Advance Care Planning

In General Practice

by

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Abbreviations

ACD	Advance care directive
ACP	Advance care planning
AD	Advance directive
AMA	Australian Medical Association
CASP	Critical Appraisal Skills Program
GP	General Practitioner
HCH	Health care home
HLQ	Health Literacy Questionnaire
ID	Identification
MBS	Medical Benefits Scheme
NP	Nurse Practitioner
NSW	New South Wales
PCMH	Patient centred medical home
PHC	Primary health care
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RACGP	Royal Australian College of General Practitioners
RN	Registered Nurse
SBREC	Social and Behavioural Research Ethics Committee
SD	Standard Deviation
USA	United States of America

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: Joanne Risk

Date: May 29, 2020.

Abstract

Advance care planning in general practice

Background

Within the Australian primary health care policy framework, advance care planning (ACP) is intended to ensure quality care according to individual wishes at end of life. An advance care directive (ACD), sometimes called a 'living will' describes how an individual would prefer to be treated in the event of a loss of capacity to direct their own care. In Australia, policies and/or laws have been enacted across all States and Territories to support the uptake of ACP.

A 2014 national prevalence study identified uptake of ACP in Australia was approximately 14%, although another found rates as low as 3% in general practice patients. ACP is viewed as an important and emerging issue in the public health domain. A preliminary search of the literature highlighted the need for a system-wide and multi-faceted approach to ACP though specific guidance to support systematic general practice facilitation of ACP was lacking.

Aim

The aim of this dissertation was to achieve increased uptake of ACP in general practice. Four key components were a) co-designing a socio-ecologically engineered approach to ACP in general practice; b) determining the perceived feasibility of the ACP intervention in general practice; c) determining patient experiences of the ACP intervention in general practice; and d) determining the effectiveness of the approach in general practice.

Research design, methods, and analysis

A mixed methods quasi-experimental case study approach was used. An exemplar general practice was identified to co-design and implement a complex ACP intervention. The participating general practice became the single case study for the purposes of evaluating the approach. The intervention design was based on understanding barriers to ACP and enhancing enablers to improve ACP uptake by the practice's patients aged over 75 years. Patients attending the practice for an annual 75+ health assessment were engaged in a 3-step intervention. Step 1 involved being asked about having an advance care directive (ACD). Step 2 involved the provision of an ACD booklet, and Step 3 was an invitation to participate in an ACP group information session. The intervention was evaluated over a 12-week period.

To measure and understand the impact of the complex ACP intervention, qualitative and quantitative data were collected across individual, interpersonal, provider and system levels within this case. Quantitative data analysis involved comparison of ACD prevalence between control and intervention groups. Before and after health literacy data were collected for the intervention group and process measures of implementation were assessed. Qualitative analysis involved thematic analysis of participant and provider interviews.

Findings

During the intervention evaluation period (12 weeks), 123 patients were involved in Step 1, 85 patients were involved in Step 2, and 19 patients consented to participate in Step 3. At the end of the evaluation period, patients who had attended the practice for a 75+ health assessment during the study period were 1.79 times [CI 1.1–2.9; *p*=0.012] more likely to have an advance care directive than those patients attending in the six months prior to the study period. Patients who participated in all three steps of the process had the highest uptake of ACD, with eight of 19 [42%] participants completing an ACD [*p*=0.012].

In total, 17 interviews were conducted with eight randomly selected participants and nine health care providers. Thematic analysis of interview data confirmed the general acceptability of the intervention approach to ACP in general practice with endorsement from patients and providers about the role of the general practice in systematically engaging patients in ACP discussions. Key themes arising included the important role of provider as *initiator*, and the concept of *shared wisdom* and *social support* enabling discussion about *things we don't talk about* for participants.

Conclusion

The study demonstrates that a 3-step ACP intervention in general practice is a feasible and effective way to increase uptake of ACP in patients aged over 75 years. The co-design approach and subsequent guidance contribute to new evidence supporting future implementation of the approach in general practices interested in increasing uptake of ACD by their patient population.

Acknowledgements

The following list of people to whom I owe a debt of gratitude is long though perhaps not as long as it could or would be. We live in a connected world and my doctoral experience has been touched by many in big and small ways over the past seven years. Within this wonderful community offering broad support I make special mention of the following:

I wish to acknowledge Prof Colin MacDougall firstly for endorsing my admission into the doctoral program, and then some years later, for his advocacy and flexibility when my attention was required elsewhere for a period of time. I remain so grateful for the compassion and understanding.

I have been blessed with stellar supervision. Professors Paul Ward and Lucie Walters have been the Perfect Pair. Affectionately known as good cop and bad cop [I'll leave them to make their own claims about which is which or whom is who] they have together been instrumental in guiding me to reach this endpoint. [I remain hopeful that having worked through this process with me, everyone will now know how important it is to consider the endpoint, well before ever reaching it] … [Paul☺] Seriously though… Thank You Thank You.

Thanks also to Joel Rhee for sharing his expertise and being available to provide periodic wise council; and at work, to my CEO Dianne Kitcher and fellow Primary Health Network colleagues for keeping the faith and supporting me professionally over many years.

To my lovely friend Wendy, who, after heeding my advice to write an advance care directive, spurred me on at a low point explaining just how useful it had been when caring for her late husband. And so too in memory, vale dear Jim.

To the fabulous doctors and staff at the Queen Street Medical Centre in Moruya, your commitment to your patients and to delivering the best quality care is extraordinary and I thank you for allowing me to work with you. To Loren, who makes such a positive difference in the lives of so many elderly people every day, and without whom this could not have happened. Thank You seems insufficient.

And finally, to my family. There are no words…

Preamble

I could not have predicted back in 1986, watching the miserable decline of my beloved grandfather, that advance care planning would be 'a thing' of the future. We, the family, watched passively as health professionals confidently prescribed intervention after intervention to save his much loved and increasingly wretched form. And he, oblivious to it all, would have wanted none of it.

Less than a decade later, I was working as the operating theatre team leader in a large Colorado trauma hospital. I was now one of those health professionals working hard to salvage the sometimes unsalvageable. Whether it be due to sudden onset or slow decline, the extent that a health service was able to intervene and sustain a life, regardless of the resulting quality of life, was troubling. How much was enough? What would be acceptable to this person? Where was the patient's voice in all of this?

Since that time, the concept of advance care planning (ACP) has been introduced in countries around the world, creating a mechanism to give the patient a voice at a time when they have historically not been heard. There remains widespread lack of community awareness and limited uptake, with ACP slow to gain traction in the Australian community.

As I consider my own and my parents' mortality, I have cause to question how they and others like them might reasonably be expected to know about ACP? There is no clear answer.

My motivation now, by building on existing research, is to try and help people access the information they need, at a time before crisis, and to assist their health care providers to understand the important role they could play in facilitating the voice of their patients.

In doing so I make a small contribution to humanity and honour the memory of my grandfather.

Chapter 1: Introduction

1.1 Australia's ageing population

As a consequence of the huge improvements in social determinants of health and management of communicable and non-communicable illness in the last century, Australia's population profile is increasingly aged with an increasing life expectancy.(1) For most Australians, death will occur 'after the eightieth decade following a period of chronic illness and gradual deterioration in cognitive and physical function'.(2) Associated with increasing age, loss of cognition may limit an individual's ability to make autonomous decisions at end of life.(3) Advances in medical technology have resulted in increased ability of practitioners to intervene and maintain life past what was previously possible, even though quality of life resulting from the interventions is not assured.(4)

Within the Australian health policy framework, advance care planning (ACP) is intended to ensure quality care according to individual wishes at end of life.(5) An advance care directive (ACD), sometimes called a 'living will' describes how an individual would prefer to be treated in the event of a loss of capacity to direct one's own care.(6) In the 1980s, ACP emerged as a rights-based initiative in the United States of America (USA) in response to societal demand for the right to self-determination about medical care at end of life.(5) This concern resonated internationally including in Australia where policies and/or laws have been enacted across all States and Territories to support the uptake of ACP.(5-8)

Despite clear need, little is known about how ACP is understood by people in Australia (9) or where responsibility lies for initiating ACP. A 2014 national prevalence study identified uptake of ACP in Australia as approximately 14%. A more recent prevalence study attributed general practice patients with rates as low as three percent. (10, 11) In this context, ACP is viewed as an important and emerging issue in the public health domain.(2, 3)

1.2 Primary health care and dying

When considering public health, *primary health care* (PHC) has been identified as a key strategy of public health derived from a social model of health.(12) PHC was defined by the World Health Organization in the declaration of Alma-Ata in 1978 as 'the first level of contact of individuals, the family and community within a national health system bringing health care as close as possible to where people live and work, and constituting the first element of a continuing health care process'.(13) PHC in Australia involves health promotion, prevention and screening, early intervention, and management of chronic and complex conditions across the life span.(14) It is delivered by a range of service providers operating across the public, private and non-government sectors. These services are variously funded by the Commonwealth government through the Medical Benefits Scheme (MBS), State and Territory governments through their respective health systems, and/or through private payments from individuals.(15)

In 1986, broader prerequisites for health were outlined in the Ottawa Charter, defined as peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity.(16) These broader 'social determinants of health' were understood as the conditions in which people 'are born, grow, live, work and age'.(17) There was silence about how people die in this expanded understanding of factors contributing to health. Given humankind unequivocally experiences 100% mortality, this silence about death in an age of unprecedented medical technology and lifesaving enhancements warrants attention as an area of significant public health interest and arguably places ACP squarely in the PHC domain.

1.3 General practice in Australia

This study is set in Australia where general practice is viewed as the centre of the PHC system, with the general practitioner (GP) delivering primary care to individual patients within this system. According to the Royal Australian College of General Practitioners (RACGP), the GP coordinates care of patients, is the gatekeeper for referrals to other specialists, and cares for the patient over time.(14) General practice is a medical specialty which in some countries is called family medicine or primary care.(14) Most Australians receive primary care through a GP, where they attend a private business and are billed for the services provided. Bills for each attendance are subsidised (for most people) or fully reimbursed (for most low socio-economic groups and elderly people) through the government's Medicare system. Although general practice is the most common model of primary care in Australia, community members can access primary care services in a range of less common models of care including community health centres and Aboriginal community-controlled health services.

1.4 General practice policy environment

In 2013, the importance of general practice in comprehensive PHC in the Australian health system was recognised in the *National Primary Health Care Strategic Framework.*(15) Subsequent governments have continued to engage in shaping primary health care, recognising the value of keeping people well and out of hospital. In 2016, the Primary Healthcare Advisory Committee recommended the adoption of a new model of primary care intended to create universal access to primary care and better meet the needs of Australians with chronic and complex conditions into the future.(18) The recommended approach balanced the need for enhanced quality of care for an increasing number of people with chronic and complex health needs with a recognition of a need to pace change. The proposed model of care was called the 'health care home' (HCH) or patient-centred medical home (PCMH). Originating in the USA and being implemented in a number of countries internationally,(19) HCH was a model for how primary care might be re-organised to deliver patient-centred, comprehensive, team-based, coordinated, accessible care, focused on quality and safety.(14) The most significant change in the Australian context was that within HCH sites, patients could sign up to have all their primary care services provided by a single general practice at no additional cost for additional services (much like a gym or club membership). Interestingly, the great majority of people in Australia already considered general practice to be the equivalent of a HCH (20) although funding models had not been structured to support this comprehensive approach to care. Outcomes of the 2016 HCH reforms are still being evaluated.

In 2019, *Australia's Long Term National Health Plan* was launched. This included the formation of a Primary Health Reform steering group, tasked with providing independent advice on the development of a primary health care 10-year plan. The public narrative includes a focus on healthy ageing and aged care, however ACP is not explicitly included in the information available to date.(21)

1.5 Advance care planning policy environment

The Australian Health Ministers Advisory Council (the Council) released a policy paper in September 2011 titled *A National Framework for Advance Care Directives*.(22) In this, the Council sought to establish a national code of ethical practice and best practice standards around ACP across Australia. Despite being a comprehensive document, responsibility for initiation of ACP was not clearly identified or allocated, funding was not aligned or structural incentives to drive change identified, and there was no funding mechanism or specific MBS item number to drive activity. An updated or revised policy position has not been released. In response to this 2011 policy paper, the RACGP released a statement in 2012 titled *Advance care planning should be incorporated into routine general practice* in which they suggested that, ideally, ACP should be conducted in primary care settings *before* people became ill.(23-25) In 2015, the Australian Commission on Safety and Quality in Health Care issued a consensus statement on end of life care with an implicit understanding that ACP occurs *after* diagnosis of a life-limiting condition.(26) This example of divergence in the ACP policy environment leaves general practice with unclear guidance about important aspects of ACP.

1.6 Advance care planning and the broader community

The broader community also lacks guidance about ACP and end of life choices.(27) An underlying societal and structural community avoidance of death is problematic.(28, 29) As noted by Tucker in 2009, 'we are living in a death-defying culture; we fear death, and we avoid it at all cost' and this view is sanctioned by innumerable writings and discussions in popular Western culture.(30) Internationally, social movements focused on changing this structural silence and increasing individual agency over death have become more mainstream.(28) Community volunteers and ambassadors host public forums for informal discussions about death and dying with examples including Death Cafes, Dying to Know Days and ACP week celebrations.(31, 32) These community activities are designed to normalise the consideration of 'death as part of life' in society, with a stated objective on one site *'to increase awareness of death with a view to helping people make the most of their (finite) lives'.* (33)

Even with community- based normalisation initiatives, Australia has not seen a groundswell of uptake in ACP. This demonstrates a gap which the candidate argues may be filled by primary health care.The concept of ACP, where individuals have the opportunity to exercise their agency in the present day, in order to be heard at a future time when agency is lost, is important. Most specifically, the candidate was interested in exploring the role of general practice in facilitating the uptake of advance care directives. Clarity regarding terminology is required.

Advance care planning [ACP] has been described as an ongoing process in which individuals think about their values and beliefs, and based on these values consider their preferences for future health care.(27) The process generally involves the appointment of an enduring guardian, and the completion of an advance care directive.

An **enduring guardian** is the person appointed to make future health and lifestyle decisions on behalf of another person, in the event they are unable to make their own choices. In New South Wales, this person is also known as a substitute decision maker. This is the person from whom health care providers will seek advice in the event of loss of capacity of an individual to make their own health care decisions. In the absence of an advance care directive, the enduring guardian will be asked to make decisions based on their understanding of what the individual would have wanted.

An advance care directive [ACD] is a written document that provides a record of an individual's preference for future care. It can record values, life goals and preferred health outcomes or directions about care and treatment. It provides guidance for the enduring guardian. An enduring guardian cannot change the wishes expressed in a person's advance care directive.

For clarity, when referring to ACP in this dissertation the candidate is referring to the *process* of ACP which may result in an ACD.

1.7 Advance care planning in general practice

There is widespread agreement that primary care providers are well placed to initiate ACP with their patients before the onset of serious illness or impairment.(24, 34-36) Many people engage with their general practitioner (GP) at times of illness and otherwise periodically throughout their lives. It is often a GP together with the patient who identify primary diagnoses and subsequent health care management.(14) Despite this, specific guidance to support systematic general practice involvement in ACP uptake is lacking, although the need for a system wide and multi-faceted approach to ACP is noted.(37)

There is an extensive body of ACP research literature in which the barriers to and enablers of ACP are described, but the literature has lacked a cohesive conceptual framework to anchor, link and give coherence to the important heterogeneous range of research findings therein. This heterogeneity has made it difficult to navigate and understand the body of evidence. The body of ACP research generated in an Australian general practice context remains sparse. The candidate has sought to address an important gap in the evidence -base regarding general practice management in supporting people to undertake ACP and prepare for decision making at their end of life.

1.8 Structure of the dissertation

To address the issue of low levels of ACP uptake in the community, the candidate determined to explore existing approaches and, where needed, develop enhanced approaches to support an increase of ACP activity in general practice. A critical interpretive synthesis of the ACP literature was undertaken using a conceptual framework to filter and organise the evidence. Mechanisms and approaches to ACP used with effect were understood through a socio-ecological theory. The literature review findings are outlined in Chapter 2. There was a gap in the literature regarding 'how a complex intervention would influence uptake of advance care planning in general practice'.

Four key aims were developed to inform the research question. These are outlined in the thesis a) co-designing a socio-ecologically engineered approach to ACP in general practice; b) determining the perceived feasibility of ACP intervention in general practice; c) determining the patient experience of ACP intervention in general practice; and d) determining the effectiveness of a socio-ecologically derived model of care in general practice. In addressing these aims, the next stage of the research involved partnering with an exemplar general practice to design and run a proof of concept ACP intervention. A process of co-design was used to translate evidence-informed strategies from the literature review into a feasible day-to-day model of care. This is described in Chapter 3.

To evaluate the effectiveness of this ACP intervention, a quasi-experimental case study was developed. A mixed methods approach including quantitative measures and qualitative analysis was chosen. Of note, patient perspectives on and experience of ACP in general practice were rarely evident in the limited general practice research literature available. This research design explicitly included patient experience as an outcome measure. The trial outcomes were reported against four parameters – patient experience, provider experience, feasibility, and effectiveness. Considerations relating to research methodology and methods are explained in Chapter 4.

The case study involved evaluation of the implementation of a complex intervention. Components of this intervention involved:

- active management of the practice population through proactive targeting of care,
- provision of a 75+ health assessment,
- provision of ACP information to enhance knowledge,
- prompts and reminders, and
- facilitated interaction in a group ACP information session.

Results of the intervention are presented in Chapter 5. ACD prevalence data demonstrated that the intervention lifted the percentage of patients aged over 75 years with an ACD from 29% to 41%, with no notable change in health literacy. In Qualitative findings pointed to how individuals work through the decision to act or not. This was seen to include reflections on how infrequently participants talked about death and ACP, who they needed to involve in ACP and who and when they engaged their spouse, chosen one, family members, friends and peers. Providers reflected on the congruence of the intervention aligned to their professional and personal values and the importance of teamwork and collaboration. Both participant and provider experience of the ACP intervention in general practice was described as experientially and operationally feasible. In Chapter 6, there is discussion of the overall study outcomes including how the results address the study aims.

In relation to the research literature, through the findings presented in this dissertation the candidate has

- demonstrated the application of a conceptual framework to better understand and harness the large volume of existing ACP literature to generate new understanding,

- applied the conceptual framework to trial an enhanced model of care in a general practice setting and reported the findings,
- generated guidance for transferability to enhance ACP in general practice settings using a socio-ecologically engineered approach with some demonstrated applicability,
- contributed to the limited Australian general practice literature,
- included patients' voices in meaningful contribution to determining an acceptable model of care, and
- identified opportunities to further improve the ACP evidence base.

A summary and conclusion are provided in Chapter 7.

