or outcome (i.e., increasing risk of side effects) (420-431,433,435). For example, the PDA for osteoarthritis lists health factors which might complicate treatment options:

What other health factors may affect your choice? Check any that apply and discuss your concerns with your doctor. I have had recent trauma to my knee. I have another condition that could be causing the pain in my knee. I have metal in my knee such as an artificial joint or prosthesis, I have a skin infection or open wound. I am in the active stage of any cancer. (427)

Four decision aids suggested patients ask their clinician about the potential impact their other conditions may have on the provided options or index condition (418,434-436). For example, questions raised in the decision aid for early stage chronic kidney disease include: “What should I talk about with my doctor? ...What medicines you take for other conditions and how they might interact with a new medicine” (436).

The second approach, used by ten PDAs, discussed how the treatments, medications or index condition might increase a person’s risk of developing a comorbid condition or severe side-effects (418-421,425,429,431,434,436,437), as illustrated by the PDA for Chronic Kidney Disease:

[Why is CKD dangerous?] It can cause problems with your heart and can increase your risk of bone loss, broken bones, anemia (a low number of red blood cells, which carry oxygen throughout the body), complete kidney failure, and other serious problems. It can also lead to death (436).

The third approach, used by six PDAs, outlined how the relevant treatment and medication options might reduce a person's risk of developing additional conditions (431-434,436,437), as this example from the PDAs for Type 2 Diabetes demonstrates:

What are the benefits of using insulin? Insulin is the most effective medicine for lowering blood sugar levels. Keeping blood sugar under control reduces your risk for other health problems caused by diabetes, such as eye problems, kidney disease, and nerve damage (433).

Table 7.4 - Appraisal of the included patient decision aids according to the multiple condition framework

Name of Patient Decision Aid	Potential complication		Increase risk	Reduce risk
	Pre-existing conditions	Ask your doctor		
“ACE Inhibitors” and “ARBs” To Protect Your Heart? (437)	-	-	+	+
Medicines for Early Stage Chronic Kidney Disease: A Review of the Research for Adults With Kidney Disease and Diabetes or High Blood Pressure (436)	-	+	+	+
Medicines for Treating Depression: A review of the research for adults (434)	-	+	+	+
Medicines for Type 2 Diabetes: A review of the research for adults (431)	+	-	+	+
Managing Osteoarthritis pain with medicines: A review of the research for adults (418)	-	+	+	-
Medicines for Psoriatic Arthritis: A review of the research for adults (419)	-	-	+	-
Therapies for Treatment-Resistant Depression: A Review of the Research (435)	+	+	-	-
Methods for Delivering Insulin and Monitoring Blood Sugar (432)	-	-	-	+
Should I take etanercept (Enbrel) for rheumatoid arthritis? (421)	+	-	+	-
Should I take tocilizumab (Actemra) for rheumatoid arthritis? (422)	+	-	-	-
Should I take Risedronate (Actonel®) for osteoporosis? (423)	+	-	-	-
Should I take Etidronate (Didronel®) for osteoporosis? (424)	+	-	-	-

Should I take abatacept (Orencia®) for rheumatoid arthritis? (425)	+	-	+	-
Should I take alendronate (Fosamax®) for osteoporosis? (426)	+	-	-	-
Should I have ultrasound treatment for osteoarthritis (OA) in my knee? (427)	+	-	-	-
Should I have transcutaneous electrostimulation (TENS) for osteoarthritis (OA) in my knee? (428)	+	-	-	-
I have never taken medication for rheumatoid arthritis before. Should I take methotrexate (Rheumatrex®) alone or with other disease-modifying anti-rheumatic drugs for rheumatoid arthritis? (420)	+	-	+	-
Diabetes, Type 2: Should I Take Insulin? (433)	+	-	-	+
Osteoarthritis of the knee (429)	+	-	+	-
Osteoarthritis of the hip (430)	+	-	-	-
Ottawa Personal Decision Guide (438)	-	-	-	-

Shared decision-making components

Twenty-one PDAs were examined in relation to ability to contribute to the three SDMCs outlined by Charles et al. (246). As tools designed to assist patients to participate in decision-making about health care options, their most significant contribution to the shared decision-making process appears to be linked to components one and two.

Components 1: supporting both participants to share or exchange information

PDAs are themselves a means of sharing or exchanging information, particularly related to the benefits and harms of treatment options. Through the use of PDAs clinicians can facilitate the first shared decision-making component (246). By participating in this step they are preparing their patients to participate in steps one and two.

Benefits and harms

All of the included PDAs (418-437), with the exception of the generic one (438), provided information on the benefits and harms of the provided options. However, there was considerable variability in how this information was provided. Nine PDAs (420-428) presented the benefits and harms using best estimate charts. Three PDAs (429,430,433) presented the benefits and harms in a table format. Five presented the benefits and harms using a combination of a comparison table and/or 'best estimate image' and plain text (418,419,431,434,437) and three PDAs did not use any comparison tables or best estimate charts, presenting the benefits and harms as text only (432,435,436).

Component 2 – supporting both participants to deliberate to reach a shared understanding.

Across the PDAs, the second shared decision-making component was addressed in four ways: the inclusion of processes to assist with value clarification, the provision of

reminders to talk to your clinician, the inclusion of questions to ask your clinician; and prompts to discuss other treatment options with your clinician (see Table 7.5).

Processes to assist with clarifying preferences

In addition to providing information on the benefits and harms of the various options, the PDAs also included processes to assist clinicians and patients to deliberate regarding the provided information (i.e., assist in clarifying preferences or the value placed on various benefits and harms). Eleven PDAs included processes to assist with eliciting patients' preferences or values for care (420-428,433,438), thereby assisting patients to participate in component two. These included rating exercises and preparedness quizzes. The rating exercises asked patients to rate (five point scale: zero = not important, five = very important) reasons for choosing options. The preparedness quizzes assessed patients' readiness to participate in decision-making by providing a short quiz regarding the information presented in the PDA to ensure the patient understood the provided information.

One PDA included personal stories from other patients who had faced the same decision, to assist patients to clarify their own feelings about the provided options. As this example from the PDA for type 2 diabetes demonstrates:

"My mom had diabetes. She had to give herself insulin shots, and it looked so messy and painful. I swore that it would never happen to me. Well, for 8 years now I've had type 2 diabetes. I feel like I've done everything I can at this point. I don't really want to start insulin, but it's more important to me that I stay as healthy as I can. I know that insulin can help me. — Jeff, age 48" (433).

Talk with your clinician

Ten PDAs (418,419,429-432,434-437) prompted patients to discuss or talk with their clinician regarding the information presented. For instance, the option grid for osteoarthritis of the knee included the following statement: "use this grid to help you

and your healthcare professional talk about how best to manage your knee pain and activity level” (429).

Ask your clinician

A further eight PDAs (418,419,431,432,434-437), all developed by the AHRQ, listed specific questions patients might pose to their clinician to prompt discussion and deliberation. The following example from the patient decision aid for diabetes demonstrates this approach:

“Ask your doctor

- *Do you think my blood sugar level is controlled well?*
- *Is there anything I should change to better manage my diabetes?*
- *Would a continuous monitor or insulin pump help me control my blood sugar?*
- *What else can I do to keep my blood sugar at a healthy level?” (432).*

Discuss other treatment options with your clinician

Thirteen PDA (420-430,433,435) prompted patients to discuss other treatment options not presented in the PDA, with their clinician as illustrated. This was usually presented as a generally worded prompt as in this example from the PDA for osteoporosis: “You may wish to discuss other treatment options with your doctor” (423).

Component 3 – An agreement is achieved between both participants on the choice

Ten PDA (420-428,438) asked patients to document their final choices. For instance, the PDA considering whether to take alendronate for osteoporosis, prompted patients to choose from the following choices at the end of the PDA: try alendronate; discuss other treatment options; or other, please specify. However, none of these PDA encouraged or suggested that a date be set for reviewing choice or decision, which as highlighted in the care plan review (chapter 6) is a critical element of effective multimorbidity care.

Table 7.5 - Appraisal of the included patient decision aids according to the shared decision-making framework

Name of Patient Decision Aid	SDMC 1	SDMC 2				SDMC 3
	Benefits and harms	Value clarification	Talk with your clinician	Ask your clinician	Discuss other treatment options	Check option
“ACE Inhibitors” and “ARBs” To Protect Your Heart? (437)	+	-	+	+	-	-
Medicines for Early Stage Chronic Kidney Disease: A Review of the Research for Adults With Kidney Disease and Diabetes or High Blood Pressure (436)	+	-	+	+	-	-
Medicines for Treating Depression: A review of the research for adults (434)	+	-	+	+	-	-
Medicines for Type 2 Diabetes: A review of the research for adults (431)	+	-	+	+	-	-
Managing Osteoarthritis pain with medicines: A review of the research for adults (418)	+	-	+	+	-	-
Medicines for Psoriatic Arthritis: A review of the research for adults (419)	+	-	+	+	-	-
Therapies for Treatment-Resistant Depression: A Review of the Research (435)	+	-	+	+	+	-
Methods for Delivering Insulin and Monitoring Blood Sugar (432)	+	-	+	+	-	-
Should I take etanercept (Enbrel) for rheumatoid arthritis? (421)	+	+	+	+	-	+
Should I take tocilizumab (Actemra) for rheumatoid arthritis? (422)	+	+	-	-	+	+

Should I take Risedronate (Actonel®) for osteoporosis? (423)	+	+	-	-	+	+
Should I take Etidronate (Didronel®) for osteoporosis? (424)	+	+	-	-	+	+
Should I take abatacept (Orencia®) for rheumatoid arthritis? (425)	+	+	-	-	+	+
Should I take alendronate (Fosamax®) for osteoporosis? (426)	+	+	-	-	+	+
Should I have ultrasound treatment for osteoarthritis (OA) in my knee? (427)	+	+	-	-	+	+
Should I have transcutaneous electrostimulation (TENS) for osteoarthritis (OA) in my knee? (428)	+	+	-	-	+	+
I have never taken medication for rheumatoid arthritis before. Should I take methotrexate (Rheumatrex®) alone or with other disease-modifying anti-rheumatic drugs for rheumatoid arthritis? (420)	+	+	-	-	+	+
Diabetes, Type 2: Should I Take Insulin? (433)	+	+	-	-	+	+
Osteoarthritis of the knee (429)	+	-	+	-	+	-
Osteoarthritis of the hip (430)	+	-	+	-	+	-
Ottawa Personal Decision Guide (438)	-	+	-	-	+	+

7.4 Implications for practice

Twenty-one PDAs were identified and reviewed. The majority focused on discrete medication related decisions and were intended for use in the clinical consultation. Key methods used by PDAs to acknowledge multiple conditions included flagging potential complications, prompting discussion between the patient and clinician and identifying how further illness could be prevented. In flagging multiple conditions and providing assistance to clinicians and patients to work through decision-making processes, PDAs have demonstrated some potential to contribute to the management of multiple conditions, albeit within the context of discrete decisions. In particular, generic PDAs warrant further investigation as a means of working through the complex and potentially infinite number of decisions associated with multiple conditions.

The PDAs most strongly informed components one and two of the SDMCs: of the PDAs reviewed, all but the generic decision aid contributed to the first and second SDMCs. Just over half the PDAs contributed to the third SDMC, demonstrating scope for PDAs to support shared decision-making in a systematic and consistent way.