1.9 Chapter summary

Given Australia's ageing demographic profile, an identified societal concern about quality of life at the end of life, an evolving policy position and social movements to encourage ACP uptake, it is difficult to explain why there has been limited uptake of ACP by consumers. This has been identified as an emerging public health issue and some studies have suggested PHC settings including general practice may be optimal for initiation of ACP discussions. To achieve increased uptake of ACP in general practice it is important to understand mechanisms and approaches that have been used with effect. This introduction provided an overview of the structure of the dissertation which outlined steps taken to address an important gap in the evidence base regarding general practice management in supporting people to undertake advance care planning and prepare for decision making at their end of life. Chapter 2 outlines the contemporary evidence relating to ACP in the general practice setting.

Chapter 2: Literature review

Introduction

In seeking to increase uptake of ACP in general practice it is important to understand and build on the existing evidence. In this chapter, the approach and findings of a systematic review and critical interpretive synthesis of the peer reviewed literature relating to ACP in general practice is presented. This was undertaken to understand what mechanisms and approaches to ACP had been previously reported. A socio-ecological perspective applied to the body of literature generated new associations linking the body of evidence and determining potential gaps in understanding.

The findings of this literature review were published in *BMJ Open* in September 2019 as a peer reviewed paper titled *Barriers, enablers and initiatives for uptake of advance care planning in general practice: a systematic review and critical interpretive synthesis*.(29) [Appendix 1] The published review has been updated and revised in this chapter, with relevant research evidence from recent publications through until March 2020 included in the synthesis. In accordance with rules relating to the inclusion of publications in theses, the candidate as primary author was responsible for literature review design (75%), data collection and analysis (90%), and writing and editing (90%). Co-authors have approved inclusion of the publication in this dissertation. [Appendix 2]

2.1 Search strategy

Database searches were undertaken from inception to March 2020 across Ovid Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, ProQuest and Cochrane databases. The selected databases are considered the most useful to identify peer reviewed articles relating to this topic. The search strategy was developed for Ovid Medline (see Table 1) and was modified to suit the language requirements of other databases. It included Subject Headings and free text words. During the searches, wildcards and * truncation were used to ensure broad inclusion of related search terms. Boolean operators 'OR' and 'AND' were also used. Proximity searching was not used.

The search strategy was developed with the expert assistance of a medical librarian. Search terms were determined with the intent of capturing broad representation of the ACP literature, and then refined to focus on the specific context of interest, thus minimising the risk of incomplete data. Search terms included concepts of advance care planning, advance care directive or advance health directive or living will; AND concepts of knowledge, attitudes, practice AND concepts of behavior, engagement, barriers, participation among both consumers, and health care providers AND general practice OR family practice or patient centred medical homes. A review protocol submitted to PROSPERO is available at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018088838 [Appendix 3]

TABLE 1: EXAMPLE OF SEARCH STRATEGY – OVID MEDLINE

Search history

#	Searches
1	Advance Care Planning/
2	((advance* adj3 (plan* or directive*)) or living will*) tw, kw.
3	1 or 2
4	Knowledge/ or Health Knowledge, Attitudes, Practice/
5	(concept* or attitude* or belief* or practice* or experience* or knowledg*or uptake* or utilis* or implement*) tw, kf.
6	4 or 5
7	(Consumer Behavior or Consumer Participation or Consumer Health Information or consumer engag* or decision making or consumer uptake or barriers to uptake or consumer concepts or Primary health care* or general practice or family practice or GP or general practitioner or patient centred medical home or patient-centred medical home or health care home or practice nurse or community nurse) tw, kw.
8	Physicians, Family/ or General Practitioners/ or Family Practice/
9	Primary Health Care/
10	*Health Personnel/
11	Consumer Behavior/
12	Consumer Health Information/
13	7 or 8 or 9 or 10 or 11 or 12
14	3 and 6 and 13

2.1.1 Inclusion/exclusion criteria

Determining the most appropriate search terms and inclusion/exclusion criteria required consideration of nomenclature. Nationally and internationally, consistent terminology about research studies in ACP is lacking. It is variously characterised as ACP, an advance (care or health) directive or living will. The search strategy included all derivations. To identify literature relating to low uptake of ACP required consideration of consumer and provider knowledge, attitudes, and practices about ACP. This included studies considering consumer and provider engagement, behaviour, and participation.

The review was bound within general practice. As previously noted, general practice in Australia is described by one peak body as an entity that 'provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities'.(14) It was understood from preliminary searches that a substantial body of research about ACP had been generated in countries other than Australia, and within this there were nuanced differences about how 'general practice' was described. It was determined not to include or exclude studies based on geographical limits but to filter results based on the description of the health care provider and the setting. Studies from countries describing general practice, family medicine and primary care services sufficiently comparable to the definition of Australian general practice were included. Examples included Canadian family practice and Belgian family medicine, each understood to be similar to Australian general practice. In the USA, general practice differed around types of organisational structure, professional roles and responsibilities, and service descriptors; however, American primary care clinics and family practice outpatient clinics have been described as analogous with Australian general practice.(39) A further consideration and inclusion was the 'patient centred medical home' or 'health care home'. This emerging model of primary care was thought to be changing the structure of general practice, both in Australia and internationally, and consideration of ACP in this context warranted inclusion in the review.

Studies were included if they met the following criteria: written in English, published in a peer reviewed journal, primary care research with scope limited to general practice, and adult participants. Studies that focused on acute care, inpatient care, aged care facilities, palliative care, or clinical management at end of life were considered out of scope and excluded from the review. Other exclusion criteria included legal focus, mental health focus or issues for minority groups.

2.2 Search results

An online search was conducted in July 2019 and updated in March 2020. In total, 7092 online studies were identified as potentially relevant. At the completion of the database searches identified studies were catalogued in Endnote®. Duplicate studies were removed, and the remaining 5271 studies were screened by title for inclusion. Of these, 613 studies were considered potentially relevant and screened by abstract, after which 555 studies were excluded, and a further 18 studies were identified through targeted citation and reference list review resulting in a total of 76 studies for full text review. Year of publication ranged from 1991 to 2019 and the research was from nine countries. The earliest publications came from the USA where the antecedents of ACP originated, and the majority of publications also originated in the USA.

2.2.1 Study selection process

The search process was conducted by the candidate. Studies were reviewed and catalogued by the candidate using a template to identify key features of interest relevant to review. These were:

- type of study,
- year and country of publication,
- study setting,
- barriers identified,
- enablers identified,
- initiatives identified.
- outcomes / recommendations.

A **barrier** was understood to be 'a circumstance or obstacle that keeps people or things apart or prevents communication or progress'.(40) An **enabler** was understood as a moderating factor to be defined as 'to make able; give power, means, competence, or ability to'.(41) An **initiative** or **intervention** was defined as 'a specified strategy or set of strategies designed to change the knowledge, perceptions, skills, and/or behaviour of individuals, groups, or organisations, with the goal of improving health outcomes',(42) specifically in this case ACP uptake. Studies were accepted when the primary focus of the study included all key search terms and aligned with inclusion and exclusion criteria. The resulting list of studies meeting the inclusion/exclusion criteria was subject to a quality review performed by the candidate and one supervisor.

2.3 Quality

The heterogeneity of approaches found within the search literature made it difficult to apply a standardised quality framework, however, the Joanna Briggs Institute provided a suite of critical appraisal tools considered suitable for quality assessment covering a range of methodological approaches. The candidate undertook the initial screening of search results with strict adherence to the review protocol and inclusion and exclusion criteria. The candidate and one of the supervisors then independently reviewed all shortlisted papers using Joanna Briggs Critical Appraisal Checklists.(43-47) Tools used included randomised control trial; systematic review and meta-analysis; cohort studies; analytical cross sectional studies; qualitative studies and quasi-experimental studies. Results were compared and when reviewer findings differed, discussion ensued to reach a consensus understanding and search results were adjusted accordingly. This process was considered important to reduce reviewer bias. Following completion of this process, all studies agreed by both the candidate and her supervisor were included in subsequent review and critical interpretive synthesis. The quality assessment resulted in the exclusion of 18 studies. There were quality concerns with three papers, and on closer analysis 15 studies were identified as lacking relevance. At the completion of the quality review, 58 studies were included in the critical interpretive synthesis. These comprised eight systematic reviews, eight randomised control trials, 15 analytical cross section studies, three cohort studies, nine quasi-experimental studies and 15 qualitative studies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] framework used to summarise the search process is outlined in Figure 1.(48)

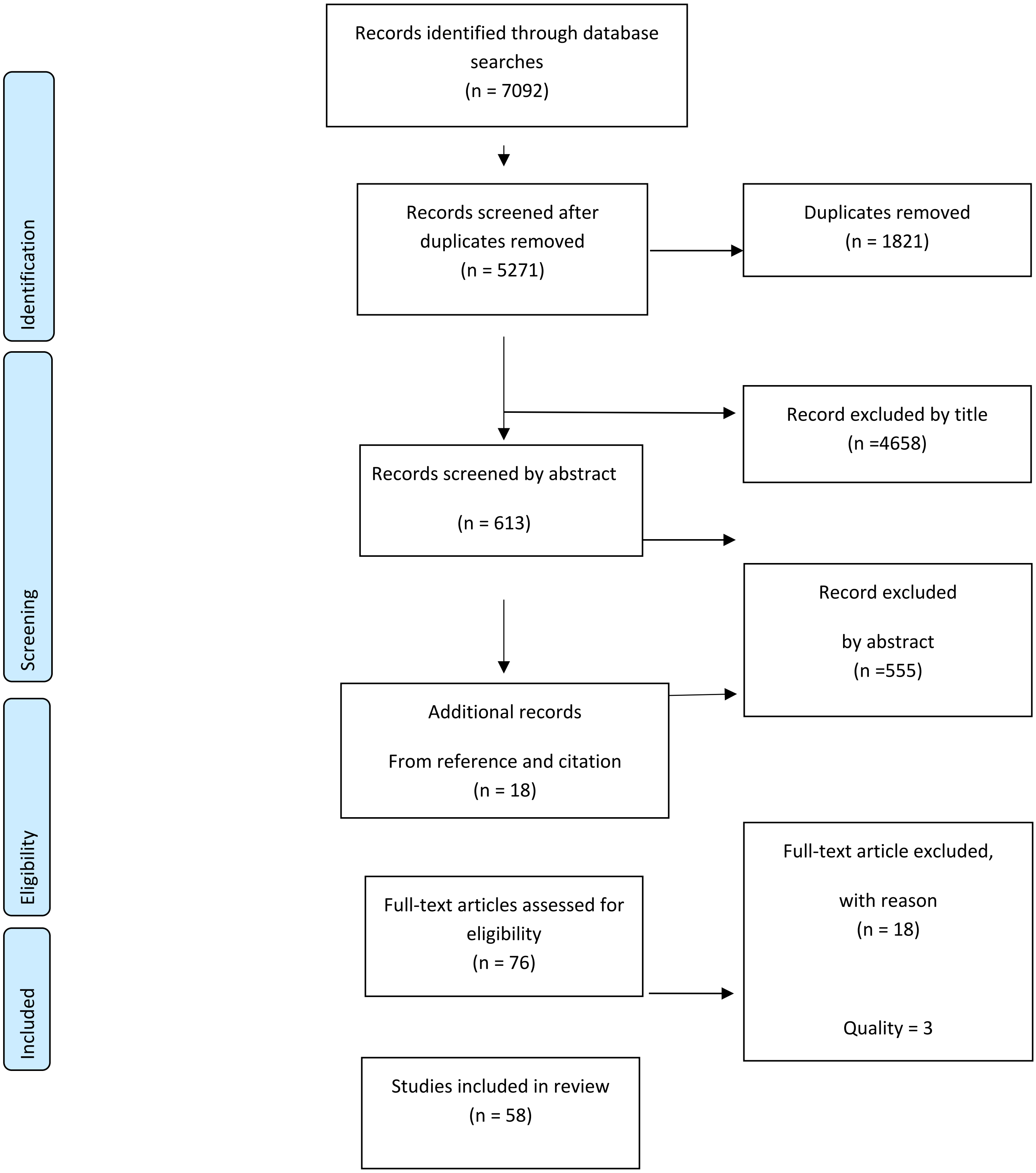


FIGURE 1: PRISMA FLOW DIAGRAM (PRISMA: PREFERRED REPORTING ITEMS FOR SYSTEMATIC REVIEWS AND META-ANALYSES).(48)

2.4 Conceptual framework

A socio-ecological conceptual framework was used to organise the literature. This framework has been frequently applied in health promotion research over the past years(49) and has been found to have applicability to complex health systems.(50, 51) The multiple factors that influence health are attributable to *levels of influence*, often depicted as nested concentric circles representing contextual layers of increasing scope. McCormack et al. (2017) applied this framework in considering the problem of low health literacy and patient engagement in health systems, presenting an argument in support of this theoretical approach. In a general practice setting, individuals as patients bring their own understanding and attitudes when engaging with providers to seek care. Providers operate within their own frame of reference and within a broader system supported by processes and models of care. Figure 2, adapted from McCormack et al.,(50) outlines levels of influence depicted from a socio-ecological perspective appropriate to general practice as the functional system of interest.

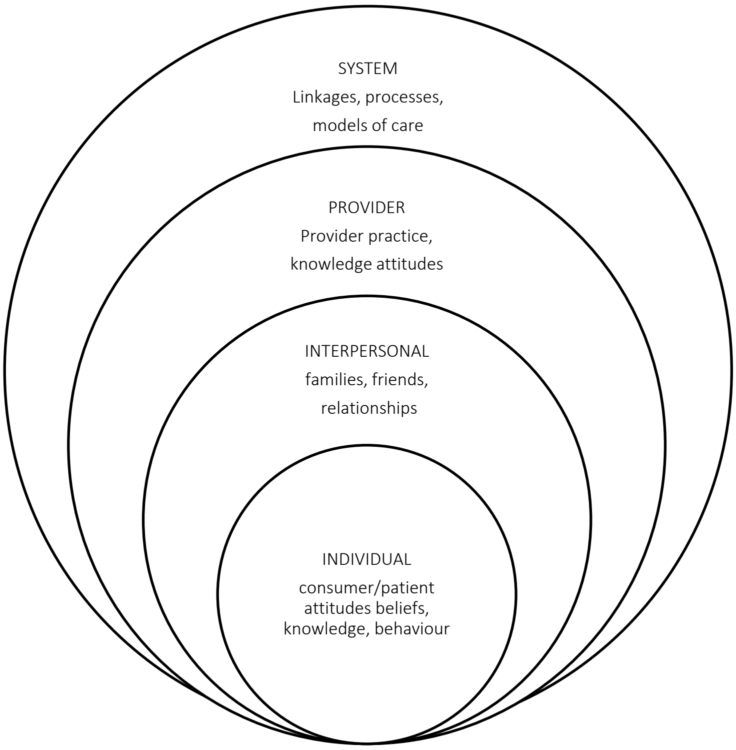


FIGURE 2: SOCIO-ECOLOGICAL PERSPECTIVE FOR GENERAL PRACTICE. ADAPTED FROM MCCORMACK ET AL. (50)

Each study was reviewed and the barriers, enablers, stated aim and methodology were mapped into one or more of the contextual levels of influence across a socio-ecological perspective.

2.4.1 Mapping of studies

A decision matrix (Table 2) was developed to guide a consistent approach to categorisation of studies across the four contextual levels of influence. The development of the decision matrix was informed by background reading of the literature to understand the theoretical origins and iterations of this socio-ecological approach over time and to capture the intended distinction and relationships between levels of the model.(50-52). This understanding was translated into a general practice context by preliminary testing of the matrix criteria with a sample of the literature and was found to be applicable.

TABLE 2: DECISION MATRIX

Contextual level of influence	Criteria used to determine level of influence.	Example in general practice context
Individual	If the primary focus of the study was to seek understanding about or to effect change at an individual/patient/consumer level	A study to ask patients about their views on ACP
Interpersonal	If the primary focus of the study was to seek understanding about or to effect change at a relationship level – involving family, friends, trusted others including health care providers	A study exploring link between caring for someone at end of life and the likelihood of engaging in ACP discussion
Provider	If the primary focus of the study was to seek understanding about or to effect change at a provider level within general practice including knowledge, attitudes, practices	A study to understand general practitioner (GP) knowledge of ACP
System	If the primary focus of the study was to seek understanding about IT tools, templates or to effect change in routines in practice, linkages between providers and or models of care	A study to test the efficacy of a range of ACP discussion tools
Multi-level	If the focus of a study was to influence more than one contextual level	A study to test efficacy of written material for patients combined with IT prompts for GPs during patient consultation

2.4.2 Distribution of studies

A summary of the distribution of studies across socio-ecological contextual levels of influence was undertaken to understand the scope of research interest and existing evidence (Table 3).

TABLE 3: DISTRIBUTION OF STUDIES ACROSS SOCIO-ECOLOGICAL CONTEXTUAL LEVELS OF INFLUENCE.

Level of Influence	Number of studies	Reference
Individual	5	(35, 53-56)
Interpersonal	2	(57, 58)
Provider	18	(59-76)
System	11	(24, 37, 77-85)
Multi-level	14	(23, 25, 34, 60, 85-95)

2.4.2.1 Individual level studies

Five studies were identified in the individual category. The authors of these studies sought to understand the points of view of patients attending general practice regarding ACP. Two studies involved patient surveys with researchers seeking to explore attitudes, barriers and enablers;(53, 54) one study mapped prevalence of ACP discussions with patients in practice;(35) two studies included before and after consultation patient surveys.(55, 56)

2.4.2.2 Interpersonal level studies

Two studies were identified in the interpersonal category. In one interview study researchers sought to understand if previous experience with illness and end of life care was associated with readiness to participate in ACP.(57) Researchers in the second study sought to determine if a positive experience of care in general practice was associated with the likelihood of having an ACP discussion.(58)

2.4.2.3 Provider level studies

The provider level of study was the most common focus of research in and about general practice, with 18 studies identified. In 14 studies, researchers tried to understand GP perceptions of ACP. Five of these involved GP surveys,(59, 62, 66, 67, 75) four employed focus group discussions,(65, 70, 72, 96) and five used interviews.(68, 69, 73, 74, 76) Five of the studies focused on knowledge,(59, 62, 67, 74, 76) and eight on attitudes.(65-70, 73, 96) One study sought to audit GP practice in initiating discussion.(64) Researchers in two studies explored the role of non GP providers,(63, 72) and researchers in two other studies sought to test educational interventions.(61, 71)

2.4.2.4 System level studies

A total of 11 heterogeneous studies were identified at the system level. Two studies explored the effect of different models of care in practice, one in real time(24) and one retrospectively.(77) Seven studies considered different interventions relating to tools,(56, 79, 80, 84, 85) and processes,(78, 83) with a focus on screening and/or enabling the patient through technology; one study sought to determine views on a system wide approach(81) and one study involved an ACP prevalence audit.(37)

2.4.2.5 Multi-level studies

A multi-level study was one that had relevance across multiple levels of the socio-ecological perspective. There were 14 studies categorised in this way that used multi-step processes and more complex research methods than other levels. Three randomised control trials reported level of efficacy of three different interventions tested in general practice.(25, 86, 90) These studies sought variously to test two different approaches to patient and doctor appointment;(25) undertake an educational intervention for provider motivation,(90) and to test efficacy of health record(86). In one study, researchers undertook a complex qualitative study addressing known barriers (95). Others explored patient and GP attitudes to participation with multi-level surveys,(25, 87) and one interview study.(91) Four studies described as complex interventions explored alternative models of care,(88, 89, 93, 94) and three studies described mixed methods approaches all aimed at determining patient and provider satisfaction with advance care planning while conceptualising approaches to normalise ACP activity.