Contribution of existing tools to the SDMC

This thesis has consistently highlighted the necessity of shared decision-making as a foundation for effective multimorbidity care. Shared decision-making, a central component of patient-centred care (137,244), assumes even greater salience in multimorbidity care because there is often not a single 'correct' treatment option. Charles et al. (246) argue shared decision-making must involve at least two people, traditionally the clinician and patient, sharing or exchanging information, jointly deliberating, and agreeing on a treatment choice. In practice, shared decision-making is rarely achieved due to a range of barriers including: short consultation times; limited training for clinicians on how to participate; threats to power relationships; and limited access to, or availability of, resources or tools that can support shared decision-making (262,263,439,440). Acknowledging these barriers, and in recognition of the importance of shared decision-making, particularly in a multimorbidity

context, clinicians (19,224,230) and professional organisations (33,54) have called for methods or tools to support this process.

Primary care practice tools such as clinical practice guidelines and care plans are designed to support primary care clinicians and patients to manage single chronic conditions. Broadly, these tools were developed to support practice wide change and enhance the uniformity of care provision (39,269) and they have been directly linked to improvements to care (271,288,291,330), but challenges arise when they are required to adapt to new situations inconsistent with their original purpose (62,303). In line with this, our findings indicate clinical practice guidelines and care plans in their current form have limited transferability from the management of single chronic conditions to the management of multiple chronic conditions. The question arises is to whether these tools might be adapted to support a multimorbidity care approach. Having argued the central place of shared decision-making in multimorbidity care, the remainder of this chapter briefly revisits clinical practice guidelines and care plans to map their contribution to the three SDMC outlined by Charles et al. (246) in order to demonstrate how these tools could be capitalised on (see Table 7.6).

Clinical practice guidelines

As chapter three outlined, clinical practice guidelines are designed to translate the best available evidence into recommendations for clinical practice (227). Through the translation of evidence into practice they have demonstrated effectiveness in guiding the management of single chronic conditions (288,291,292). This translational role allows guidelines to provide clinicians and patients with evidence-based information on the benefits and harms of decision options thereby contributing to the first SDMC: *information exchange* (246). However, in line with systematically conducted research, guideline recommendations are derived from research trials engaging participants who must meet narrow inclusion criteria (i.e., those experiencing single chronic conditions), thereby limiting their generalisability to patients with multiple conditions (227). As chapter five concluded, some guidelines have made steps towards acknowledging potential preference-sensitive decisions through the development of patient-preference recommendations but, more, guidelines remain inconsistent in how they present these recommendations and provide little guidance on how

clinicians should work through these recommendations. This is the foundational next step needed for guidelines to contribute to component two of the SDMCs: *deliberation*. As a consequence, their ability to assist both clinicians and patients to *decide on a treatment to implement* (component three) is limited. The clinical focus of guidelines, while critical to their purpose of informing clinicians, appears to undermine their ability to serve the dual purpose of translating evidence in a way that supports the patient voice, particularly for those managing multiple conditions.

Care plans

As previously discussed in chapter six, care plans were introduced in Australia to encourage and support multidisciplinary approaches to chronic disease management (4,39). Care planning processes are intended to involve both clinicians and patients reflecting on clinical evidence and the patient's preferences, needs and values to inform the development of a joint strategy for managing the patient's chronic condition(s) (438). In line with this goal, care plans can play a key role in supporting component one of the SDMCs: *information exchange*. However, as our findings revealed, many care plan templates are pre-filled and disease-specific, directing the organisation of care and treatment goals to support single disease-specific outcomes rather than the cross-disease outcomes central to the management of multiple conditions (438). As a consequence, the current format of care plans available to primary care clinicians in Australia do not appear to comprehensively encourage patient involvement in the care planning process, but are instead oriented to clinical decision-making and meeting the Medicare requirements, further highlighting the need for congruence between policy and practice. The findings also indicate that currently available care plan templates do not provide guidance to clinicians and patients on how to work through preference-sensitive decisions and the conflicts in preferences and goals for care that can arise from competing health conditions. This restricts their contribution to component two of the SDMCs: *deliberation*, but as argued in chapter six is a feature of care plans that could be harnessed. Care plans do provide an avenue for decisions to be documented and reviewed, in accordance with component three of the SDMCs: *decide on a treatment to implement*, but the pre-filling of information undermines their ability to support this component as the direction and focus of care has to some extent been determined.

Restructuring care plans, to emphasis shared decision-making and the identification and review of patient preferences and priorities, rather than individual conditions, may assist to refocus care plans on the patient and their care needs.

In summary, clinical practice guidelines and care plans are core contributors to the management of single chronic conditions, but their role in identifying and incorporating the preferences of patients with multiple conditions is inhibited by the primacy of their focus on disease and clinician decision-making. PDAs, as tools specifically designed to operationalise shared decision-making, could help fill this void.

Table 7.6 - Summary of each of the tools mapped against the shared decision-making components

SDMC	Primary care practice tool		
	Patient decision aids	Clinical practice guidelines	Care plans
1) Information exchange	A form of information exchange themselves they provide information the benefits and harms of the various options	Provide information on the benefits and harms. Flag patient-preference recommendations and the need to engage patients, but this is not consistently applied.	Consideration of cross-disease outcomes or engagement of patients in decision-making processes is not systematically encouraged.
2) Deliberation	Include processes to assist patients to engage in deliberations with their clinician including value clarification activities, knowledge quizzes, and provision of discussion questions.	Do not provide guidance or processes to assist patients and clinicians to work through or deliberate about preference-sensitive recommendations.	Limited guidance or processes to assist patients and clinicians to weigh up clinical evidence, individual preferences or priorities.
3) Deciding on treatment to implement	Are intended more as an aid to reaching agreement rather than as a means of documenting agreement.	The focus in on clinician decision-making and single chronic conditions.	Focus is on clinician decision-making and single disease-specific outcomes, but do they provide an avenue for documenting and reviewing decisions.