2.5 Results

Synthesising the diverse and disaggregated body of ACP literature was challenging. There was a lack of coherence in literature about the nature and causality of barriers and enablers. Some studies inherently described barriers and enablers as linked and binary; for example, lack of knowledge as a barrier was frequently linked to provision of education as an enabler. Other studies described factors independent of each other in non-binary relationships. Cataloguing these variations was achieved by interpreting the barriers and enablers independently. This resulted in instances of apparent duplication but remained important to capture at each level and is explored further in the discussion. The results of the review are outlined in the following four sections:

1. Critical synthesis of systematic reviews
2. Barriers to ACP in general practice
3. Enablers of ACP in general practice
4. Initiatives/strategies to increase ACP in general practice

2.5.1 Critical synthesis of systematic reviews

Eight systematic reviews with relevance to ACP in general practice were included, generated from four countries and spanning publication dates from 2007 to 2019. In general, the reviews were quite heterogeneous, with one focused on barriers and enablers to uptake of ACP in general practice,(97) one focused on the attitudes of the public and GPs to ACP,(98) and one focused on the effect of structured ACP communication tools.(99) Four studies looked at the efficacy of a range of interventions,(100-103) and the remaining study was a narrative review of other systematic reviews.(104)

In a 2009 review of reviews, Tamayo-Velasquez et al. reported that most studies, although heterogeneous in approach, had reached very similar conclusions,(104) and subsequent reviews have continued to have largely consistent findings. Common barriers were identified and attributed to lack of patient and provider knowledge; lack of provider skills and experience; patient, family and provider attitudes; and system issues related to time pressure, documentation challenges and mechanisms of information sharing. A common theme was noted with a number of reviews categorising data across a combination of patient level, provider level and system level findings.(97, 98, 100) In one study,(100) interventions at patient and physician levels were reported, and in another, categories of individual autonomy versus personal circumstance or health system effects were considered.(98) These levels were consistent with contextual levels of influence when viewed from a socio-ecological perspective, although none of the reviews explicitly linked the described levels to a theory, model or framework.

It was important to observe the described levels in order to understand if interventions described in the literature were targeting specific levels to achieve their effect. Some studies reported targeting interventions across multiple levels, e.g. patient, provider and system, whereas others were understood to be applying multiple interventions within a *single* level, e.g. mail outs, telephone calls, or websites aimed at the individual, which was a nuanced but important difference. As suggested by Weiner et al.,(51) interventions where multiple level approaches were applied were more effective than single intervention approaches.(100-103) When studies investigated the outcome of combinations of actions in achieving an effect, provision of information alone did not increase ACD completion rates above the background community level.(100) The least successful interventions were mail outs without reinforcement, and one review reported inconsistent findings for all types of interventions.(101) The most successful interventions exerted influence over multiple levels and involved direct and iterative patient–health care provider interaction over multiple visits. Studies reached similar conclusions in so far as person-to-person interaction was seen as a strong enabler when compared with more static approaches.(100, 102)

There was some consensus across reviews about the need to better understand barriers to and enablers of ACP.(97, 100, 103) Some reviews went further to suggest interventions needed to be based on these understandings.(97, 98) There was general consensus that more research was required. Oczkowski et al. challenged the quality of available evidence in considering efficacy of documented approaches to ACP in primary care,(99) describing it as low to very low in quality, echoing the findings of an earlier 2010 review.(101)

Analysis of the systematic reviews alone did not sufficiently answer the current review questions. A number of limitations diminished the value of review findings. The inclusion and exclusion criteria for individual reviews differed widely, making direct comparison problematic. A number of studies included in the reviews were sourced from non-general practice contexts, making more generalised findings not directly relevant.(100-102) These reviews were conditionally included only where general practice findings were explicitly reported as discrete categories. A number of papers considered in one or more systematic reviews were also included for individual consideration in the current review because the questions posed were different to the reported aims of the systematic reviews in which the studies originally appeared. A brief overview of the reported findings of the systematic reviews is provided in Table 4.

TABLE 4: OVERVIEW OF REPORTED FINDINGS OF SYSTEMATIC REVIEWS

First Author	Ref	Year	Country	Aim	Studies	Summary of outcomes	Recommendations
De Vleminck	(97)	2013	Belgium	To identify the perceived factors hindering or facilitating GPs in engaging in ACP with their patients	16	A range of barriers and facilitators were identified and attributed to GP characteristics, perceived patient characteristics and health system characteristics.	Understanding barriers and facilitators and targeting GP and health system related barriers was considered important for development of interventions aimed at facilitating ACP in general practice.
Durbin	(101)	2010	USA	To systematically analyse evidence about the outcome and percentage of newly completed ACD, focusing on effectiveness of a) types of educational interventions versus controls; and b) one educational intervention over another.	16	After examining various combinations of intervention including single approaches, combined approaches and multiple combinations, the authors determined the evidence base for effectiveness of specific interventions was weak, with the exception that combined approaches were more effective than single approaches in increasing the percentage of newly completed advance directives.	More research is needed to address the low number of studies looking at specific interventions.

Jezewski	(102)	2007	USA	To synthesise the state of the science regarding effectiveness of interventions to increase ACD completion rates	25	Interventions with repeated multiple contacts or stimuli were found to be most effective. Not all intervention designs may be effective across the life span and that 'a single approach' will likely not be effective because the same approach will probably not work for all people.	A knowledgeable person who can answer questions should be an integral component of any intervention. Creative interventions need to be developed that are matched to the individual's needs at a particular point in time.
Oczkowski	(99)	2016	USA	To determine the effect of structured communication tools for end-of-life decision making on completion of ACP	67	Low quality evidence that structured communication tools assist with end-of-life decision making resulting in uncertainty about the magnitude of the effect.	Given the heterogeneity of populations, interventions and effects, more work is needed to guide the selection, adaptation and tailored implementation of tools in local settings and contexts.
Ramsaroop	(100)	2007	USA	To systematically review studies designed to increase advance directive completion in the primary care setting	18	There was increased efficacy in achieving advance directive completion with direct patient-to-health professional contact, with this being a consistent finding among studies.	Barriers to completion of advance directives warrant attention in future intervention studies.

						The more effective approaches used iterative interactions over multiple visits. Passive education of patients using written materials alone was relatively ineffective Uptake remains low.	
Sharp	(98)	2013	UK	To investigate attitudes of the public and health care professionals to ACP discussions with frail older people	26	Many frail elderly people would welcome the opportunity to discuss ACP but a significant minority would not. There was no consensus for optimal timing of the conversation. Reluctance of family members to engage is a significant barrier.	Categorised across three levels: **health system issues** – health providers require support and training to initiate discussions **individual autonomy** – raised questions about how to achieve this **(inter)personal circumstance**– raised questions about how to achieve this
Solis	(103)	2018	USA	To evaluate strategies used in primary care settings to initiate ACP leading to completion of AD	12	The use of multipronged approaches was most successful for initiating ACP discussion. Effective interventions included patient education materials, computer	There is a gap in empirical knowledge, and this opens an opportunity for more research. Providers should consider increasing ACP discussions with patients and create

						generated triggers for providers and multidisciplinary team involvement.	opportunities to do so more systematically.
Tamayo-Velazquez	(104)	2009	Spain	To identify, appraise and synthesise the results of systematic reviews of the literature that examine effectiveness of interventions to increase advance directive completion rate.	7	Determined that each of the systematic reviews reached very similar conclusions. Passive informative material in isolation does not significantly increase advance directive completion rates. Effectiveness is increased over multiple visits where patients are provided opportunity to interact with an expert in the field and are afforded an individual who will answer any queries.	Further research is required to identify new strategies to increase ACP completion rates.

2.5.2 Barriers to ACP in general practice

A barrier is understood in the general practice context as something that limits uptake of ACP. A barrier can have effect at an individual, interpersonal, organisational or system level. The same barrier can also occur across a number of levels. Barriers identified in the literature across four socio-ecological levels of influence are shown in Table 5.

TABLE 5: KEY BARRIERS TO ACP SORTED BY SOCIO-ECOLOGICAL LEVELS OF INFLUENCE AND RANKED BY FREQUENCY

LEVEL IDENTIFIED	BARRIER	Number of studies	References
INDIVIDUAL level	Lack of [consumer] knowledge about ACP	15	(24, 55, 60, 66, 68, 75, 77-79, 81, 82, 86, 91, 93, 95, 105)
	Attitudes – perceived irrelevance	7	(34, 54, 55, 64, 66, 87, 95)
	Trust/questions of efficacy	4	(53, 54, 66, 68)
	Denial/emotions/reluctance	10	(54, 55, 60, 66, 68, 81, 86, 87, 95, 98)
INTERPERSONAL level	Role ambiguity – GP expectation patient will initiate discussion about ACP	7	(34, 65, 81, 84, 91-93, 106)
	Role ambiguity – Patient expectation GP will initiate discussion about ACP	5	(24, 35, 53, 87, 92, 106)
	GP–patient relationship	5	(24, 66, 68, 71, 91)
	Concern with family relationships	6	(34, 55, 66, 94, 95, 98)
	Preference for informal discussion with family	1	(34)
PROVIDER level	Lack of [GP] knowledge/skills/ confidence	20	(24, 61, 63, 65-67, 71, 72, 74, 76, 78, 81, 85, 86, 93-97, 105)

	Lack of time	13	(55, 64, 65, 70, 71, 75, 77, 85, 86, 93-95, 105)
	Various concerns including legal uncertainty, prognosis, best time	10	(25, 59, 63, 70-73, 86, 90, 106)
	Doubts about efficacy of ACP	3	(65, 66)
SYSTEM level	Lack of linkages and mechanism for sharing ACP	6	(63, 65, 66, 75, 83, 86, 97)
	Lack of funding mechanisms	2	(63, 81)
	Lack of standard templates, tools, documents, IT systems	6	(65, 66, 68, 78, 82, 85)
	Accountability	1	(93)

2.5.2.1 Barriers at an Individual level

When considering barriers to ACP in general practice from an individual perspective, there were very few general practice studies directly involving patients.(35, 53-56, 95) A few studies described patient experience by proxy through opinions obtained from GPs. The most common barrier described at the individual level, largely attributed by clinicians, was patient lack of knowledge and awareness about ACP, including lack of knowledge about clinical considerations at end of life.(75, 66) Attitudes of individuals about ACP were reported to vary widely. Researchers reported the perceived irrelevance of ACP was a barrier, with the relevance of ACP described with ambivalence when associated with an existing state of wellness or absence of terminal diagnoses.(34, 95) Furthermore, an identified lack of trust in the health system was reported with concerns that an ACP would in some way limit care or negatively impact the individual.(54) The concepts of poor literacy,(82) and poor health literacy,(93) as contributing factors were also noted.

2.5.2.2 Barriers at an Interpersonal level

Barriers identified across the interpersonal level involved the individual in relation with others. Very few general practice studies focused specifically on this interpersonal aspect.(57, 58) Many studies described confusion and role ambiguity about initiation of ACP. When considering the doctor–patient relationship, studies reported differences in expectation about whose role it was to initiate the ACP discussion. Described as a lack of role clarity, this uncertainty in the doctor–patient relationship was understood as a barrier to ACP.(24, 35, 53, 62, 84, 87, 92) Studies cited GP concerns about initiating the ACP discussion, not doing so in order to avoid being a source of anxiety or loss of hope. Concern about jeopardizing the doctor–patient relationship was a recurrent theme described in studies. Patient expectation that GPs should initiate ACP discussions (35, 53, 92) was understood as a barrier when the GP did not initiate the discussion. Studies found patients were willing to discuss ACP when asked. This contrasted with other findings that discussing ACP and end of life preferences was potentially distressing for some individuals who might prefer to avoid the topic as unpalatable, while conversely, trust in an absolute deity was cited as reason to not need ACP.(55)

One study explicitly studied interpersonal barriers,(55) finding a range of relationship concerns. Poor family relationships were reported as a barrier for some. Not wanting family involved, or not wanting to burden family members was also a consideration.(95) Difficulty conversing with family about ACP and the need for assistance to achieve these conversations was raised. Conversely, studies also identified family members were not willing to support GPs in discussion about ACP with patients.(66, 98) Patient preference for informality and choosing to discuss end of life matters privately within the family were more common in more educated people and resulted in lack of formal documentation in the medical record.(34)

2.5.2.3 Barriers at a provider level

Studies that focused on barriers to ACP at a provider level had largely consistent findings, echoing those of the previously reported systematic reviews. GPs' lack of knowledge, skills, and confidence in relation to ACP were most frequently cited (see Table 5). GPs' lack of knowledge was identified in a number of studies variously outlining knowledge gaps relating to patient competence, legal considerations, documentation and processes. Time pressure to maintain busy consultation schedules limited GPs' ability and willingness to initiate time-consuming ACP discussions during consultations.(75) GPs were also reluctant to engage patients in ACP discussions because of the complexity of diagnoses, (86, 71) or doubts about individuals' ability to comprehend the issues involved. GPs questioned the efficacy of ACP, particularly about application at end of life, and one study described paternalistic views including a sense that the GP knew what the patient would prefer, so ACP was unnecessary.(81)

2.5.2.4 Barriers at a system level

System level barriers to ACP were commonly considered in the available literature. Common system level concerns included, for example, the suitability of ACP templates,(68, 82) or uncertainty about the efficacy of one information kit over another.(85) Lack of consensus about what information was required in a written ACP contributed to a lack of clarity, including the relative importance of value statements.(82) Difficulties associated with poor system linkages resulting in lack of availability of ACP at point of care were highlighted.(65, 75) Barriers associated with uptake of electronic medical record reminder prompts were identified.(78) Context specific issues were described, for example, lack of suitable funding mechanisms was problematic in some jurisdictions.(63, 81) In one study, it was suggested that providers' ACP activity was not important because there was no performance monitoring of it. If it was not measured at a system level, it was thought to be not important to the system outcomes.(93) This lack of reporting for providers was described as a barrier because there was no incentive to drive ACP activity.(93)

A recurrent barrier to ACP across the levels of influence was a lack of shared understanding by providers and patients about whose role it was to initiate ACP discussions and when ACP was best initiated. Studies reported conflicting views. Tierney et al. sought to explore the perceived barrier about whether patient or provider should initiate ACP discussions, identifying many arguments in support of broad ranging views.(92) The following studies highlight widely contrasting views.

Emanuel et al. found that lack of physician initiative was the most frequently cited barrier to ACP according to patients.(87) Physician reluctance to initiate ACP discussions was compounded by patient expectation that it was the physician's responsibility to do so,(107) and this was somewhat consistent with findings in a British study where 60% of respondents would only talk about ACP if the topic was raised with them.(53) In other instances, patients were reported to have raised the issue themselves.(70) A Canadian study found patients preferred to initiate the discussion themselves and often did so with family or friends in preference to their family physician.(35) In contrast, Pfeifer et al. found physicians accepted responsibility to initiate discussions but retained a level of concern about the right time to do so,(91) and this despite evidence that counselling by a clinician was the best catalyst for the completion of advance directives.(78) In a British study, the most important predictor of patients completing an ACP was having been asked.(53) GP reported barriers to initiating ACP discussions included concern for causing the patient distress or triggering unwanted negative responses,(91,70) however, at least one study demonstrated significant improvement in patient satisfaction in primary care consultations when physicians initiated discussion about advance care directives. De Vleminck et al. found GPs deliberated about actively initiating discussion of ACP versus passively waiting to discuss it and this varied qualitatively according to GP knowledge, experience and communication skills.(96)

In other studies, the need to encourage a wider group of health professionals to become involved in ACP was suggested.(81) Nurse care coordinators were found to be well positioned to leverage opportunities to discuss ACP with patients in primary care,(88, 92, 95) but Fletcher et al. explored the role of nurses and identified the majority of nurse participants looked to the doctor for leadership in ACP and pointed to lack of role clarity in this regard across providers generally.(65)

There was uncertainty about optimal timing for initiating ACP discussions.(91) An emerging consensus was that ACP discussion should occur in the community prior to hospitalisation and before critical situations. (58, 63) Concepts about timing varied from routine inclusion of ACP discussion for all patients when illness became predominant,(69) to waiting passively for the patient to raise the topic directly or listening for patient triggers during consultation as a signal of readiness to participate in conversation.(96)

Barriers were often not considered in relation to their effect on each other. Some barriers were specific and applicable to a particular study modality. For example, studies requiring patients to receive an electronic message relied on the person being able to access the technology. An inability to do so would be reported as a barrier that was specific and limited to the mechanics of the particular intervention. Other barriers were more complex and multi-faceted, summarised as lack of patient and provider understanding of roles; lack of knowledge; lack of provider skills and experience; patient, family and provider attitudes; and system issues related to time pressure, documentation challenges and mechanisms of information sharing.

2.5.3 Enablers for ACP in general practice

An enabler was understood as a moderating factor, defined as ‘to make able; give power, means, competence, or ability to.’(41) An enabler can have effect at an individual, interpersonal, organisational or system level. The same enabler can also occur across several levels. Enablers identified in the literature as having influence at one or more of the four levels across the socio-ecological perspective are shown in Table 6.

TABLE 6: KEY ENABLERS MAPPED TO SOCIO-ECOLOGICAL LEVELS OF INFLUENCE AND FREQUENCY REPORTED.

LEVEL IDENTIFIED	ENABLER	Number of studies	References
INDIVIDUAL level	Demographic likelihood (increased age)	3	(23, 53, 77)
	Education and public awareness	8	(23, 25, 56, 67, 75, 81, 90, 97)
	Stage of change – readiness	6	(55-57, 80, 84, 100)
	Timing	6	(23, 34, 67, 69, 70, 97)
INTERPERSONAL level	Doctor–patient relationship (strength, length of, trust, familiarity)	11	(23, 24, 35, 58, 70, 76, 84, 88, 91, 95, 96)
	Nurse–patient relationship	5	(60, 88, 89, 94, 95)
	Conversation and deliberation	5	(56, 68, 69, 84, 88, 95)
	Group interaction	2	(77, 89)
	Previous experience with ACP	4	(57, 65, 84, 97)
PROVIDER level	GP and practice nurse education and communication training	8	(59, 61, 63, 64, 67, 69, 94, 95)
	GP or practice nurse initiating the ACP discussion	6	(62, 87, 93-96)
	GP with philosophical agreement to ACP	9	(24, 35, 54, 56, 65, 68, 71, 96) (75)
	GP engagement in team approach	3	(63, 77, 88)
SYSTEM level	IT systems – portals, prompts, decision aids	8	(66, 78, 80, 83, 86, 88, 93, 96)
	Templates	6	(23, 59, 68, 72, 90, 96)
	Business as usual processes and protocols	12	(23, 34, 55, 64, 67, 69, 75, 81, 86, 87, 92, 93)
	Models of care – group appointments, nurse led clinics, ACP facilitators	12	(24, 60, 63, 64, 73, 74, 77, 88, 89, 94, 95, 105)

2.5.3.1 Enablers at an individual level

Studies explicitly outlining ACP enablers at an individual level were not common in the general practice literature. An understanding of demographic profiles was suggested as an enabler in a number of studies in which people in older age groups were reported as most likely to engage in ACP discussions,(23, 53, 77) while one study found people of all ages desired ACP discussion.(87) Individuals who initiated ACP discussions were found to help overcome GP reluctance to engage in the topic,(96) and authors suggested that individuals should be encouraged to raise the subject,(25) however, concepts of individual autonomy and empowerment were largely absent from general practice literature.