7.5 Conclusion

The aim of this chapter was to consider the ways PDAs acknowledge or consider multiple conditions in decision-making and the ability of PDAs to contribute to or support the SDMCs. Extending on this discussion the chapter then explored the ability of clinical practice guidelines and care plans to contribute to the SDMCs. This highlighted that each tool has strengths and limitations and there is potential for greater integration across primary care practice tools to further support shared decision-making and multimorbidity care. The next and final chapter brings together the findings of the thesis and includes a proposed approach to integrating the three tools. The following chapter will outline how these tools could be integrated to produce a synergistic response to shared decision-making and multimorbidity care.

Chapter 8 Discussion

The thesis has presented a detailed analysis of three existing primary care practice tools, examining their ability and transferability to address one of Australia's most pressing health system issues: the delivery of care to patients with multiple conditions. The research was based on the proposition that effective multimorbidity care must incorporate patient preferences and shared decision-making to reflect the central tenets of patient-centred care and consumer engagement. By examining this topic, the thesis makes a timely contribution to the current policy agenda set out in the recently released Primary Health Care Advisory Committee (PHCAC) report "Better outcomes for people with chronic and complex health conditions" (54). The report establishes the urgent need to address multiple chronic conditions, through strengthening patient involvement and shared decision-making in primary care. Also underlined is the importance of capitalising on existing resources (54), further reinforcing the applicability of the theory of incrementalism that underpinned and guided this thesis.

This thesis found that none of the existing tools commonly (or potentially) used in primary care practice systematically incorporate the key attributes, argued in the thesis as being necessary, for achieving multimorbidity care. Each of the three tools reviewed captures elements of what is required to provide multimorbidity care, but each was also revealed to have particular limitations. The thesis argues that while these tools offer a sound basis to enhance multimorbidity care, adaptations or incremental changes are needed to improve the ability of each to contribute to patient-centred multimorbidity care. Furthermore, while these tools can contribute individually, much scope also exists for a more integrated approach to their use. There is potential to create synergies that could enhance shared decision-making and the incorporation of patient preferences, thereby supporting the provision of multimorbidity care.

This chapter draws together the individual study findings to examine the ways in which these tools could be integrated to produce a synergistic approach to facilitate shared decision-making and support multimorbidity care. Directions for future research and policy will be discussed as well as the strengths and limitations of this thesis.

8.1 Integrated primary practice tools

To support the provision of effective multimorbidity care all the tools informing primary care should, ideally, facilitate shared decision-making between clinicians and patients. Yet, this thesis confirms that existing tools centre on managing single chronic conditions and are more strongly oriented to clinician decision-making, rather than shared decision-making.

Figure 8.1 illustrates how each of the tools currently relates to shared decision-making. Clinical practice guidelines are predominantly disease-focused and designed to inform clinician decision-making. As noted in chapter five some guidelines have made efforts to support patient perspectives through the inclusion of patient preference recommendations, but this is far from consistent across guidelines. Care plans, as outlined in chapter six, were also shown to be geared to direct clinician decision-making. Despite being a tool designed to facilitate joint decision-making they do not, at present, readily incorporate the patient perspective. PDAs strongly inform patient perspectives but unlike guidelines and care plans, feature little in the Australian primary care landscape and are reliant on clinicians and/or patients to first recognise that a decision needs to be made.

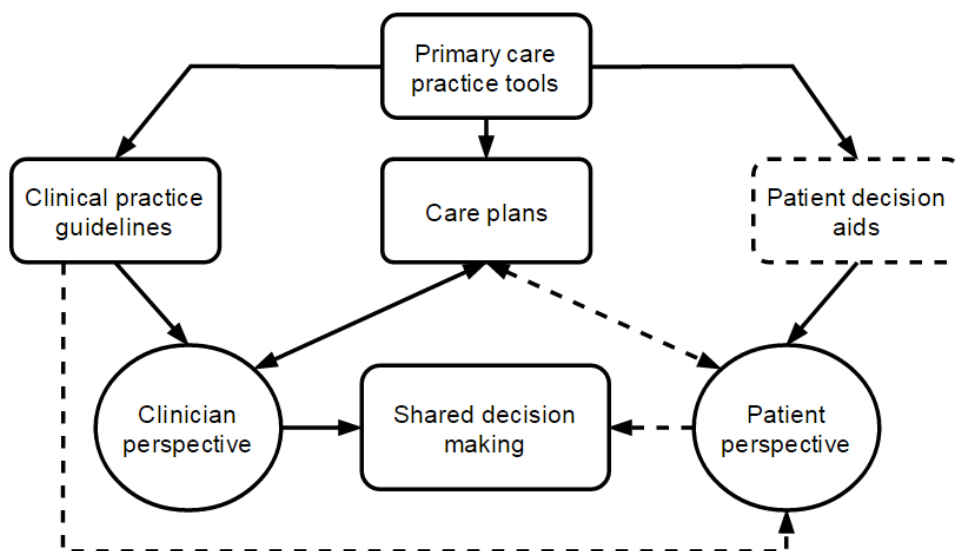


Figure 8.1 - Current contribution of primary care practice tools to shared decision-making and multimorbidity care

Drawing on the findings presented in chapters five, six and seven, this thesis proposes how the identified primary care practice tools could be used in a more integrated manner to

support shared decision-making and multimorbidity care. As Figure 8.2 illustrates, the proposed integration of primary practice tools begins with clinical practice guidelines, developed using sound and effective consumer engagement processes. This is followed by the development of PDAs, designed to accompany and complement clinical practice guidelines, to work through patient-preference recommendations identified through consumer engagement processes during guideline development. PDAs are also relevant for use alongside care plans, which include processes to elicit and incorporate patient preferences and set priorities, to ensure the discrete decision is made within the patient's broader goals and preferences for care.