Studies reported people with higher levels of education were more likely to have engaged in ACP,(23, 34) and tailoring ACP discussion and resources to an individual's literacy level was effective.(82) A number of studies reported the need for individuals to access education through public awareness raising activities.(67, 75, 81, 97) Approaches to patient education were tested in one RCT with mixed results and ongoing challenges, so while potentially useful, education was not a panacea.(90)

An alternative approach described an individual's readiness to engage in ACP viewed from the trans-theoretical stages of change approach.(55, 80) Described as an iterative process, ACP was framed as a behaviour change process which involved the individual through discrete steps.(56, 100) Determining the individual's readiness to engage prior to initiating ACP discussions was described as an important step.(55, 57, 80)

Researchers considered whether there was an optimal time to initiate ACP discussions, referring to time in relation to disease timelines rather than chronological time, for example, during first consultation, at diagnosis, in advance disease stages or at end of life. Findings included at patient's first appointment,(23) while individuals were healthy,(34) planting the seed for future discussions,(70) and when patient was chronically or terminally ill. In a binary relation, the anxiety of not knowing the best timing was a barrier so understanding the best timing would, by contrast, provide clarity and be enabling.

2.5.3.2 Enablers at an interpersonal level

Studies that explicitly focused on ACP enablers at an interpersonal level were least common in the general practice literature although the importance of relational aspects of ACP was evident. The majority of studies identifying interpersonal enablers referred specifically to the importance of the doctor–patient relationship. Enabling factors within this relationship were longevity of the association and high level of trust.(23, 24, 35, 58, 60, 70, 88, 91, 95) A more recent trend was apparent in the literature with five studies published since 2016 detailing the role of nurse–patient communication as an enabling factor in uptake of ACP. Other studies found individuals with lived experience of caring for someone else at end of life, or previous experience with ACP had increased uptake of ACP, (57, 65) and this also included GPs with personal experience of ACP.(97) Two studies reported the process of discussion and reflection of values over multiple visits as enabling ACP to be most effective, (95, 100) supported by similar findings from others.(56, 68, 69, 88) Other interpersonal enablers involved participation in facilitated discussions in group settings where group dynamics and the ability to socialise were identified as effective levers.(77, 89) One study reported the value of socialisation around ACP discussion in group settings,(77) and another described value in 'learning from the experience and perspectives of others'.(89)

2.5.3.3 Enablers at a provider level

Suggested enablers at the provider level were often interrelated. Strong communication skills, confidence, knowledge, and positive GP attitudes were described as enablers and achieving this was variously described through provider education and training, skills development, deliberative discussion, and the clarification of GP attitudes and roles. The emerging role of the broader health care team with a particular focus on extended roles of the practice nurse was evident in most recent publications.(60, 88, 94, 95) Studies provided recommendations in support of provider training. Within these, the focus of studies varied with training recommendations ranging from specific to broad including legal considerations,(59) professional mentorship and observed practice for providers engaged in ACP,(63, 93), communication skill training,(64, 69) and professional development training about ACP. One study reported the efficacy of provider training that was reported to increase GP knowledge and confidence.(61) Positive GP attitudes to ACP were shown to increased engagement in ACP discussion.(62, 87, 93, 96)

2.5.3.4 Enablers at a system level

Many studies included in the review were focused on describing and/or testing enablers at a system level. Among these, the most frequent recommendation was establishing various 'business as usual' approaches to ACP, seeking to normalise ACP in practice. Concepts ranged from a general theme,(24, 93) including and specifically targeting all patients of a certain age,(34) monthly purpose-specific clinics;(77) reminders in the medical record;(78) and provision of ACP resources to patients and providers through portals in an automated way.(86)

Systematic prompting of patients and providers with technology reminders and information was found to have some effect. Studies explored timing the prompts pre-consultation with mail out,(93) during consultations as screen prompts for providers,(78) and simultaneous prompts for both consumer and provider.(25, 93) Studies reported variable degrees of success for such initiatives,(25, 78, 88, 93) and studies implementing a combination of approaches reported greater uptake of ACP than single step processes.(25)

The importance of ACP resources such as templates and standardised documentation was a recurrent theme.(70) A number of studies recommended the need for standardised and improved ACP templates and tools to support discussion in general practice, (68) with testing and development of tools and fit for purpose approaches for target populations. There was one study with findings about efficacy of an ACP template designed for people with low health literacy,(82) while another study developed and tested a tool to assess stage of change,(80) and a third study found that personalised ACPs increased uptake.(90)

Since 1992 when researchers noted the majority of participating physicians had never seen, used or discussed ACP with any patient,(67) there have been many published studies internationally indicating growing physician support for ACP. More recently, most GPs felt ACP was important,(70) citing ACP attributes as safeguarding patient autonomy and conferring peace of mind for individuals and families.(72) Positive GP attitudes are a known enabler. Practice nurses also reported ACP as beneficial to patients and understood a potential role for nurses in this context.(63, 95) Positive attitudes have also been reported in the community, with one study describing a majority of patients and healthy people considering ACP as 'meaningful and important'.(54 p1583)

Leveraging enablers alone was not shown as sufficient for systematic improvement in ACP. Many enablers were understood to share direct binary relationships with barriers and were described in the context of overcoming particular barriers. For example, if the barrier was lack of knowledge, the enabler was provision of education, but if the barrier was lack of knowledge combined with an entrenched or cynical attitude, education alone would be ineffective. In considering the range of barriers, studies explored many complex interventions and alternative models of care with a focus on changes to practice processes that enabled alternative ways of working, for example by role delineation and delegation of responsibility. Alternative models of care were found to be complex enablers with implications across multiple levels of the socio-ecological perspective. Examples included exploring attitudes to nurse led clinics,(63) conducting group appointments,(77, 89, 105) and trialling ACP facilitators in practice.(24)

In this section, known enablers of ACP have been described across multiple contexts, with each nuanced to the study environment. An overall observation in considering the body of literature was the need for flexible and place-based responsiveness in the design of interventions. Not understanding the range of barriers at play limited effectiveness of enablers. One size did not fit all and a single approach was unlikely to work for all. (102)

2.5.4 Initiatives to increase ACP in general practice

This section synthesises current knowledge from intervention studies, with a summary provided in Table 7 below (p49). Fourteen general practice intervention studies were identified in the review. Of these, 12 studies were conducted in the USA, one in Australia and one study was reported from Belgium. Publications spanned a period from 1996 to 2019 with six of the 14 studies published after 2016. The studies consisted of six randomised control trials, two mixed methods studies, a comparison study, a cross sectional survey, a qualitative study and three studies described as complex interventions.

Intervention studies were only included if the research was undertaken in general practice. Interventions ranged in complexity from simple initiatives focused on one level of influence to complex multi-level undertakings. An intervention was considered a complex intervention when the actions occurred across multiple socio-ecological levels of influence. Each intervention aimed to increase ACP and the approaches used were different across the studies. A recent Canadian study found it was not clear that the assembled body of research had explicitly considered the known barriers and enablers when framing proposed interventions.(66) Two exceptions were found. A study by Miller et al. (2019) explicitly described intervention activities based on and intending to overcome known barriers (95) as did an earlier study (2016) by De Vleminck et al.(60)

Early research involved interventions with a common focus on prompting and reminding. Patients were prompted by mail outs,(90, 93) reminder letters,(93) and waiting room questionnaires.(23) Physicians were prompted with scripts and various systems to trigger discussion during consultations.(25, 60, 92, 93) The efficacy of combining various combinations of prompting and reminding was explored in a 3-arm blinded randomised control trial used to test the efficacy of a combination of two simple interventions. Patients with upcoming appointments receiving a mail out of patient information and this was combined with the physician receiving a computer-generated reminder during consultation. Reported findings showed a substantial increase in completed ACPs in one of the three study arms, supporting the efficacy of a mail out supported by a physician prompt, with no change between the control and the physician only prompt arms.(25) Subsequent studies commonly included one or more prompts as components of more complex interventions. In another mixed methods study, the efficacy of two different conversation guides was compared, based on a determination of the required literacy reading levels of the two documents. This was measured by patient and provider experience of use.(85) In another early study, Tierney et al. hypothesised that physicians feared initiating ACP discussion as it would cause a reduction in patient satisfaction with care. Tierney et al. used a physician computer prompt during consultation followed by a post consultation patient satisfaction survey. Study findings reported patients were more satisfied with their provider when ACP was discussed, so physician fears were found to be baseless.(92)

Weiner et al.'s contention that 'interventions that target determinants at multiple levels and mutually reinforce each other are likely to produce larger and longer lasting effects than interventions that target determinants at only one level',(51) remains to be seen. Of the one qualitative study (95) and three complex interventions,(60, 89, 93) only one study systematically and explicitly sought to address barriers and leverage enablers across multiple levels of influence.(60) In this study, by understanding the key barriers and enablers, De Vleminck et al. described a structured response that identified four key components underpinning successful ACP interventions.(60) The first key component was described as the involvement of trained and experienced facilitators. This approach was a common feature across complex studies, although the facilitation role varied with involvement of one or more of the patient's physician, social worker, registered nurse or nurse practitioner. Face-to-face facilitation was a known enabler with influence at the interpersonal level. All but two interventions (83, 86) involved discussion with knowledgeable health professionals. This interpersonal influence was further leveraged by Holland et al. who required individuals to discuss ACP with their families prior to a second appointment (88) and by Lum et al. who conducted group appointments to harness the dynamic interaction between participants in facilitated sessions.(89) The importance of skilled facilitation was also noted by Miller et al. who provided training to the providers to enhance their facilitation skills. (95)

The second key component identified in the complex intervention of De Vleminck et al. was a selection process to identify eligible patients, considered to be a key underpinning component of ACP interventions. The patients cited for inclusion on an ACP invitation register by De Vleminck et al. were those with poor health and poor prognosis.(60) Demographic targeting of older people was identified as an enabler and advancing patient age was a primary consideration for recruitment in all but three interventions, ranging from 50 years for those with known chronic disease,(25, 92) to 65 years,(83, 89) 70 years (25) and 75 years.(92) Only one study included all adults over 21 years.(23) Miller et al. were unique in recruiting both opportunistically and by use of the question: 'Would I be surprised if this patient were to die in the next twelve months?' If the answer was no, ACP discussion was considered indicated.(95)

The third key component suggested by De Vleminck et al. was a structured and patient- centred ACP discussion that was addressed in the 2016 study design by development of a GP prompt, a conversation guide and template for ACP. Similarly, Duffield and Podzamsky employed waiting room questionnaires,(23) Wissow et al. prepared physician scripts,(93) while Pearlman et al. and Lum et al. employed conversation guides.(90,89) Holland et al. sought to evaluate the feasibility of four different tools.(88) Across all studies, a range of tools was suggested as suitable, however the key point was the value of a structured approach, (60, 88-90) because several tools were reported as moderately effective. Miller et al. used an ACP workbook and an advance directive template to guide the discussion.(95)

The fourth key component cited by De Vleminck et al. was the opportunity to complete ACP documents.(60) The provision of an ACP form or template was evident in most interventions.

While most intervention studies had a mitigating effect on one or more known barriers at various levels of influence, no study was seen to mitigate the influence of all barriers or leverage all enablers. There were examples of studies testing approaches in contexts in which other known barriers predictably might be problematic, but which were not factored into the proposed interventions. For example, testing a GP reminder prompt in the middle of a busy consultation without quarantining time to respond to the prompt was not found to be an effective mechanism for change.(25) Whereas some interventions had some impact and demonstrated a level of efficacy, to create a synergistic initiative required consideration of all key barriers operating at each level, with a design structured to maximise outcome. De Vleminck et al. are yet to report their findings.(60) Miller et al. arguably addressed all four key intervention components identified by De Vleminck et al. in their 2019 qualitative study but this was described as a pilot study, suggesting further research was required.(95)

Keeping with complex approaches, in a retrospective analysis Dipko et al. explored the efficacy of a single face-to-face education session with a social worker in a primary care clinic versus a combination of multiple face-to-face sessions or participation in group education with an elderly population.(77) In this study, the ACP completion rate was positively associated with participation in group education, and higher still in multiple face-to-face sessions. From an efficiency perspective the researchers concluded group sessions provided the most efficacy with regard to time, resources and outcomes.(108)

In a more recent study in 2016, Lum et al. tested the feasibility of group medical visits in a patient-centred medical home environment and explicitly noted the importance of patient engagement through group interaction, 'leveraging the group dynamic to transform the typical patient–clinician encounter'.(89) Positive outcomes were reported from participants both in terms of individual uptake of advance directives but also in reported conversations with loved ones. Group appointments were suggested to be an effective forum for knowledge exchange, creating an efficient and less stressful situation than one-on-one office visits and overcoming a number of barriers related to process, time and role responsibilities.(64) This study was one of two reported interventions from a patient-centred medical home perspective and warrants further consideration. This approach leveraged all the key components identified by De Vleminck et al. and in addition, reduced time demands by using the group approach. The authors recommended more research to understand how to make workloads sustainable and to address ongoing barriers.

TABLE 7: GENERAL PRACTICE INTERVENTION STUDIES

First Author	**Year**	**Country**	**Method**	***Stated problem***	**Aim**	**Description of Intervention**	**Outcome**
Bose-Brill	2016	USA	RCT	*Uptake of ACP was low and ACPs were not available in medical records*	To test efficacy of a novel personal health record delivered by IT ACP framework	Develop and test a patient portal messaging system, linked to the patient's electronic medical record, with use of an IT system enabler making ACPs accessible to providers. This multi-level initiative had influence at the individual level (patients communicating their wishes), at the provider level (access to patient information previously unavailable) and at a system level (the supporting infrastructure created a process and a business as usual approach).	The aim of increasing uptake and having availability of ACP in the record was achieved at the test level. Rate of outpatient ACP documentation increased and improved in quality. A larger trial is required to determine reproducibility. Known barriers and enablers were not considered which may have limited efficacy. For example, GP time pressure was known to be a significant barrier, but no accommodation was made to overcome this, which continued to have a hindering effect during the study.
De Vleminck	2016	Belgium	Complex intervention	*General practice was lacking a practical*	To develop an intervention to support the initiation of ACP in	A complex intervention using a 4-phase approach based on the Medical Research Council Framework for design and	GPs have diverse conceptualisations about ACP. Need to develop a shared conceptualisation and agreement on the purpose of ACP among GPs and make systematic integration of ACP in routine

				approach to implement ACP	general practice – methodological paper	evaluation of complex interventions. The first phase included a systematic review and GP focus groups to identify barriers and facilitators of ACP. Findings informed the next phase. A proposed intervention was modelled based explicitly on understanding the barriers and enablers, with key components identified. Key features of the proposed intervention included involvement of trained facilitators, (to address knowledge barriers at an organisational level), a process of stratifying the practice population into age-specific target groups (a known enabler at a system level), structured discussions between patient and provider (a known enabler at the interpersonal level) and the opportunity to complete the ACP document (individual level).	practice. The next phases of the intervention have not yet been reported.

Duffield	1996	USA	Mixed method	*Need to initiate ACP in primary care prior to catastrophic or long-term illness becoming a factor.*	To determine if discussion about and distribution of Advance Directive forms in a rural primary health practice would increase completion and return of forms.	To test the feasibility of initiating ACP discussions in primary care a study involving primary care clinic patients in a short survey about their ACP attitudes (individual level), followed by a discussion with their usual doctor (interpersonal level) who then also provided a simple ACP form to be taken home for completion (system level).	Distributing AD forms in practice increased the number of completed AD without affecting consultation time. This study concluded that discussing AD with primary care patients and providing them with forms to complete for the medical record was a practical means to ensure wishes regarding EOL care were known. It also highlighted significance of GP involvement in the activity.
Hare	2019	USA	Cross sectional survey	*Problem that only 17% of patients report having ACP discussion with physician*	To establish the usefulness of a 9-item ACP survey in determining readiness and self-efficacy of patients to engage in ACP	Patients from two primary care clinics aged between 55–80 years were asked to complete a 9-item survey and provide brief demographic information.	The tool was found to be useful with participants, indicating providers should engage in ACP
Heiman	2004	USA	RCT	*Will a combination of two simple*	To assess two simple interventions in a	A 3-arm blinded randomised control trial to test the efficacy of a combination of two simple	Findings showed a small but significant increase in completed ACPs in one of the 3 study arms supporting the efficacy of a mail out supported by a

				ACP initiatives create a synergistic response for greater effect?	combined approach to improve completion of advance directives	interventions was completed. Patients with upcoming appointments received a mail out of patient information (system level) and this was combined with the physician receiving an IT reminder during consultation (system level).	physician prompt, with no change between the control and the physician only prompt arms. Findings suggested that involving patients resulted in a greater response than simply prompting a physician. Authors noted that known barriers to physician involvement were not addressed in the study which limited the efficacy. Future strategies should focus on encouraging patients to put advance directives on their agendas, to ensure the discussion is not bypassed.
Holland	2017	USA	Prospective 4-arm comparison study	*ACP discussion in primary care setting was rare, and decision aids to facilitate patient provider interactions were suggested to be valuable tools but had not been evaluated.*	To evaluate the feasibility and acceptability of a nurse-led ACP intervention in primary care	The researchers conducted a 4-arm prospective comparison study to compare the effectiveness of decision aids when used in ACP conversations with nurse care coordinators. The intervention involved training nurses (provider level), selecting decision aids (system level), enrolling individuals (individual level) and providing a one hour patient–provider consultation after which patients were instructed to go home and discuss their values and wishes	Build standardised ACP processes into nurse–patient interactions and encourage nurses to practice within the full scope of their license. With regard to differences between the 4 decision aids, the pilot study was not sufficiently powered to determine statistical differences, but the authors concluded that subsequent studies should structure the intervention to facilitate conversations between patients and their health care agents.