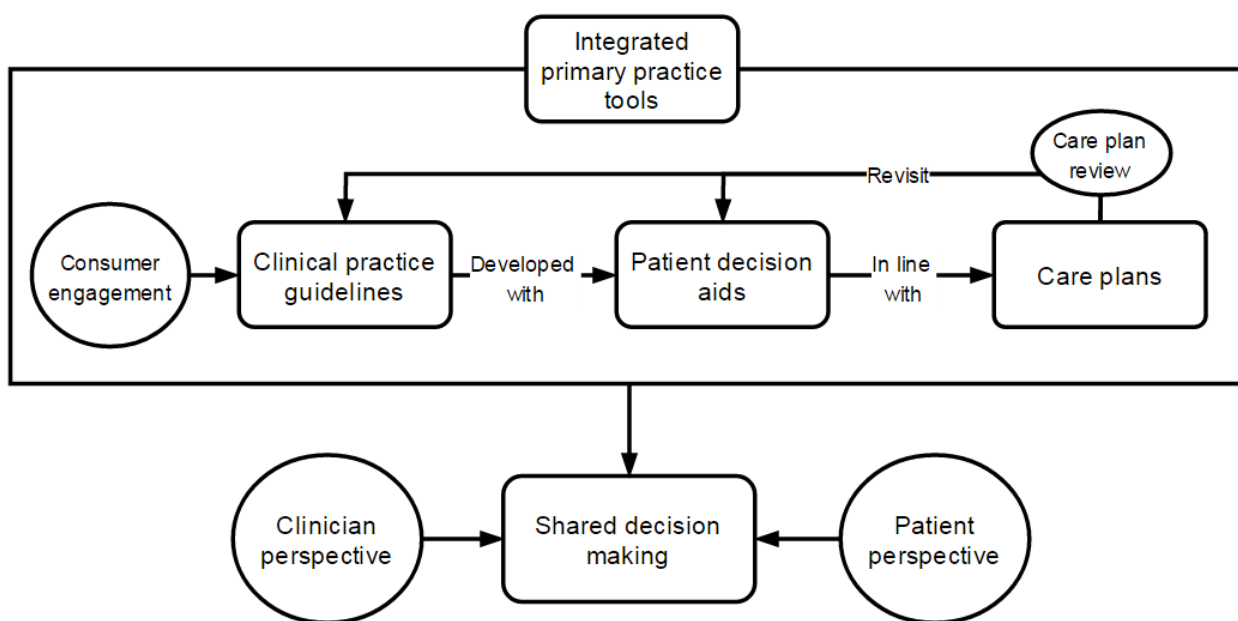


Figure 8.2 - Proposed method for integrating current primary care practice tools

Clinical practice guidelines

At the outset of the research, clinical practice guidelines were acknowledged as evidence-based primary care practice tools designed to translate evidence and inform clinical decision-making; they are not designed to promote patient-centred care or shared decision-making. However, their ability to inform clinical decision-making is not without question because many patients do not fit into the ‘average patient’ model upon which they are based. In shared decision-making, information exchange is bi-directional (246), but guidelines are predominantly uni-directional, with information on the benefits and harms transferring from

clinician to patient (441). Primary care clinicians have called for improvements that foster patient-centred management of multiple conditions and strengthen the patient voice (33,67,250,308,309). Efforts to shift guidelines into the patient space have been proposed, including the development of patient versions of guidelines (441). The use of consumer engagement processes and greater incorporation and flagging of preference-sensitive decisions key recommendations proposed in chapter five.

The reviewed guidelines used consumer engagement processes, but these processes have been criticised as passive methods limiting consumers' ability to actively engage and provide valuable input (311,314,383). Likewise, the guidelines did not provide training or establish a specific role description to consumers, elements considered essential for meaningful consumer engagement (311). These findings highlight the need not only for greater direction on how to successfully engage consumers in guideline development, but how to measure the effectiveness or outcomes of such processes. As consumer engagement continues to be encouraged in guideline development and health policy creation more broadly, there is a need for appropriate mechanisms to assess consumer engagement, otherwise it risks consumer engagement being tokenistic and having little relevance. If, as researchers argue, obtaining consumer input during guideline development lays the foundation for greater attention to patient preferences in clinical consultations (250,310,311), then conducting meaningful consumer engagement at a policy level is critical to ensure patients are supported and considered at an individual clinical consult level.

Involvement of consumers in guideline development is not a substitute for the discussion of patient preferences in the clinical consult. Rather consumer input should assist to identify recommendations which might be considered preference-sensitive. Patient preferences were more frequently presented in supporting evidence statements than in core recommendations. This could undermine the potential of guidelines to support the patient voice in primary care practice as it risks this information being overlooked by time-poor clinicians. More systematic flagging of patient-preference recommendations across guidelines could help address this. This is particularly important because as the thesis argues, clinical practice guidelines have a core role in informing disease-specific care plans and PDAs. Therefore clearer and more frequent flagging of patient-preference

recommendations in guidelines could serve as a catalyst for greater attention to patient preferences and shared decision-making in clinical consultations and across primary care practice tools.

This first stage of more active consumer engagement forms the basis for shared decision-making by promoting a reciprocal exchange of information and setting the scene for further deliberation that enables patients to participate. Information exchange is necessary but not sufficient for shared decision-making in the clinical encounter. To capitalise on the important role of clinical practice guidelines in directing care decisions and to address some of their limitations, this thesis joins van der Weijden (227) in arguing for clinical practice guidelines to be developed in combination with PDAs.

Patient decision aids

After reviewing clinical practice guidelines and care plans, it became evident that more targeted mechanisms to support shared decision-making and incorporate the patient voice within the clinical encounter is needed. PDAs were identified as a potential solution, but their applicability to a multimorbidity context had not previously been considered. Accordingly, the present study investigated the ways PDAs acknowledged multiple conditions in decision-making and their ability to contribute to the SDMCs. Key methods used by PDAs to acknowledge multiple conditions included flagging potential complications, prompting discussion between the patient and clinician and identifying how further illness could be prevented. The PDAs were found to contribute to the SDMCs, most prominently through the provision of information on the benefits and harms and the inclusion of value clarification processes; although there was scope for greater standardisation across PDAs.

PDAs provide evidence-based information on a particular condition, the various treatment options, and the benefits and harms of those options. In flagging multiple conditions and providing assistance to clinicians and patients to work through decision-making processes, PDAs have demonstrated potential to support deliberation and thereby contribute to shared decision-making. Despite these benefits, PDAs are not currently widely used within Australian primary care practice (245,336). To address this gap and to overcome some of

the criticisms made of clinical practice guidelines, the thesis suggests developing clinical practice guidelines in combination with PDAs.

PDAs could be developed alongside guidelines to ensure recommendations identified through consumer engagement processes are flagged as preference-sensitive. This could assist to increase uptake of PDAs, as clinical practice guidelines are widely used and respected tools within Australian primary care practice (233). Joint development of guidelines and PDAs could also help to overcome the criticism that guidelines are too disease centric and do not consider individual patient preferences (13,226,309) or include processes to assist with deliberation (12,67).

Care plans and PDAs could also be used to augment one another. PDAs assist patients and clinicians to work through discrete screening, treatment and/or medication decisions, but do not appear to assist with broader decisional conflicts or processes such as prioritising conditions and goals for care; key decisions faced by clinicians and patients managing multiple conditions (135,217,415). Working through these broader decisional conflicts and prioritising conditions and goals for care is something that could be integrated in care plan development.

Care plans

Care plans have been part of the primary care landscape contributing to a multidisciplinary approach to chronic disease care in Australia for almost two decades. As jointly developed strategies which outline the patient's preferences, needs and values for care, care plans are widely advocated as a means of individualising chronic disease care (159,274-276). As such they have a valuable role in assisting clinicians and patients to deliberate and reach an agreement on care decisions. However, the findings presented in chapter six revealed that care plan templates provide limited guidance to clinicians and patients on how to deliberate or set priorities within a multimorbidity context. In addition, the majority of available care plan templates reviewed were pre-filled. The inclusion of pre-filled data in disease-specific templates could result in care being decided with minimal collaboration and consultation between clinicians and patients. The inclusion of processes to facilitate the identification of

patients' preferences and priority setting; identify conflicts and synergies in care; and review of patients' goals and priorities are clearly needed in care planning.

PDA's step clinicians and patients through the decision-making process and include processes to assist with value clarification. By including processes that support deliberation, PDA's are able to assist clinicians and patients to find common ground and reach a shared understanding of the decisions made. There is potential for care plans to draw on elements of PDA's, particularly the generic PDA's, to inform their design.

Care plan templates provide an avenue for documenting the agreed decision(s) and dates for their review. Care decisions should be reviewed regularly to ensure they reflect the needs and preferences of the patient. In the event a decision needs to be reviewed, clinicians and patients can refer back to the relevant clinical practice guideline or PDA.

In summary, consideration of multiple conditions and shared decision-making cannot be viewed as an added component within standard clinical consults. For patients and clinicians to be truly supported in the management of multiple long term conditions, these issues need to be considered at a policy or primary care practice level to ensure meaningful change and engagement at the clinic level. If all primary care practice tools were to in some way acknowledge and support the patient voice and shared decision-making, meaningful practice wide change could be achieved.

8.2 Implications and implementation

Major structural reform is generally difficult and costly to achieve. Consequently most health system reform, in line with Lindblom's theory of incrementalism, occurs through incremental changes to existing practice (39,40). The mobilisation of primary care practice tools to better support multimorbidity care represents one step towards achieving a more systematic and routinised approach to multimorbidity care in primary care practice. However, it is well acknowledged that these tools are one small part of a much larger system, the elements of which influence their use and impact (140,442,443). This study has focused on the clinical context and primary care practice tools as potential drivers of the interaction between the clinician and patient. As part of a wider system, change cannot occur without systems

thinking that takes account of interconnected structures, elements and patterns (140,442,443). Contextual factors likely to impact the operationalisation of the proposed integration of primary care practice tools include financing, workforce, and information.

Financing

Australian primary care providers are paid on a fee-for-service basis (23,24,153). This payment method runs counter to the needs of patients with long-term conditions, as it encourages short consultation times (in 2013-2014 the median primary care consultation was 13 minutes (46)), and an “additive sequential” (21) approach involving a linear approach to managing individual diseases. Existing financing arrangements are not conducive to the proposed integration of primary care practice tools, which would require extended consultation times and alternative payment schemes to facilitate a multimorbidity approach to care. Calls to review existing payment schemes have been made by others including most recently the PHCAG (54).

Workforce

Providing a patient-centred care approach in primary care practice requires an adequately equipped workforce. Training, at the undergraduate, postgraduate, and continuing education levels, is required to promote the development of skills needed to manage the high levels of uncertainty and complexity associated with managing multiple conditions (28). This is reflected in the RACGP position statement for multimorbidity (33). Further development and strengthening of a workforce culture to ensure it values the perspectives of patients and supports their engagement in care decisions must also be a priority.

Information

Access to relevant and timely information is essential for clinicians to be able to engage in shared decision-making and provide effective multimorbidity care (28,141). Information to guide the management of multiple conditions is limited and further research into patients’ and clinicians’ experiences of multiple conditions and their management in primary care is needed to strengthen the evidence-base. Developing and strengthening information

systems to better monitor patients across care providers, is also essential to ensure improved continuity of care for patients and the provision of data to inform policy and practice.

8.3 Further research

Areas for further research focusing on the development and applicability of each of the individual tools to address multimorbidity care have been identified earlier in chapters five, six and seven and are not repeated here. Rather, this section considers areas for further research based on the integrated thesis findings.

Quality multimorbidity care

Further research into patients' experiences of quality multimorbidity care is needed. Existing quality indicators are often based on the assessment of individual disease or risk indicators (12). However, this approach seems contrary to a multimorbidity approach and inappropriate given effective multimorbidity care can at times necessitate an escalation of one condition to reduce the damage caused by another, or to align with the preferences of the patient. Hence, determining what constitutes quality multimorbidity care, from patients' perspective, and how this could be measured in practice requires further consideration.