						with family and friends (interpersonal level).	
Lum	2016	USA	Complex intervention	*Primary care providers faced time barriers impeding their ability to participate in ACP discussions during consultations with patients.*	To describe the feasibility of a primary care group visit ACP model	Patients (individual level) participated in a group medical visit (interpersonal level) facilitated by a physician and another health care provider (organisational level) during which handouts, discussion, questions and answers (system level) increased patient knowledge and motivation to engage in ACP.	Group appointment was acceptable to patients and clinicians. By supporting interactive discussion and working with a group of patients, time demands were compressed. (89) The authors recommended more research to understand how to make workflows sustainable and to address ongoing barriers.
Miller	2019	Australia	Qualitative	*Uptake of ACP in outpatient settings is low*	Explore patient perspectives of an ACP intervention designed to address common barriers to uptake in general practice	Training of nurses from 4 general practices to initiate and lead ACP discussions with referred patients. Patient perspectives captured by semi-structured interview following the intervention	After training, nurses were found to be capable of facilitating ACP conversations and achieving significant relational benefits for patients. Patients felt uncomfortable communicating ACP with their families.
Pearlman	2005	USA	RCT	*This study started by recognising*	To conduct an educational and motivational	The researchers' goal was to evaluate a systems orientated ACP intervention using a workbook *Your*	Findings from this multi-modal intervention were mixed, highlighting ongoing challenges. System level processes were improved with success in

				many barriers exist to ACP and many interventions had been tried to address these barriers.	intervention to increase ACP	*Life, Your Choices.(109)* A randomised control trial involved an intervention group who participated in a 4-step intervention. Patients (individual level) received a mail out of the workbook followed one week later by a reminder postcard (system level). Immediately prior to the person's next scheduled physician appointment they met with a social worker for 30 minutes (interpersonal level) and then during their physician visit a reminder prompt was provided by the physician (organisational level). Control group received the usual mail out and a standard consultation.	increasing ACP discussion. Documentation rates doubled. Clinicians need to target those who are ready to engage and likely to benefit. The study design employed a number of known enablers, including training of health care providers, providing role clarity and direction for providers with clear instruction about process.
Rose	2019	USA	Mixed methods	*Lack of physician training and lack of time*	To measure impact of physician coaching and staff training with RN support and electronic medical record [EMR]	36 primary care practices were engaged over a 31-month period. Coaching tools and EMR modifications were supported by RN case managers	29% of patient participants completed an advance care directive mostly initiated by RN case managers

					enhancements on ACP uptake		
Tierney	2001	USA	RCT	*Fear initiating discussion would cause a reduction in patient satisfaction with care.*	To determine patient and provider satisfaction with prompted ACP discussions	Researchers determined to explore the various aspects of ACP and designed a cohort study linked to an existing randomised control trial. Physicians received one of four different computer prompts during patient consultation to initiate an ACP discussion. Patient satisfaction with process was recorded.	Patients were more satisfied with their provider when ACP was discussed so the barrier was refuted by the research, however it was not clear if physicians responded to the findings. Physicians should be encouraged to initiate ACP discussions with elderly patients during consultations because this is shown to improve patient satisfaction with the visit.
Tieu	2017	USA	RCT	*Rates of completion of ACP are universally low*	To determine if ACP-specific patient electronic messaging would increase rate of ACP	Primary care patients age 65+ who were previously enrolled in a patient electronic messaging system were randomised to receive an ACP message and to determine completion after three months	There was a statistically significant increase in ACP completion, but absolute number remained low. Older frail adults were more likely to complete.
Wickersham	2019	USA	Mixed methods	ACP completion rates were less than 10%	Compare implementation performance of two advance directive forms	6 primary care practices were randomised to use one or the other form then assessed for rate of offering, acceptance, and ACP uptake.	One form was found to be more readable, understandable, appealing, and usable by both patients and clinicians

Wissow	2004	USA	Complex intervention	*Ongoing low uptake of ACP, and an understanding of previous interventions to increase uptake*	To determine efficient ways of promoting advance directives among heterogeneous populations of elderly ambulatory patients.	Complex intervention aimed at increasing ACP uptake. Patients received an appointment, a reminder letter, a handbook, a medical consultation and a follow-up letter. Providers received executive guidance about the priority, a workbook including scripts to employ in consultation. At an organisational level, administration processes were instituted and checklists included in records.	Findings showed a modest increase in ACP uptake, however providers did not engage fully with the process because the barriers that limit ACP discussions were not mitigated and remained throughout the study. Future interventions may specifically need to address doctors' attitudes and comfort when discussing advance directives.

2.6 Discussion

In seeking synergy across levels of influence, McCormack et al. reported that the socio-ecological model had demonstrated benefit.(50) This was also described by Weiner et al., who noted the potential synergies to be gained using a socio-ecological approach provided 'compelling justification for multi-level intervention'. However, both acknowledged a lack of theoretical guidance about the optimal design of multi-level interventions. In seeking clarity about design of interventions, Pettigrew et al. outlined two important considerations. The first was that complexity may be associated with the activities, singular or multiple, which comprise the actions of an intervention.(110) The second consideration was that complexity may be associated with other mediators and moderators operating *between* the actions. Feedback loops occurring between mediators and moderators have been described as mechanisms of action alternatively known as causal pathways. These pathways have been said to create or limit the effect of an intervention.(110) The first consideration could apply to many studies in this literature review in which activities, singular or multiple, were explored in various combinations. However, there were virtually no studies in the general practice ACP literature that investigated the second consideration, looking at whether combining various interventions enhanced or limited their effectiveness.

With regard to this second consideration, Weiner et al. described an approach to causal modelling in which five mechanisms of action were proposed. Each of the five mechanisms – accumulation, amplification, facilitation, cascade and convergence – was observable but not explicitly described in the intervention literature. An **accumulation strategy** occurs when **each individual intervention makes a discrete contribution to the outcome.**(50, 51) The interventions occur at different levels of influence and produce an accumulative impact to achieve the desired outcome.(51) It is accumulative because the effect of each intervention is not conditional on the other intervention(s). For example, Heiman et al. used a randomised controlled trial to test whether two separate interventions known to have positive impact individually had a greater cumulative impact when combined. The first intervention involved sending of ACP information to individual patients prior to a consultation with their GP, and the second intervention involved sending a computer prompt to the patient's GP during the consultation. Both actions were independent of the other, each targeting different levels of influence, but together had an accumulative effect resulting in a small but significant overall increase in ACP.(25) Combining interventions in this manner was commonly described in the review literature. The implication for future intervention design is that explicit combination of known enablers across multiple levels will be more effective.

When considering **amplification strategy, the effect of one intervention is conditional on another. One intervention increases the target audience's receptivity to the other intervention.**(51) This mechanism was identifiable in a study by Amjad et al. where a patient's past experience of caring for someone at end of life [interpersonal level] was found to increase the sensitivity or receptivity to ACP and directly influence (or amplify) their likelihood of engaging with their own ACP [individual level].(57) Understanding the conditional relationship or links between activities when planning interventions could be expected to enhance outcomes but was not observed in most studies.

Where an **intervention clears the way or removes barriers for another intervention,** it is facilitating the outcome. **Facilitation strategy** was commonly described in the body of general practice ACP literature.(51) To illustrate, lack of GP knowledge about ACP was widely identified as a barrier to GP participation in ACP (30,39,40,58,59,61-63,67,68,71,74,81,83,85). By delivering GP education, one intervention sought to improve GP knowledge, which in turn would remove the lack of knowledge as a barrier, and arguably clear the way for improved GP engagement in ACP discussion.(61). Interventions using facilitation to address known barriers were demonstrated in the literature but the complexity of association *between* barriers was often overlooked. For example, a study facilitating access to knowledge and ACP resources but failing to quarantine provider time for discussion overlooks a critical barrier. Facilitation alone was demonstrated to be insufficient.

The final two mechanisms were identified in more complex undertakings. In **cascade strategy**, the output of **an intervention at one level becomes the input for intervention at another level**.(51) Generally this would occur from higher levels of influence to lower ones. In general practice ACP literature, several more complex interventions described a cascade like strategy. For example, Wissow et al. sought to increase ACP uptake across a health care organisation. To make ACP part of routine business in clinic consultations, the chief of staff provided opinion leader endorsement. This act of endorsement (the output) created the environment for further intervention input. Time was allocated in consultations to discuss ACP. This output (time) led to the potential for providers to action ACP conversations, and so on. This cascade of actions from the chief of staff endorsement down constituted a cascading influence.(93)

Convergence strategy involves a process whereby elements at **different levels mutually reinforce each other by changing the patterns of interaction.**(51) The extent to which convergence strategy applied in the literature can only be assumed because it was not explicitly noted. For example, in a study by Lum et al. ACP group medical appointments were explored.(89) Providers motivated by a new model of care, were met by patients motivated by provision of ACP information and this mutually reinforced the doctor-patient–social worker communication at an interpersonal level during the group session. These actions converging changed the dynamics occurring during the group interaction. In this example there was apparent convergence across several levels including individual, interpersonal, provider and system levels of influence. Convergence strategy was implicit in several general practice ACP research studies.(23, 25, 88-90, 105)

Complex interventions designed to use particular strategies and combinations of strategies could work together in mutually reinforcing ways. (51) Future complex intervention design may benefit from consideration of the relationships between barriers and enablers operating at various levels of influence, and the factoring of causal mechanisms into intervention design, leading to greater uptake of ACP in general practice.

To note, the bulk of ACP literature originated in the USA and, as described in the introduction, was included in this review based on criteria to assimilate models of care most consistent with Australian general practice. There were no Australian systematic reviews found and only limited general practice literature. In considering the applicability of findings in the Australian health care setting, the literature presented consistent themes regardless of geographical origin. The candidate is satisfied that the findings are transferable.

2.7 Limitations

The volume of studies describing barriers and enablers to ACP in general practice was considerable, but few studies focused on interventions in general practice.(111, 112) Study quality was variable and the number of small-scale studies focused on singular aspects of ACP limited broad applicability. Existing Australian research draws heavily on international evidence to support local findings and authors have identified the need for more Australian research to inform policy and implementation.(113-116) The extent to which international ACP evidence is applicable and transferable to other Australian populations, places, or contexts is uncertain.

Lack of consistent terminology was a challenge addressed initially in the formulation of search terms and inclusion criteria, although it is possible that all relevant literature was not identified because of complex terminology. By focusing on general practice literature only, it is possible that transferable knowledge from other sectors may have been excluded. The candidate sought to reduce bias by adhering to the study protocol and by using reflexivity to monitor adherence to methods described.

The Australian Medical Association (AMA) argues that as a distinct medical specialty, general practice requires its own specific body of research and that findings from other medical research cannot simply be transferred to general practice.(20) More studies are required to contribute to the available body of general practice research, described by AMA as the missing link in the development of high quality, evidence based health care for populations. Limited general practice intervention research was available and opportunities to expand the body of ACP knowledge through effective design of complex interventions will make a useful contribution both to increasing general practice research literature and to increasing ACP uptake through general practice

In this review, the ACP literature was categorised and considered across socio-ecological levels of influence distilled from the narrative. This approach provided an insight into distribution of research interest across levels of influence. Individual and interpersonal levels of influence were the least researched in general practice, and provider and system aspects focused on GPs and processes were the most prevalent. This finding was unexpected when considering the central role of the individual in ACP, and in relationship with their family, in determining values and wishes for end of life care, and the perceived role of general practice in supporting this process. Not only were research findings in relation to individual perspectives limited, the patient voice was more commonly presented through a provider as proxy. Future studies should seek to engage patients directly.

This review was set against a backdrop in which uptake of ACP remained consistently low, despite widespread agreement that it was beneficial and with general agreement it was best achieved in primary care settings. In this review, the candidate sought to understand known barriers and enablers to ACP, and based on these, to determine what initiatives had been described to increase uptake of ACP. In seeking to understand barriers, enablers, and efficacy of interventions, it was useful to understand at which level of influence across the socio-ecological perspective the interaction was occurring, and in doing so, consider how interventions had been developed to mitigate barriers and leverage enablers targeted for greatest effect. By stratifying barriers, enablers, and interventions into levels of influence, the important relationship between activities operating across levels became evident. Within this complexity, it was understood that some interventions were more effective than others, and combinations of interventions were more effective again. There appeared to be a shift away from considering ACP as 'a singular action' to be achieved or documented, instead to view ACP as a set of discrete steps in a complex process.(56) Interventions targeting multiple levels of influence were said to reinforce each other, and consequently were expected to yield greater and more sustainable effects than interventions targeting only one level of influence.(51)

2.7.1 Gaps identified in the literature review

Despite a significant body of ACP evidence, there was a lack of practical guidance to enable general practice to support uptake of ACP effectively. Literature sourced from and/or generated in general practice contexts was sparse, raising questions about the transferability of evidence across different contexts. The absence of the patient voice in the ACP literature was notable also. Findings from this review have identified a gap between historical research approaches that involved asynchronous testing of multiple mechanisms for ACP across all levels of influence and the potential for strategically applying evidence across targeted levels of influence and with an understanding of mediators and moderators to inform the design of new and effective ACP models of care.

2.8 Research question, aims and objectives

A recommended approach that achieved a balance between effectively translating key themes arising from the literature and crafting a real time solution for ACP in general practice was not found. In order to translate research recommendations into reality, the candidate's understanding of the literature suggested the need for an intervention designed to ensure compatibility with a busy general practice work flow, and that this action was required for ACP initiatives to be sustained. Given these findings, the question emerged: 'How might a complex intervention work to influence uptake of ACP in general practice'?

To respond to this emerging question and address the gap in research knowledge, it was determined to undertake a research activity grounded in the literature review findings. A complex intervention designed by and with general practice would address the following research aims and objectives:

Aim 1. Co-design a socio-ecologically engineered approach to ACP in general practice

Objective 1.1 Recruit a progressive general practice to participate in research

Objective 1.2 Consider known socio-ecological barriers and enablers to co-design a general practice ACP intervention with participating practice

Objective 1.3 Run a proof of concept ACP trial based on design output of 1.2

Aim 2. Determine perceived feasibility of ACP intervention in general practice

Objective 2.1 Interview participating general practitioners and practice staff to determine their views on the ACP intervention

Aim 3. Determine the patient experience of ACP intervention in general practice

Objective 3.1 Interview participating patients to determine patient experience of ACP intervention

Aim 4. Determine the effectiveness of a socio-ecologically derived model of care in general practice

Objective 4.1 Measure prevalence of ACP in intervention and control groups to compare ACP levels and determine effectiveness of intervention in increasing uptake of ACP in general practice

Objective 4.2 Determine the feasibility of process flows in implementation

Objective 4.3 Measure self-reported health literacy scores before and after exposure to model of care

2.9 Summary

In this literature review, the candidate applied a socio-ecological lens to explore an extensive body of international ACP literature. In seeking to increase uptake of ACP in general practice it was important to understand and build on the existing evidence, however the body of available literature was found to provide unclear guidance to inform effective approaches to ACP in general practice. A critical interpretation of existing ACP literature resulted in a new synthesis of this body of evidence. The use of a socio-ecological perspective was demonstrated to be helpful in identifying relationships between barriers and enablers, and the mechanisms operating across and between theoretical levels of influence. This synthesis led the candidate to identify mechanisms and associations within the described body of evidence, which were understood to be linked and causal. Evidence gaps were described and the question considering these causal links was ‘How might a complex intervention work to influence uptake of ACP in general practice’? Aims and objectives to guide a proof of concept trial were introduced. In the next chapter, the approach to designing the intervention based on the literature review findings will be considered.

Chapter 3: Co-design of the intervention

Introduction

In Chapter 1, the importance of advance care planning (ACP) as a public health consideration was established. It was also established that uptake of ACP was low and general practice was potentially a useful place to initiate uptake. In Chapter 2, findings of a systematic review and critical interpretive synthesis of the literature were described. The application of a socio-ecological conceptual framework to existing evidence informed a model of care with potential applicability in general practice. Considering this guidance, an emergent question was 'how might a complex intervention influence uptake of ACP in general practice'? In this chapter, the candidate outlines a process of co-design undertaken with an exemplar general practice to shape a socio-ecologically derived complex intervention.

3.1 Co-design as a key to knowledge translation

In this section, the candidate's active contribution to the ACP intervention is demonstrated through a co-design process with members of the GP practice. Firstly, the GP practice's strong philosophy and track record of continuous quality improvement is outlined. Next, it will be shown how socio-ecological theory generally, and the literature review results specifically, influenced the design of the model of care for the ACP intervention.

To test the conceptual approach to the model of care the candidate wanted to recruit a progressive general practice to partner in the intervention design. A collaborative approach would be required to design and test the model. Each step of the intervention needed to articulate with the existing day-to-day processes at work in a busy general practice. It was known from past studies that busy clinicians fail to engage in processes imposed on them.(29) If GPs and practice staff were to be supportive of an ACP initiative, it was the candidate's contention they needed to be involved in its design.

3.2 Identifying an exemplar general practice

The candidate had worked as a health administrator at a regional level and in that professional capacity was familiar with the operations of many regional general practices. It was decided to approach a known exemplar practice to determine their interest in co-designing an evidence informed model of care to increase uptake of ACP. The candidate categorised the practice as an exemplar in part based on the current models of care employed by the practice, which demonstrated a strong systems approach to practice population health management. A commitment to patient centred care was evident through innovative schemes that demonstrated a willingness to engage in adaptive and flexible approaches to service delivery. For example, the practice regularly conducted diabetes group clinics. People with diabetes shared their knowledge and experiences of living with diabetes in group discussions with other patients and clinicians. To establish these clinics, the practice actively interrogated their practice data to identify the target group, and robust practice systems were required to organise and run the group sessions.

This approach stood in contrast to other practices that were less mature in their data management and organisational capabilities. The existence of these clinics was a positive indicator of practice capacity to undertake complex interventions. A proposal was written outlining the research idea, including the aims and objectives and detailing proposed steps and timelines. [Appendix 4] A meeting was scheduled and conducted with the practice management team to discuss the proposal. This was attended by the candidate along with one of the GP directors, the practice manager and the nurse manager who collectively would be responsible for making the decision. After deliberation, the practice contacted the candidate to say they would be very interested to participate. A formal invitation to participate was issued by the doctoral supervisor, [Appendix 5] and the practice provided a letter of support for the required ethics application. [Appendix 6]

3.2.1 Description of the general practice

This large accredited general practice is located in a regional area of NSW with a census catchment population of 38,473 people.(117) The health needs of 350–400 patients a day were managed by the practice team which included six administration staff, six registered nurses and up to twelve general practitioners working at any one time in the purpose built facility.

3.3 Co-design is a two-way street

The candidate's aims and objectives were clearly defined [see Chapter 2], but it was also important to understand the outcomes sought by the participating practice, to ensure the design process and outcomes would be successful for all parties. In discussion, it was evident the practice's motivation to be involved arose from a culture of continuous quality improvement with an aim of driving system improvement to deliver better quality care. When considering ACP, GPs were regularly faced with difficult care decisions at the end of life. By increasing uptake of ACP, patient wishes would be known and more readily acted upon. An *ad hoc* approach was already in place in the practice to discuss ACP and opportunities existed to enhance this system. Participation in the research was viewed as a way of understanding the effectiveness of their clinical approach. They believed their approach was effective but only had anecdotal evidence to validate the belief. Given the commitment to quality, there was a willingness to explore their current approaches and enhance these approaches as feasible, to measure and improve outcomes.