Evaluation of models

Rigorous evaluation of different models for providing multimorbidity care, including the one proposed earlier in this chapter, is needed. The proposed changes to the identified primary care practice tools and their potential benefits are at this point theoretical and require empirical testing to determine acceptability to clinicians and patients. This requires careful assessment of individual patient outcomes, examination of clinician and patient perceptions of care, along with assessment of the acceptability, feasibility and health system impacts, including cost.

The identification of core attributes for integrating primary care practice tools

This thesis highlights how three existing tools, clinical practice guidelines, care plans, and PDAs, could be integrated to produce a synergistic response to multimorbidity care. This was done by examining the strengths and limitations of each of the tools and considering how the strengths of one could be used to augment the limitations of another. In thinking about the broader implications of these findings, and how other primary care practice tools could be similarly mapped and integrated, a number of preliminary attributes or dimensions, upon which tools could be evaluated, have been identified. These attributes, illustrated in Figure 8.3, could be considered along a scale from high to low attainment. Locating/mapping tools against these attributes could assist policy makers and clinicians to identify the strengths and limitations of existing tools and highlight opportunities for integration. For example, a tool that has a high evidence-base but low consideration or encouragement of patient preferences, would be flagged as needing to be partnered with a tool that better facilitates integration of patient preferences. These preliminary attributes, which emerged from the thesis as significant, require further detailed consideration and testing to determine their broader applicability and relevance.

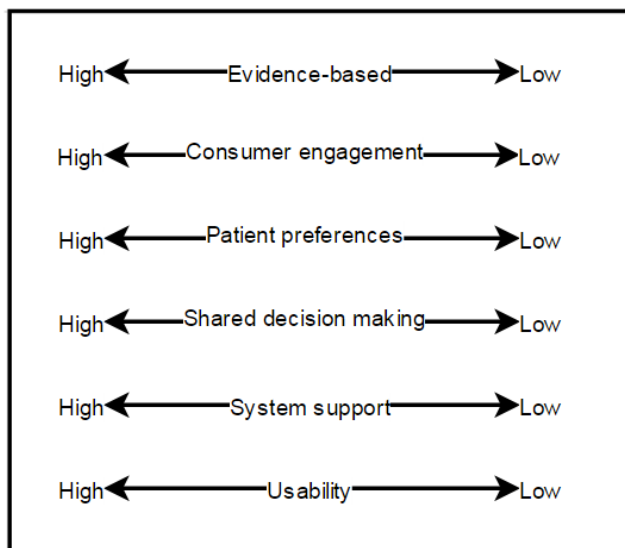


Figure 8.3 - Preliminary primary care practice tool attributes

Role of IT in supporting the integration of primary care practice tools

Electronic and interactive versions of each of the tools are available, with most now being developed in this format to increase accessibility and usability at the point of care. This should allow for greater integration and cross referencing of tools. Further research is needed to identify how tools could be electronically integrated to produce a tool which supports patients and clinicians throughout the clinical consult. Consideration would need to be given to the potential risks of increasing clinicians' engagement with electronic tools at the point of care.

8.4 Thesis strengths and limitations

The perspective taken for thesis was novel, no other study appears to have collectively examined primary care practice tools and how they may be adapted and integrated to better support multimorbidity care. This research provides new insights into how these tools could be adapted and better integrated to support a system level shift towards multimorbidity care and shared decision-making.

The thesis focused on the applicability of primary care practice tools from a primary care practice level. It did not examine how primary care practice tools are used or perceived by clinicians and patients in the clinical consultation. The rationale for this approach was twofold:

- 1) examining how primary care practice tools are used in clinical consultations for patients with multiple conditions, seemed superfluous if the tools themselves were ill equipped for this purpose;
- 2) examining primary care practice tools and how they could be adapted (if necessary) was considered more likely to bring about practice wide change than focusing on the individual actions of individual clinicians.

The thesis focused on the clinical encounter and the relationship between clinicians and patients. However, patients with multiple conditions are known to attend numerous health care providers (12,121,204). The role of practice nurses was not examined in this thesis

despite their increasing role in chronic disease management in primary care practices (41,444). The main rationale for focusing on the relationship between primary care clinicians and patients, was based on primary care clinicians' significant role as the major providers of chronic disease care who typically have overall responsibility for the coordination of care across other health care providers (13). If the relationship between the patient and their primary care clinician is not operating effectively then the continuity of care between other health professionals is likely to be comprised. How well these findings apply to other practice arrangements has not been addressed.

A rigorous approach was taken to the identification and analysis of the various tools. The study identified three primary care practice tools, all of which were validated through consultation with expert stakeholders as important to chronic disease care. It is important to note other tools, initiatives and resources are available to support primary care clinicians (e.g., HealthPathways (445)). These are provided by non-profit and private organisations, Primary Healthcare Networks (formerly Medicare Locals), and state and territory governments around Australia. However, these initiatives were not flagged by our expert panel and therefore were not included.

An extensive search of published and grey literature was conducted to identify relevant documents (primary care practice tools) for analysis. Searching the grey literature was a necessary and important step as this is where the majority of primary care practice tools are disseminated. If the reviews had been restricted to focus solely on peer-reviewed publications identified through database searches, then critical documents would have been overlooked.

Framework analysis is a well-regarded, systematic and comprehensive method for reviewing and evaluating data of the type included in this thesis (143). The quality, rigour and transparency of the data analysis, using the framework approach, relies heavily on the skill and experience of the researcher (277,446). Critical reflection and detailed discussion with supervisors, together with comprehensive index frameworks and detailed charts, occurred at all stages to enhance rigour and transparency.

The implications of this research extend beyond an Australian context. Multimorbidity is challenging health systems globally. Although, this thesis focused principally on primary care practice tools developed in Australia, for use in Australian primary care practice, these tools have been developed and used in primary care practices around the world. International studies have examined the use of clinical practice guidelines in a multimorbidity context (27,62,67,71,304,388). Adding to this literature, this research has identified how the strengths of guidelines could be harnessed and used in concert with other primary care practice tools to provide a systematic approach to multimorbidity care. Despite the long history of care plans, they have received surprisingly little review. Beyond Morgan et al. (136) who trialled a new care plan template for multiple conditions, literature examining the use of care plans for patients with multiple conditions is negligible. Although, previous studies have commented on the disease-specific nature of care plans templates (136,389), this thesis appears to be the only research which has formally analysed care plan templates to consider their relevance in providing multimorbidity care. Likewise, research examining the use of PDAs for patients with multiple conditions is scarce. This thesis appears to be the first to consider the use of PDAs within a multimorbidity context.

8.5 Conclusion

Health systems are ever evolving and need to adapt in line with changing disease profiles of the populations they serve. The limitations of an almost exclusive disease focus are well-documented, as are the challenges of consistently delivering patient-centred care. A contemporary challenge is that of shifting focus from a single chronic disease to one that accommodates multiple chronic diseases. Hence, there is a need for a paradigm shift within Australia's primary care system from one focused on single diseases to one that considers and supports multimorbidity care across primary care practice. Primary care practice tools have previously contributed to practice wide change for those managing single chronic conditions and therefore may hold one of the keys to shifting Australia's primary care system towards its next iteration of chronic disease management – multimorbidity care.

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Appendices

Appendix 1 Expert stakeholder invitation email and questions

Appendix 2 Expert stakeholder information sheet

Appendix 3 Ethics approval letter

Appendix 1. Expert stakeholder invitation email and questions



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Dear [Title Name],

A study investigating 'system tools currently available to guide GPs management of multiple long term conditions' is being undertaken by PhD student Charlotte Young, under the direction of Dr Allyson Mutch (tel. 3346 4682) and Associate Professor Fran Boyle (tel. 3346 4681) from the School of Population Health, University of Queensland.

An aim of the project is to identify which tools are used in primary care to enable GPs to manage multiple chronic conditions. As an expert in primary care we would be grateful if you could assist us by answering the questions below. The questions relate directly to your views and will not require you to divulge information on specific patients. All personal information will be kept confidential.

We would greatly value your participation, input and views. Please be assured that participation in this study, is entirely voluntary and you are free to withdraw at any stage.

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. You are of course, free to discuss your participation in this study with project staff (Ms Charlotte Young contactable on 0420307578). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

If you are agreeable to taking part, please complete the questions below and return via email to c.young@sph.uq.edu.au or click on the following link to complete the questions via surveymonkey: <https://www.surveymonkey.com/r/Q9HFGMQ>. Returning your responses by email or completing the survey online is accepted as an indication of your consent to participate in this project.

We would greatly appreciate your assistance.

Yours Sincerely,



Charlotte Young

School of Population Health | The University of Queensland | Public Health Building |
Herston Rd | Herston Qld 4006 | Australia | Ph: +61 7 3381 1215 | Email:

c.young@sph.uq.edu.au

Question 1: Based on your experience how would you rate the following tools for use in the management of multiple long term conditions in primary care? Please rate on a scale of 1 (not useful) to 5 (very useful).		
<i>Tools</i>	<i>Rating</i>	<i>Particular strengths or weaknesses</i>
<i>Care plans</i>		
<i>Clinical practice guidelines</i>		
Question 2: What additional Australian tools would you add to this list?		
Question 3: What do you believe are the essential features of a tool designed to support GPs in the management of multiple long term conditions in primary care?		
Question 4: What do you think is most needed to assist GPs in the management of multiple long term conditions? (Please list what you see as the 3 main priorities).		

Appendix 2. Expert stakeholder information sheet



Project Title: Critique of system tools currently available to guide GPs management of patient care from a multimorbidity perspective

Thank you for taking the time to read this information sheet about a research project designed to investigate system tools currently available to guide GPs management of patient care from a multimorbidity perspective.

Who is conducting the study?

The study will be conducted by The University of Queensland PhD student: Charlotte Young, under the direction of: Dr Allyson Mutch, Senior Lecturer (tel. 3346 4682) and Associate Professor Fran Boyle (tel. 3346 4681) from the School of Public Health, University of Queensland.

What is the purpose of the study?

We are investigating GPs professional opinion regarding current tools available to support the management and care of patients with multiple conditions.

What would your participation involve?

We would ask you to participate by completing a short one-off questionnaire. Your participation in the study will cease upon return of the completed questionnaire.

We would greatly value your participation in the above ways and have attempted to ensure that this process is minimally disruptive to your life. Please be assured that participation in this study, is entirely voluntary and you are free to withdraw at any stage. All information provided will be treated in confidence and will be available only to members of the research team for the purposes of the research project.

If you are agreeable to taking part, please complete the attached informed consent form and return via email to c.young@sph.uq.edu.au or fax to 3365 5442.

Who do I contact for more information?

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. You are of course, free to discuss your participation in this study with project staff (Ms Charlotte Young contactable on 0420307578). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

Thank you very much for your consideration in becoming involved in this research study. I look forward to hearing from you.

Yours sincerely,

Ms Charlotte Young

School of Public Health

The University of Queensland

Appendix 3. Ethics approval letter



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To Ms Charlotte Young

From Lisa Fitzgerald

Date 03 June 2014

Re Ethics Approval CY030614

CC Dr Allyson Mutch

Associate Professor Fran Boyle

Dear Charlotte,

Thank you for your application for ethics approval for your research:

Research topic: *What system tools support general practitioners management of multimorbidities?*

The School of Population Health Research Ethics Committee has reviewed the materials submitted and ethics approval has been given.

Yours faithfully

A handwritten signature in black ink, appearing to read 'L. Fitzgerald'.

Lisa Fitzgerald

Chair, School of Population Health Research Ethics Committee

School of Population Health, University of Queensland