3.4 Developing a shared understanding

In thinking about the translation of ACP research into practice, many small and seemingly insignificant considerations interact and combine to become important in a nuanced approach to improving ACP in general practice. Designing an intervention in which activities proposed in the literature overlaid, co-existed with, or replaced existing day-to-day activities required a process of dialogue.

3.4.1 Applying the theory

The first step involved the development of a shared understanding of the theoretical components of a socio-ecological model, and the extent to which these were considered relevant in a general practice setting. To what extent did the practice team consider influence was achievable across the individual, interpersonal, provider and system levels? This understanding was not explicitly important at the clinical interface but was critical during the design phase to make clear how one factor contributed to or undermined another factor in a causal pathway. For example, if patient knowledge was able to be enhanced [individual level] by a provider with enhanced knowledge [provider level] and this was achieved through communication [interpersonal level] and reinforced by using a template that provided clarity [system level], a better outcome would be achievable. If any one of these areas was weak it would potentially undermine the efficacy of the whole process. Conversely, where an intervention was effective across each of these levels, the combined result would be enhanced quality.

3.4.2 Translating the theory

The second step involved understanding what was currently occurring during day-to-day operations in the practice. A process map detailing existing ACP activity using a step-by-step approach was developed. [See Table 8]. The practice had recently decided to align ACP conversations with the 75+ health assessment funded under the Medical Benefits Scheme as part of their systematic approach to managing ACP with their ageing population. The steps that were in place in this practice for patients attending for a 75+ health assessment *prior* to the intervention commencing are outlined in Table 8. This was the ‘business as usual’ pattern. The candidate mapped each step of the process into a corresponding level of influence relative to the socio-ecological perspective, as previously outlined in the systematic review. Barriers and or enablers addressed by each step were noted.

TABLE 8: PROCESS MAP - PRE APRIL 2019

#	**Action**	Description	**Who**	**S-E Level**	Barriers (B) Enablers (E)
1	Patient population database searched to identify all patients eligible for 75+ health check	Australian general practice is largely computerised. Each regular patient has a unique identifier in the practice system. Software tools are available to the practice and can facilitate database searching of custom fields within the patient database allowing for the identification of patient cohorts based on defined search characteristics.	Admin	System	(E) business as usual approach
2	Invitation to attend 75+ health check issued	In Australian general practice, quality accreditation standards require practices to ensure a process of patient recalls and reminders in which patients are prompted and notified of upcoming due dates and agreed health service activities. Some practices actively manage the health needs of their patient population by using recall and reminder notices to trigger and prompt preventative health screening activities. The 75+ health assessment is one such activity.	Admin	Inter-personal System	(E) trusted relationship (E) business as usual approach
3	75+ health check appointment scheduled with choice of appointment times to suit patient.	Patient scheduled in advance to attend appointment for 75+ health assessment. It is a multi-step process. The first component of the assessment is completed by the patient with a practice nurse. A summary is prepared for the doctor. Once the nurse–patient step is complete, the patient is then seen by the doctor where the health assessment	Admin	Individual System	(E) triggers activation (E) business as usual approach (E) patient autonomy

		is completed. This all occurs during the single visit.			
4	SMS reminder sent prior to appointment	'No show' is when a patient with a scheduled appointment does not arrive. Significant no show rates for appointments scheduled in advance are not uncommon. An SMS reminder sent by the practice the day before the agreed appointment is a reminder prompt to the patient. If the patient is unable to attend the appointment, a decision can be made to reschedule for a future date.	Admin	System	(E) triggers activation
5	Appointment bulk billed under medical benefit scheme (MBS)	In Australian general practice, patients are required to pay for services they receive. Under the Australian system, patients are covered by a federally funded universal health system. A patient receiving a service in general practice is required to pay, and to do so may choose to sign over their medical benefit to cover the cost of the service. Each type of eligible medical service has a medical benefit scheme (MBS) item number and corresponding dollar amount associated with the service. For elderly patients in the Australian health system, an item number under the MBS covers an annual medical assessment for everyone aged 75+ years, once a year. As a private business, general practice as the provider of the service may charge as much for the service as they wish, and this amount may be more than the	Admin	System	(E) overcomes cost barrier

		corresponding MBS item value. This gap between actual cost and MBS amount is considered an ‘out of pocket’ expense. When a practice says it will ‘bulk bill’ it is agreeing to charge the MBS fee only, in which case the patient will not have an out of pocket expense. By agreeing to bulk bill this service, the practice is ensuring financial access to preventative health care for the practice population.			
6	Health assessment conducted – information collection and information sharing	Required components of a health assessment are described by the MBS. An assessment provides a structured way of identifying health issues and conditions that are potentially preventable or amenable to interventions to improve health and/or quality of life.	Practice nurse	Individual Interpersonal Provider	(B) Knowledge (B) role clarity
7	Patient asked if they have an ACD during 75+ health check	Patient database has a dichotomous field creating opportunity to ask the patient if they have an advance care directive (ACD). It is not a mandatory field, and literature suggests health service providers have been reluctant to ask people if they an ACD. Numerous reasons have been reported for this reluctance to engage including lack of time, knowledge, confidence, concern for patient response, etc. There is no process to monitor if this has been completed.	Practice nurse	Interpersonal Provider	(E) trusted relationship (E) business as usual approach (B) role clarity
8	Health assessment completed	Each person 75+ is entitled to access a yearly health assessment. This cycle will repeat in 12 months’ time.	GP	Provider System	

Analysis of these process steps showed a systematic, population-based approach to care delivery, in which ACP was explicit. Strategies were in place to overcome some known barriers. For example, to overcome concerns about affordability, the practice offered a bulk billing service. Strategies to prompt participation were also employed, for example the invitation and subsequent reminder prompts to attend the appointment, and the provision of flexibility and scheduling choice for patients when making appointments.

As an exemplar practice with a systems approach to service delivery this was a strong starting position. The candidate’s knowledge of the ACP research literature highlighted further opportunity to optimise practice processes and potentially achieve greater ACD uptake. New opportunities based in the evidence were proposed for consideration. These opportunities were mapped and discussed in a co-design process.

3.5 Tailoring the approach – the details are important

Several meetings were held with the practice management team [a GP director, the practice manager and the nurse manager] during which the process map was discussed, and possible new actions determined. The candidate working with the practice team sought to understand the ‘business as usual’ approaches operating within the practice to determine where change may be indicated. This included identifying additional steps potentially required to increase the uptake of ACD most effectively. One additional step that was considered of interest was the introduction of a group ACP information session, similar in implementation to the existing diabetes group sessions. To implement a weekly ACP group session with existing practice resources was challenging and the practice decided to reach out to a local aged care nurse practitioner for assistance. An invitation was issued by the practice to collaborate with them in delivering ACP information sessions. The nurse practitioner was already undertaking this type of activity in aged care facilities and saw significant value in linking information sessions to patients’ regular general practice. An agreement with the nurse practitioner to provide in-reach was finalised. There was no financial cost involved. This collaboration was endorsed by the nurse practitioner’s employer and considered to be an acceptable activity within the existing position description. The practice set a start date.

Implementing a socio-ecological model of care required multiple steps with each step contributing by design to enhance a causal mechanism, the results of which conceivably would lead to an overall increase in uptake of ACD. The business as usual, day-to-day processes already included important process steps and new steps were proposed, some of which required a nuanced discussion. For example, if group information sessions were to be conducted, they would need to be scheduled at times suitable to concurrent practice activities. Navigating this mapping of process to develop a shared understanding of the most feasible path to increase uptake of ACD was important. Determining and aligning practice resources to support the proposed activity was important. Developing a shared understanding of the concept and importance of the required process steps and how each contributed to strengthening causal mechanisms occurred iteratively and over time. The premise of the conceptual model to be tested was that by aligning all possible actions across multiple levels of influence, improved ACD uptake would be achieved.

For example, in considering a single barrier – lack of knowledge – a complex analysis ensued. At an individual level, patients' lack of ACP knowledge as a barrier to uptake is identified in the literature. The practice was aware that patients lacked knowledge of ACP and included patient education in their existing approach. At a provider level, staff capability and willingness to discuss ACP with patients was assumed but had not been determined. The practice understood the need to provide patient educational material but at a system level had not standardised the information provided. Different providers gave different information. Where written information was provided, it had not been assessed for readability. In this one example, there are multiple opportunities to streamline processes demonstrating a string of complexities to be considered across the individual, interpersonal, provider and system level for this one barrier.

By working together with the practice team, existing activities were considered as described above to determine where new activities may be useful and feasible to better align actions to causal pathways.

At each level of influence key themes arising from the literature were listed and mapped to existing practices and possible new actions proposed. This is outlined in Table 9 below.

TABLE 9: POTENTIAL NEW ACTIONS ACROSS SOCIO-ECOLOGICAL LEVELS

Socio-ecological Level of influence	Key themes for consideration based on literature	Existing ACP process steps in practice	Additional steps	Potential mechanism of action
Individual	Knowledge of ACP Motivation/Activation Autonomy Health literacy (HL)	Provide educational material	Determine level of HL Trigger activation Invite participation	Accumulation
Interpersonal	Relationships Role clarity Trust Authority	Provide information via a health professional with whom there is a trust relationship Endorsement of ACP process	Create opportunity to discuss ideas with peers/others in a group ACP session Involve family/carer	Amplification Convergence
Provider	Knowledge of ACP Attitude Influence Time	Initiate discussion Provide information	Create time-efficient processes Engage knowledge expert	Facilitation Convergence
System	Appointments Reminders Templates Records	Use population-based approaches to define target group Systematic scheduling Reminders Model of care	Supply standard easily accessible template Test an enhanced business as usual process Enhanced model of care Evaluation of efficacy	Accumulation Cascade

3.6 Designing the intervention - the agreed way forward

After working with practice staff and reviewing and studying their day-to-day approach to ACP as described above in the process map, (Table 8) additional actions were considered. These actions took into account the researcher's timeframe and the practice requirements. The practice identified six additional steps that could enhance the existing ACP process. These additional steps are outlined in Table 10 below and included standardisation of the written information provided to patients; providing patients with an invitation to attend a group education session; sending a reminder prior to the session; conducting a group session in partnership with the nurse practitioner and finally encouraging the patient to follow up with their GP at their next scheduled appointment.

TABLE 10: PROPOSED ACP APPROACH AFTER APRIL 2019

Step	Action	Who	Level of influence	Barriers overcome (B)/enablers (E)
1	Patient population data base searched to identify all patients eligible for 75+ health check	Administration	System	(E) business as usual approach
2	Invitation to attend 75+ health check issued.	Administration	Interpersonal System	(E) trusted relationship (E) business as usual approach
3	75+ health check appointment scheduled with choice of appointment times to suit patient.	Administration	Individual System	(E) triggers activation (E) business as usual approach (E) patient autonomy
4	SMS reminder sent prior to appointment	Administration	System	(E) triggers activation
5	Appointment bulk billed under MBS	Administration	System	(B) overcomes cost barrier
6	Health assessment conducted – information collection and information sharing	Practice nurse	Individual Interpersonal Provider	(B) Knowledge (B) role clarity
7	Patient asked if they have an ACD during 75+ health check. The dichotomous ACP [sic] field was checked and updated based on the patient's response.	Practice nurse	Interpersonal Provider	(E) trusted relationship (E) business as usual approach (B) role clarity
NEW STEPS				
8	Eligible patients provided with ACDbooklet	Practice nurse	System	(E) simple information
9	Eligible patients [and including family, spouse, carer] invited to	Practice nurse	Interpersonal System	(B) triggers activation

	participate in a group ACP information session: If yes: Patient scheduled in ACP session of their choice If no: Patient not scheduled in ACP session If undecided, patient invited to contact practice at their leisure.			(E) includes significant others
10	Health Assessment completed. GP asks about ACP	GP	Interpersonal Provider	(B) role clarity (E) trusted relationship
11	For those attending group session - SMS reminder sent prior to group ACP session	Administration	System	(B) triggers activation
12	Participation in group session	Nurse practitioner GP	Individual Interpersonal Provider System	(B) knowledge (B) attitudes (E) open discussion
13	Participants are encouraged to discuss their ACD with their GP at their next practice visit	Individual	Individual Interpersonal	(E) follow up

3.7 Preparation for rollout of the ACP intervention

To determine if the agreed approach was effective and acceptable to patients and staff, an evaluation period was proposed during which the new multi-step model of care would be implemented, and research designed to evaluate this new approach.

3.7.1 The agreed approach

Regular 75+ health assessment clinics were conducted by the practice in their usual format but were enhanced as follows:

Step 1 of the intervention was patient attendance at a 75+ health assessment.

- Individuals in Step 1 were screened for eligibility. Any patient identified with palliative care needs, cognitive impairment and/or a pre-existing ACD was not eligible to participate further. Ineligible individuals underwent their 75+ health assessment in the usual manner.

Step 2 of the intervention was conducted as part of the same 75+ health assessment.

- Eligible individuals were included in Step 2, in which health care providers discussed ACP and provided individuals with an ACD booklet [Appendix 7]. At the completion of Step 2, an invitation was extended to participate in Step 3, including the option to bring a family member or friend.

Step 3 of the intervention involved attendance at an ACP group information session.

- Individuals who agreed to participate in Step 3 attended a one-hour group session held in the practice meeting room, one or two weeks after completing their 75+ health assessment.

3.7.2 Practice preparation

In readiness for implementation of the proof of concept trial, the following actions were taken. One key administrative team member was appointed to the task of identifying and scheduling patients to attend a “Better Health” clinic. The practice population database was regularly audited to determine which patients were due to attend their annual 75+ health assessment. Invitations to attend were issued using a combination of approaches.

A digital flag was placed into each medical record so when/if the patient presented to the practice for health care, the health care provider was alerted to invite the patient to attend a health assessment. Letters were sent to the homes of those not presenting at the practice. Email was used where this was noted as the preferred mode of communication, however in this age cohort there was less engagement using digital methods. Telephone follow-up was made when no response was received after a one month period. Once an appointment had been scheduled, an SMS or telephone message was sent as a reminder the day before the scheduled appointment. The age cohort was readily contactable using this combined approach.

Only patients who attended a 75+ health assessment appointment during a specific time period were included in the study. This was a pragmatic decision made to accommodate the researcher’s timetable. Changes to the business as usual way of working required time for embedding and staff to familiarise themselves with the new procedures. This communication occurred before the intervention period commenced. The practice management team met with the nurse practitioner responsible for facilitating the ACP sessions and identified any logistical requirements. The group meeting room was booked for the agreed dates. The practice management team introduced the new model of care to nursing and administration staff during regular team meetings, outlining the objective as a quality improvement initiative aimed at increasing the uptake of ACD in their practice population. Roles and responsibilities were discussed and allocated. An online calendar for proposed ACP information sessions was established in the patient appointment system. A supply of ACD booklets was sourced. These activities occurred over a four-week period before the intervention commenced.

3.7.2.1 Nursing team

All nursing team members (n=5) were involved in conducting “Better Health” clinics and undertaking 75+ health assessments. The format of the 75+ health assessment was prescribed and followed as a standard format by all practice nurses. The new ACD toolkit was introduced to the format and nursing staff became familiar with the content during team meetings.

3.7.2.2 Medical staff

There was little practice change required for the medical staff, most of whom continued to operate in their usual way. When a patient completed the nursing component of the 75+ health assessment, he/she would visit the doctor to complete the process.

Three GPs were rostered in turn to attend and discuss ACP in the scheduled group sessions. A GP would attend each group for 15 minutes to emphasise the importance of ACP and answer general questions. In the current fee for service billing environment there was no specific funding allocation for GP group activity, however the GPs involved considered the brief contribution of their time to be acceptable. Future funding models will likely cover this type of engagement.

The study period started on an agreed date once the internal practice preparations had been completed. This coincided with receiving ethics approval for the associated research component.

3.8 Chapter summary

In this chapter, an approach to the co-design of an enhanced model of care within an exemplar general practice has been outlined. Literature review findings and a socio-ecological framework were applied to explore approaches to ACP and identify opportunities to enhance current practice. The practice agreed to introduce new actions, described as a 3-step process, to become the new model of care. Practice preparations to introduce the intervention were outlined. This co-design process was used to define an approach to ‘improving uptake of ACP in general practice’ within the context of an exemplar general practice and this became the case for analysis in this research study. In Chapter 4 the research design and methods to evaluate this intervention are outlined.

Chapter 4: Research Design and Methods

Introduction

In Chapter 3, the process of co-design used to shape and determine components of a new model of care aimed at improving quality by increasing uptake of advance care planning (ACP) in a single exemplar general practice was described. The general practice sought to enhance quality of care by increasing the likelihood of patients engaging in ACP activity. In this chapter, the candidate's professional experience as a registered nurse was useful in translating the proposed model of care outlined in Chapter 3 into an appropriate research design. In this chapter, case study design as the research methodology, and the design and methods used to evaluate the intervention to determine the extent to which it was feasible and effective are described.

4.1 Case study design

A quasi-experimental case study approach was used. Case study technique has been described as 'a methodologically flexible approach, commonly applied where the area of interest is complex and highly contextualized'.(118) Introducing a new therapeutic or preventative activity into general practice is understood to be a complex and highly contextualised challenge (60, 70) so case study methodology was considered to be the optimal approach. Case studies provide a 'paradigmatic bridge' because 'they are not assigned to a fixed ontological, epistemological or methodological position'(119). This methodological flexibility supported the collection and use of a range of data to better understand the context, design the intervention, and assess the effectiveness of the approach.

An instrumental case study design allowed the candidate to gain insight into the particular issues relating to ACP in a general practice setting.(120). As described, an exemplar general practice was selected as an appropriate site for a proof of concept trial. The participating general practice became the single case for the purposes of addressing the research aims and objectives. Case study methodology allowed for the generation of new knowledge to provide a useful example for other general practices who may seek to increase uptake of ACP among their patients in future. Within the case study design, qualitative inductive techniques were used and combined with collation and analysis of quantitative measures.

4.1.2 Case study schema and methods

As outlined in the literature review and co-design chapters, socio-ecological theory was used as the underlying theoretical framework for developing the case study schema.(50, 51) A schematic representation of the proposed case study was developed. As described by Rosenberg and Yates, a schema allows 'complex and multifaceted concepts and processes to be deconstructed into their elements'(119). The schema was intended to provide a useful overview and provide clarity about the methodological rigor and methods used to answer the research question. To measure and understand the impact of a complex intervention through a socio-ecological perspective required methods allowing data collection across individual, interpersonal, provider and system levels within this case. Methods were selected to enable collection of data across these four levels of influence. The sections below describe the methods applied and key data sets [as introduced in the case study schema], including the rationale for inclusion. These data are control and intervention group prevalence data, process implementation data and health literacy data, understood using quantitative methods; and qualitative methods applied to data from patient and provider interviews.

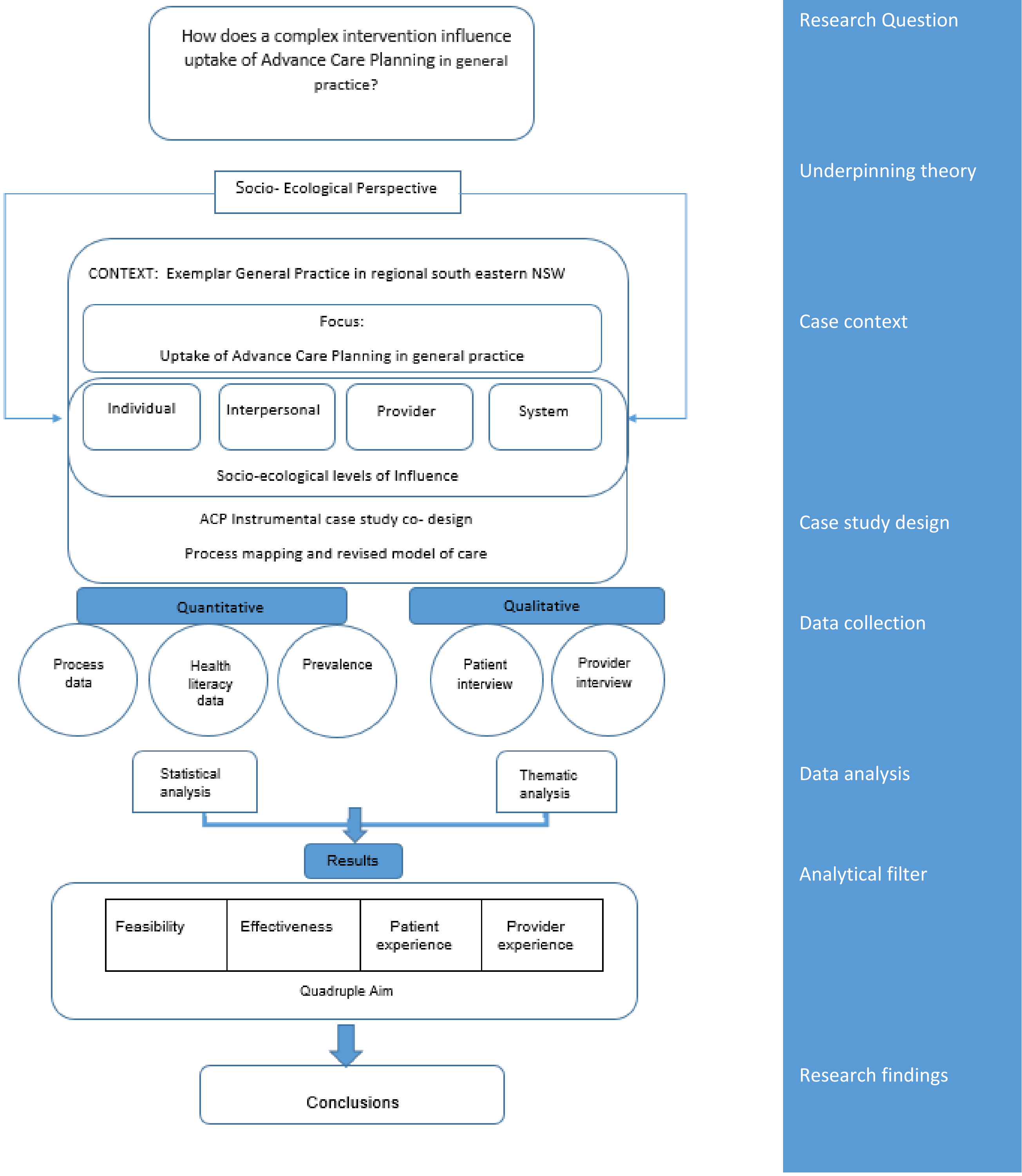
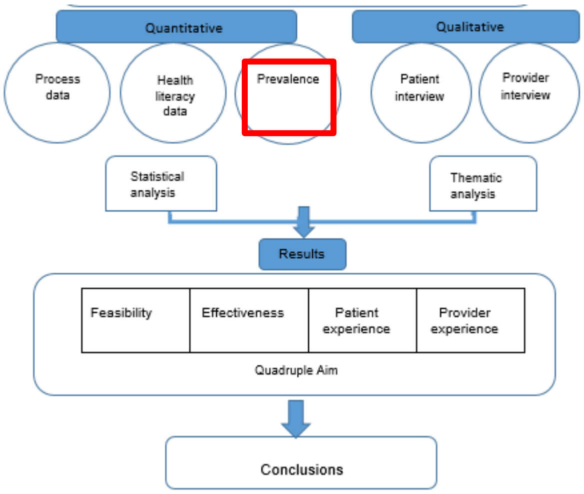


FIGURE 3: SCHEMA OUTLINING COMPONENTS OF CASE STUDY (119)

4.2 Quantitative methods

In this section, the methods and rationale for inclusion of prevalence data, process data, health literacy questionnaire and final survey data in the case study design are described.

4.2.1 Control and intervention group prevalence data



To determine the effectiveness of the intervention, a control group for comparison with the intervention group was identified. Prevalence data was compared.

4.2.1.1 Control group

A medical record audit was used to collect advance care directive (ACD) prevalence data. Practice staff provided de-identified ACD data for all patients who had attended the practice for the purpose of an annual 75+ health assessment in the six months preceding the defined intervention. Data were was stratified into:

- Total number of patients attending for 75+ health assessment
- Total number with an existing ACD notation in their medical record.
- Average age by gender

The key rationale for collecting this data was to compare ACD prevalence data between the two groups as an indicator of the effectiveness of the intervention in increasing uptake of ACD.

The practice determined it was not feasible for the day-to-day running of their business to attempt to randomise their patient population into control and intervention groups. This would require delivery of two different approaches to care, one to the intervention group and a different one to the control group, and this was *not* considered feasible. In the absence of randomisation, it was important to ensure the best possible control group was selected to make the comparison and conclusions believable, applicable, and generalisable .(121) To strengthen the validity of results and to avoid or minimise bias in the absence of randomisation, the mutually acceptable solution was to consider de-identified data from patients who had recently completed their 75+ health assessment and in this way the *timing of attendance* was used to distinguish the control and intervention groups. De-identified data were considered an acceptable control because they represented patients who had experienced a 'business as usual' approach to 75+ health assessment in the six months preceding the commencement of the intervention. The practice team determined that the time period immediately preceding the intervention period was comparable with consistency of staffing, standard processes and procedures. This period also ensured there would be no overlap between people included in the comparison group and those included in the intervention group. This was assured because in this practice the 75+ health assessment was scheduled annually, covered by the Medicare Medical Benefits Scheme and permitted to occur once only in a twelve-month period. This requirement ensured the control and intervention groups were mutually exclusive and that no individual could be included in both.

Data for the control group were collected as a retrospective audit of the patients who underwent a +75 health assessment in the six months preceding the introduction of the Three Step ACP intervention as a single cross-section at this point in time. . This approach was considered acceptable based on a number of factors. From the literature review findings, it seemed unlikely that significant natural change would have occurred in the control group over the study period. Existing RCT studies demonstrated the rate of ACD uptake in controls was reported as minimal during ACP intervention study periods. (122, 123) Further, a prevalence study conducted in Australia in 2014 and repeated in 2019 concluded 'despite long-standing efforts to increase ACP, community prevalence of ACD remains low'.(124) Based on these findings, and in the absence of capacity to collect baseline ACD control data, the assumption was made that there was likely to be minimal change in ACD uptake in the control group during the evaluation period, and the ACD control data collected at a single point in time at the end of the evaluation period would be used as a measure of both pre- and post-ACD prevalence.

4.2.1.2 Intervention group

The intervention group was comprised of all patients attending the practice for a 75+ health assessment during the evaluation period (May 6th through to July 19th, 2019). The intervention occurred when patients at the general practice who were routinely invited to attend a 75+ health assessment were screened for eligibility by the practice nurse. Details were confirmed in the medical record and de-identified data were entered onto an intervention register, including:

- Total number of patients attending for 75+ health assessment
- Total number of patients meeting eligibility criteria
- Total number of patients provided with ACD booklet
- Average age by gender

4.2.1.3 Eligibility for intervention

During Step 1 of the 75+ health assessment, nurses conducted individual assessments to determine whether patients were suitable to participate in additional steps. Patient suitability to participate in Steps 2 and 3 was determined based on three factors:

- Was the person receiving palliative care?
- Was the person cognitively impaired?
- Did the person have a pre-existing ACD?

If the answer to any of these questions was yes, the person was not invited to participate further. Individuals identified with palliative care needs and/or cognitive impairment were understood to have a need for engagement to discuss ACP however it was determined these patients required specific and focused individual attention from their GP and were not considered suitable to participate in a group setting.

4.2.1.4 Invitation to participate

Eligible patients who completed Step 2 during the 75+ health assessment were invited to attend Step 3. Those who expressed interest were provided with written directions to the group meeting venue and were also provided with a research information pack to take home and read. The research information pack contained a letter of introduction [Appendix 8], a patient information sheet [Appendix 9], a research ID number and a consent form [Appendix 10]. The letter of introduction invited patients to consider the information, and if interested in being involved in the research to bring the consent form with them to the group session. Research participation was *not* a requirement of attendance at the group session, and this was made explicit.

4.2.1.5 Participant enrolment

Those who arrived at their scheduled ACP group session and consented to be part of the research were included in the research participant group. The candidate attended the group information sessions to collect signed consent forms from interested persons and collect baseline data. At the end of the study period, a practice nurse completed a medical record audit to collect ACD prevalence data for the control and intervention groups. All data generated at Steps 1 and 2 were aggregated and de-identified. Data in the research participation group were individual and coded for privacy.

4.2.1.6 Randomisation of research participants

Research identification (ID) numbers were randomised ahead of the evaluation period into two groups, (i) for interview and (ii) not for interview. Randomisation was done for two reasons. Selecting individuals for interview was subject to sampling bias, and secondly, there was a risk that participating in the interview process may influence participant behaviour.(125) By randomising participants, sampling bias was avoided and any interview effect was detected.(125) In this instance, randomisation was acceptable to the practice team because it did not require their involvement in managing two different approaches to delivering care. The method of randomisation involved pairing a list of ordinal research identification numbers with a list of random numbers, ordering the paired list by random number, and allocating the first 100 numbers on the re-ordered list for interview. The ID number was included inside the research information package provided to patients expressing interest during the 75+ health assessment consultation. When participants presented with one of the predetermined randomised research ID numbers at the group information session, the candidate sought consent for interview.

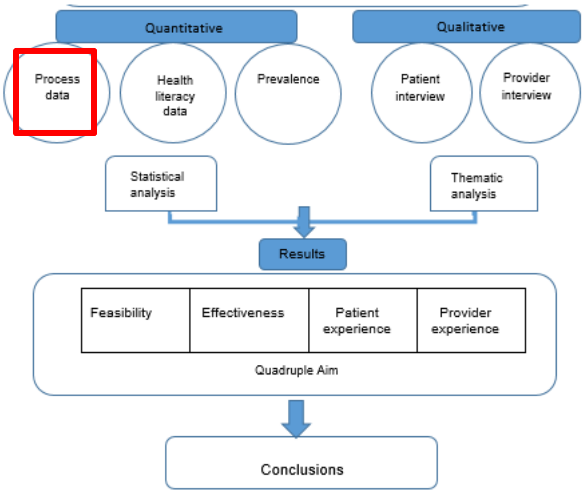
4.2.2 Final survey

Final survey data were categorical data in response to a single question, collected over the telephone requiring an independent Yes/No response to each option. Twelve weeks after participation in the Step 3 group session, the candidate telephoned each participant to complete a post-intervention health literacy questionnaire and answer a final survey question (Table 11). The instructions for the final survey question were scripted. The candidate as interviewer said: ‘I am going to ask you a question about the actions you may or may not have taken since the group information session. There are no right or wrong answers, and if you could just answer yes or no to each of the following options as I read them to you: do you understand?' After asking the question, each response was presented individually, with a yes/no answer received before proceeding to the next option.

Table 11: Final survey question administered 12 weeks after participation in Step 3.

	Question	Response
1	Since attending the ACP session at [general practice], what (if any) of the following actions have you taken in regard to ACP? Select all that apply	a) Communicated wishes to next of kin/family b) Put my wishes in writing in an ACD c) Still thinking about what to do d) I haven't done anything

4.2.3 Process data



Process data were quantitative data used to track implementation of the intervention over time, including how many participants undertook each step in the intervention. Data were collected by practice staff using scheduling records, appointment books and group session attendance over the evaluation period. Data included:

- Number of patients who undertook Step 2 of the intervention
  De-identified data were provided to the candidate indicating the number of patients by age and gender that undertook this step and who were invited to attend Step 3 of the intervention. Importantly, at the time patients were invited to participate in Step 3 of the intervention they were provided with an information sheet about the study and a copy of the consent form.

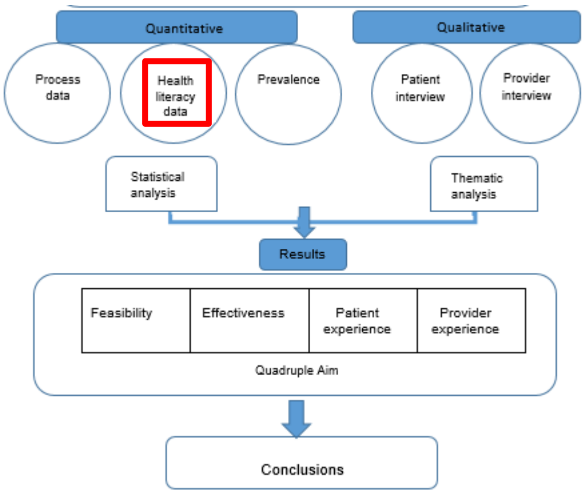
- Number of patients who participated in Step 3 of the intervention
  The candidate attended the practice prior to group ACP information sessions to document the numbers of patients arriving, those consenting to participate in the study, arrange interviews when indicated and provide participants with pre-Step 3 survey. The candidate also observed the group session.

- Number of group sessions conducted

Group session dates with the confirmed patient numbers scheduled to attend, were provided by practice staff.

The research objective achieved by considering process implementation was twofold. It provided a measure of the practice's ability to implement the model of care effectively, and secondly, provided a measure of the likelihood that a patient attending the 75+ health assessment without an ACP would complete the whole process. This information enabled the candidate to determine the impact of day-to-day implementation. Analysis of process measures of implementation in addition to other data outlined below contributed to the candidate's understanding of the standardisation of approach, quality of data collection, the ability to collate patient and provider experience, and potential contribution to understanding effectiveness. Recruitment, group session content and conduct, scheduling and participation data provided insight into uniformity, feasibility, and acceptability of approach.

4.2.4 Health literacy data



Individual health literacy scores were collected using the Health Literacy Questionnaire [HLQ] administered to all participants in group information sessions [Step 3]. The HLQ was repeated at the end of the 12-week period to provide individual pre- and post-intervention comparison. Individual and aggregated data were compared to understand any significant changes in health literacy before and after the intervention across five domains. The main research objective achieved by analysing this data set was to understand if the intervention created a change in health literacy as a consequence of attending Step 3 of the intervention or in the subsequent weeks in response to personal activity undertaken by the participants. The hypothesis tested was that increase in personal health literacy was a contributing factor to the effectiveness of the intervention.

In considering uptake of ACP in general practice, patients' lack of knowledge about ACP was a recurrent theme arising in the literature. Barriers to ACP at the individual level were known to include lack of knowledge, autonomy, and agency, and at the interpersonal level, perceived lack of support and role confusion. These barriers were understood to be closely related to the issue of health literacy,(56) defined as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health';(126) and further updated in 2006 to make explicit the relationship between health literacy and empowerment.(127) An individual's knowledge of ACP and their level of activation to initiate an ACP may be associated with their level of health literacy.

Given the potential links between health literacy, empowerment and uptake of ACP, an understanding of baseline levels of health literacy was considered useful. A validated health literacy instrument, the Health Literacy Questionnaire (HLQ), was used to determine baseline HLQ scores for participants at the outset. This was to measure if the intervention would lead to a change in aspects of health literacy before and after exposure. The full HLQ contained 44 questions across nine scales. Individual scales have been found to have construct validity providing all items from the individual scale are used and the question order is not changed.(128) In this study, a pragmatic decision was made by the candidate to limit the number of questions asked of participants to reduce the risk of survey fatigue. Five of the possible nine HLQ scales were selected by the candidate after careful consideration of which sections best aligned with the socio-ecological conceptual framework of the study. A reduced version of HLQ containing 23 questions across five scales was used. Each of the included scales could be understood to align with a specific level of influence within the socio-ecological perspective, as outlined in Table 12 below.

TABLE 12: SELECTED HLQ SCALES AND RATIONALE FOR INCLUSION.

Health Literacy Questionnaire (HLQ) © Scales Part 1		
Scale number	**Scale name and abbreviation**	**Rationale for scale inclusion**
1	Feeling understood and supported by healthcare providers (HPS)	Scale 1 outlined in Appendix 11 is about feeling understood and supported by healthcare providers. A person with a high score on this scale 'has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information to assist them to understand information and make decisions about their health'.(129) I surmised this was an important domain to include because the relationship between health service providers and patients is identified in the literature as an important consideration in ACP. I was interested to know if the complex intervention enhanced or changed the perception of the strength of this **interpersonal** relationship as measured by a change in baseline on HLQ Scale 1 measured before and after participation. I was also interested to see if the aggregated baseline for all participants was low or high.
2	Having sufficient information to manage my health (HSI)	Scale 2 outlined in Appendix 11 is about having sufficient information to manage one's health. A person with a high score on this scale 'feels confident that they have all the information that they need to live with and manage their condition and to make decisions'.(129) I surmised this was an important domain to include at **an individual level** because lack of patient knowledge about ACP is identified in the literature as a barrier and limitation to uptake. I was interested to see if this self-reported perception was generally lower or higher among participants.

4	Social support for health (SS)	Scale 4 outlined in Appendix 11 is about social support for health. A high score in this scale indicates 'a person's social system provides them with all the support they want or need.(129) I surmised this was an important domain to include at **an interpersonal** level because interpersonal relationships are identified in the literature as a key consideration in the completion of ACP. Social support for health was inferred to mean supportive interpersonal relationships.
Health Literacy Questionnaire (HLQ) © Part 2		
6	Ability to actively engage with healthcare providers (AE)	Scale 6 outlined in Appendix 11 is about ability to actively engage with healthcare providers. A high score in this scale indicates a person is 'proactive about their health and feels in control in their relationships with health care providers. Is able to seek advice from additional health care providers when necessary. They keep going until they get what they want'.(129) I surmised this was an important domain to include at **an interpersonal level** because engagement between health service providers and patients is identified in the literature as an important consideration in ACP. I was interested to determine where participant scores lay within this domain.
9	Understand health information well enough to know what to do (UHI)	Scale 9 outlined in Appendix 11 is about understanding health information well enough to know what to do. A high score in this scale indicates a person 'is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required'.(129) I surmised this was an important domain to include from an **individual** and a **system** perspective because it implied the relationship between knowing and doing may be influenced by a person's sense of ability to engage in the required steps.

The four HLQ scales that were not included in questionnaire during the intervention included actively managing my health, appraisal of health information, navigating the health care system and ability to find good health information. The reasons for excluding these scales are outlined below in Table 13.

TABLE 13: SELECTED HLQ SCALES NOT INCLUDED WITH RATIONALE

Scale	Scale description	Rationale for exclusion
3	Actively managing my health	This scale was excluded because it focused on active management of health status. While a focus on being healthy was important, this scale was considered less relevant and not directly related to future ACP.
5	Appraisal of health information	This scale was excluded because the focus was on ability to resolve conflicting health information. While this had some relevance, it was not as directly relevant to future ACP as other scales.
7	Navigating the health care system	This scale was excluded because it had a focus on finding the right healthcare/provider and navigating the health system to address current health care needs, which was less relevant than other scales in an ACP context.
8	Ability to find good health information	This scale was excluded because it focused on people exploring health information from a diversity of information sources and as such was less relevant than other scales in an ACP context.

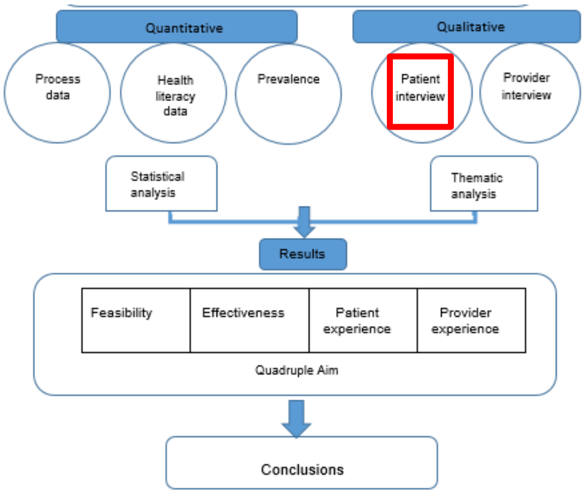
4.3 Qualitative methods

In this section, the methods used and rationale for inclusion of qualitative methods are described, including field notes taken during Step 3 of the intervention (ACP group session), patient and provider interviews.

4.3.1 Field notes

The candidate attended and observed most of the ACP group information sessions. All patients attending the sessions had consented to participate and their accompanying spouses had agreed to the presence of the candidate. The candidate's reflections after each session were informally recorded for her future reference including themes arising, observation of how participants interacted with each other and with facilitators, and levels of engagement in the discussions.

4.3.2 Patient interviews



A semi-structured interview guide was developed in which open-ended questions were framed using an *a priori* approach (Table 14).(130) Interview questions were structured to gain insight into various components of the intervention design across each of the socio-ecological levels of influence. For example, questions were framed to learn about individual knowledge, interpersonal experiences, the perceived role of the provider, and system level considerations during the intervention. Key principles used in structuring interview questions included a) using simple language so participants would understand what was being asked, b) avoiding yes–no questions so responses would yield more information, and c) starting with more general aspects, for example views on the process, and then becoming more specific about personal experience.(131) Because the underlying theme was about ACD and preparing for end of life, the topic was considered potentially sensitive. Participant reluctance during interviews has been described in the literature as being more likely when delving into personal experience.(132) To overcome anticipated resistance, discussion prompts were prepared to assist information flow during interviews. It was also determined to limit the number of questions to avoid participant fatigue among the elderly.(132) Open ended questions were used to allow participants to reply in their own words about their experience.

A draft interview guide was prepared by the candidate and critiqued by co-research supervisors. Questions were modified and revised until a final draft was prepared and submitted as part of the study ethics approval process. An identified limitation of the development process was the inability to test the guide on a pilot sample of elderly participants.(131) The main purpose of the interview was to address the research aim of determining patient experience of the complex intervention, and achieving this by understanding if and how different aspects of the complex intervention contributed to participant experience.

Table 14: Semi-structured interview questions for step 3 participants

Question 1 Please tell me about your recent experience learning about and considering advanced care planning in the GP practice. Potential prompts Are you able to describe how and when you first found out about advance care planning? How useful did you find the ACDP booklet? Why? Is general practice a suitable/not suitable place to start this discussion? Why? Why not?
Question 2 Why did you decide to attend the advanced care planning session? What things helped you in deciding to attend? Potential prompt Please talk to me about the experience of sitting in a room with other people and talking about advance care planning. Did you have any concerns about doing this? If so – please discuss. Is this something you would suggest others consider and be part of or not? Why? Why not?
Question 3

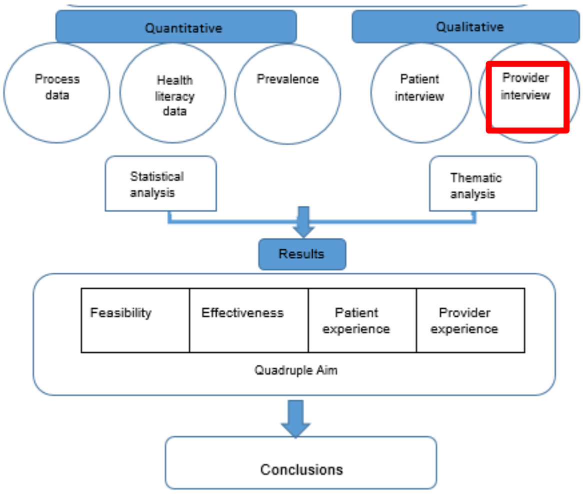
What factors influenced the likelihood (either positively or negatively) that you will develop your own advanced care plan? Why?

Potential prompt

How important or useful (or not) do you think it was to have a nurse and a doctor as part of the discussion? Why?

One week after each Step 3 information session, the candidate telephoned and interviewed participants who had been randomly allocated to the *For Interview* group as outlined in section 4.2.1.3. Thematic prompts were used to guide the conversation as required. Interviews were audio recorded and transcribed. The research objective achieved by thematic analysis of these data was making meaning of the patient experience of an ACP intervention in general practice. Findings collated from interviews informed understanding about patient experience of the ACP approach.

4.3.3 Health care provider interviews



Similar to the patient interview guide, a semi-structured interview guide was developed in which open-ended questions were framed using an *a priori* approach targeting health care provider views.(130) (Table 15) Interview questions were structured to gain insight into various components of the intervention design across each of the socio-ecological levels of influence. For example, questions were framed to learn about individual knowledge, interpersonal experiences, the perceived role of the provider, and system level considerations during the intervention. Key principles used in structuring the provider interview questions included an awareness that being interviewed by fellow health professionals carried the risk that individuals would feel scrutinised or that their knowledge was being tested, described as creating vulnerability.(133) Questions were based on the same principles as the patient guide, a) using simple language so participants would understand what was being asked; b) avoiding yes–no questions so responses would yield more information, and c) starting with more general aspects, for example views on the process, and then becoming more specific about personal roles and opportunities for improvement.(131) It was determined to limit the number of questions because participants had limited time available for interview in their busy work schedules. A draft interview guide was prepared by the candidate and critiqued by co-research supervisors. Questions were modified and revised until a final draft was prepared and submitted as part of the study ethics approval process. The purpose of this interview was to address the research aim of determining the feasibility of the intervention from the perspective of practice health care providers. Feasibility in this context primarily related to' the state of being easily or conveniently done'.(134)

TABLE 15: SEMI-STRUCTURED INTERVIEW QUESTIONS FOR PROVIDERS

Question 1 What is your understanding of how the 75+ health assessment works at this practice? ***Potential prompts*** What is the process? What are the important aspects of this? (invitation, reminders, scheduling, roles) Why do people come? Are no-shows or rejections common?
Question 2 As part of the 75+ health assessment, please talk to me about your experience over the past few months of engaging patients to talk about ACP. ***Potential prompts*** Provider view of patient knowledge, attitudes, practices. To what extent do you think people knew about ACP? How useful was the ACD booklet as a tool for patients? Why? What sort of responses did you get? To what extent were you surprised by people's responses?
Question 3 I'd like to focus on your role in this process. Can you describe your role? ***Potential prompts*** How important or useful (or not) do you think it was for you to be part of the process? Why? How prepared do you think you were to have these conversations with people? How comfortable or uncomfortable were you in doing this?

If relevant: Please talk to me about your experience of sitting in a room with a group of patients and talking about advance care planning.
Question 4 In your view – is general practice the best place to initiate discussions about ACP? Why? Why not? ***Potential prompts*** What do you think would make a difference to increasing uptake of ACP, an improvement? How could it be done better?
Question 5 What factors influence the likelihood (one way or the other) that you will continue to apply this approach in your practice now that the study period is finished? Why? What is your personal view? ***Potential prompts*** Tell me about the resource implications for practice staff? Is there any advice you would give to other practices considering this type of activity? Why?

At the end of the trial period, practice staff who had been involved in delivering the new model of care were provided with an opportunity to share their experiences with the candidate. An indirect recruitment approach was used to avoid any sense of obligation or coercion. Research information packs including a research information sheet [Appendix 13], a consent form [Appendix 14], and candidate contact details were made available in the staff common area for interested parties to access. Interested individuals contacted the candidate directly to express interest. The candidate then undertook a formal consent process with each participating health care provider before proceeding to interview. It was understood that all responses were confidential and de-identified. The research objective achieved by analysis of this data set was an understanding of the perceived feasibility of ACP intervention in general practice from a health care provider perspective. Health care providers responding included GPs, nurses, a nurse practitioner, and a medical assistant.

4.4 Ethics

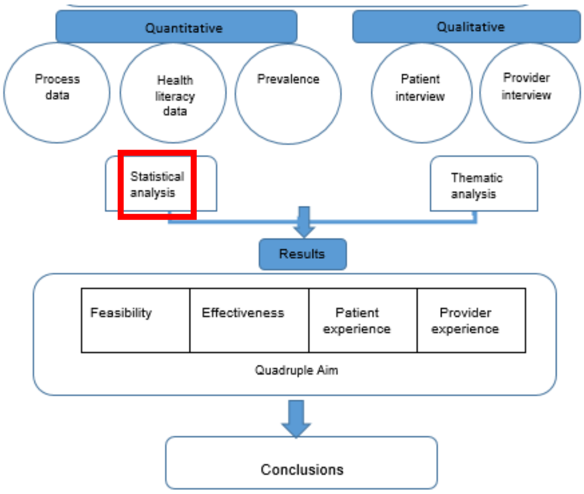
Ethics approval for this study was provided by the Flinders University Social and Behavioural Research Ethics Committee (SBREC) as an original study conducted in the College of Medicine and Public Health. Approval number 8288 [Appendix 15].

The research was justifiable by its potential contribution to knowledge, aimed at improving approaches to advance care planning across a socio-ecological perspective. The research was based on a thorough understanding of the existing advance care planning literature. It built on the evidence of a strong body of research recommendations and sought to refine and synthesise approaches to enhance future care outcomes.

The research design was built on respect for the individual and their right to self-determination about care at end of life. Participating individuals benefited by improved understanding of advance care planning. The research was grounded in respect for individual rights, and respect for and understanding of the responsibility for ensuring integrity throughout the conduct of an ethical research process. Privacy and confidentiality of participant information and adherence to all assurances provided to participants was absolute. Being sensitive to the needs of the individual during the conduct of the research was important, evidenced by providing support as requested and empowering individuals to make their own decisions based on an understanding of an individual's right to autonomy and self-determination.

The research approach was considered *just* in so far as participant recruitment was systematic, transparent, and based on predetermined and universally applied inclusion and exclusion criteria. The criteria were determined from recommendations in the existing literature and consistent with current practice. As a minimum, all participants received at least the usual level of care. The intervention participants were exposed to the intervention in addition to usual care. Upon completion of the research, findings were made available to participants through their general practice. At the interpersonal and organisational levels, there was intention for benefit for individuals and clinicians from clarification of roles, understanding of future wishes and improved communication. At a system level, outcomes of new processes and structures relating to an innovative model of care were apparent. Aspects of the study considered potentially sensitive included the prompting of individuals to explore issues of end of life care, the role of power relationships, and privacy issues about the auditing medical records. All concerns were addressed to the satisfaction of the ethics committee and approval was granted to proceed.

4.5 Quantitative data analysis



In this section quantitative techniques used for analysis are outlined. Results are presented in Chapter 5.

4.5.1 Control versus intervention prevalence data

4.5.1.1 Sample comparison

Control and intervention group data were tested statistically to assess observational, structural, and representative uniformity. Control and intervention samples were assessed for statistical differences in age and gender distribution using a two-tailed chi-squared test for variance with the significance level set at 0.05. Numeric and percentage descriptors were also used. Chi-squared statistic is commonly used for testing relationships between categorical variables (in this case gender, age, and ACP yes or no). The null hypothesis of the chi-squared test is that no relationship exists on the categorical variables in the population; they are independent.

A power calculation was undertaken to determine required level of participation. Based on the best case scenario observed in the ACP literature, a two-fold increase had been reported.(77) The practice team determined a two-fold increase would be acceptable. It was estimated that to show a two-fold increase in ACP uptake (20% to 40%), at the power of 80% with a significance level of 0.05, the study would need 212 controls and 53 participants in the intervention group.

4.5.1.2. Outcome

Numeric and percentage descriptors of the primary outcome (having an ACD) were reported using descriptive analytics. The Mann–Whitney U test was used to compare differences between the two independent groups before and after the intervention. This test is often considered the nonparametric alternative to the independent t-test and is used to compare differences between two independent groups when the dependent variable is either ordinal or continuous, but not normally distributed.

Odds ratio calculation with probability and confidence intervals was used to quantify the outcome effect. Odds ratio is a measure of association between an exposure and an outcome. It represents the odds that an outcome occurred after exposure to an intervention compared to the outcome occurring in the absence of exposure to the intervention.(135)

4.5.2 Process data

Numeric and percentage descriptors and descriptive graphs were used to report and provide a meaningful overview of important process measures. These related to participants who completed each activity in the intervention. Proportional analysis was undertaken to assess whether there was a statistically significant difference in the participation across age and gender according to each step of the intervention.

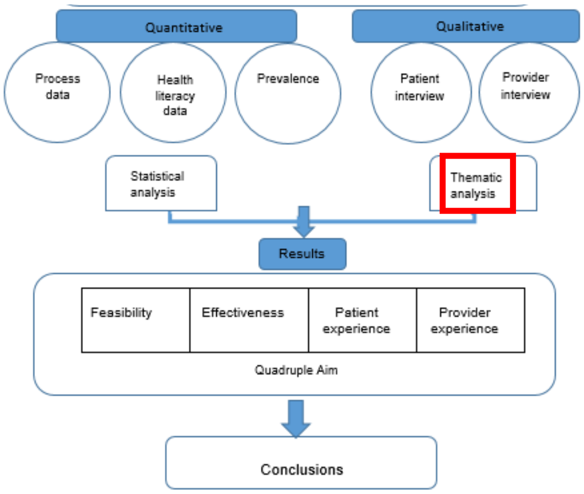
4.5.3 Health literacy data

Pre- and post-intervention HLQ scores were compared at individual and aggregated levels across each of the five domains. Mean and standard deviation measures were used and tested for significance. Normal distribution was confirmed prior to applying a paired t-test. A statistically significant change would suggest an intervention effect on participant health literacy.

4.5.4 Final survey data

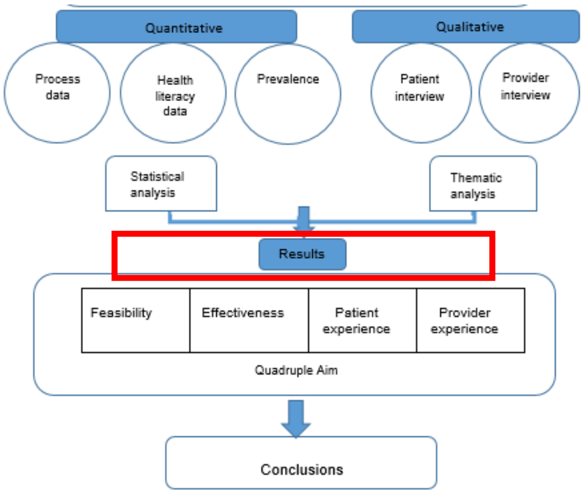
Descriptive statistics were used to describe the number and percentage of participants who completed each activity after the intervention.

4.6 Qualitative data analysis



A theoretical thematic analysis approach was used. Transparency of process has been described as critical in making a convincing case for the validity of one's findings and interpretations.(136) During the thematic analysis, codes were first developed at a semantic level and further analysed to generate themes at an interpretive level.(137) The candidate followed a six-phase process, detailed in the qualitative research literature as a deliberate and rigorous approach.(137, 138) The following six steps were undertaken. 1) The candidate became familiar with the data. Familiarisation began during the interview process when initial impressions were formed and then continued with a process of listening to audio recordings and reading interview transcripts. 2) A process of coding the transcripts was undertaken. The candidate and two research supervisors independently coded a transcript and met to compare their codes and to determine a shared understanding. The remaining transcripts were then analysed by the candidate based on the common schema. 3) Identified codes were mapped onto relevant socio-ecological levels of influence [individual, interpersonal, provider, system] to inform the identification of themes relating to the research question. 4) Themes were reviewed with regular discussion between the candidate and research supervisors, refining the meaning making process. 5) Naming and refining of themes involved interpretation of the themes in relation to the research aims with discussion and reflection between the candidate and co-supervisors. Understanding at an interpretive level drew on the experience of the candidate as an informed insider, by considering the ways the identified themes contributed to an understanding of a participant’s experience, the feasibility of the ACP approach and/or its effectiveness , in order to generate conclusions. The final step was 6) presenting the analysis report by providing sufficient evidence of the veracity of the themes. Given the advice, ‘quotes lay bare the emergent themes for all to see. They are the foundation upon which good qualitative data analysis is based,' (139) extracts and narrative quotes were used to demonstrate the findings.

4.7 Triangulation



Qualitative and quantitative data were considered individually and in relation to each other. This section outlines the candidate's approach to making meaning of the data through the process of triangulation. The approach is said to 'improve the accuracy of judgement by collecting different kinds of data bearing on the same phenomena'(140) This convergence provides 'an alternative to validation which increases scope, depth and consistency in methodological proceedings'. (141)

The candidate started by interrogating the process data. Had implementation occurred? Did the health assessments occur? Were the patients invited, were the groups conducted? Once satisfied that implementation had been achieved, a deeper look was required to determine meaning behind the numbers. Individual data sets were examined to identify any patterns e.g. patients or participants not arriving, or gendered differences in attendance. This understanding was overlaid with an analysis of the qualitative themes – was there congruence in the findings? For example, did lack of attendance relate to restrictive scheduling times described by patients?

How a complex intervention might work in general practice cannot be answered by a single data set. The answer required a combination of all. For example, in considering whether patients found the experience acceptable, interview responses would provide some insight about the experience, and this insight may be validated or called in to question when combined with an understanding of attendance data. If both patient and provider found the experience positive, and it was implemented effectively and no change was seen in the AD uptake, the effectiveness of the complex intervention would be in question.

By considering each data set in relation to the others, an answer to the research question took shape. The candidate looked for contradictions and similarities across data sets supporting or refuting interpretation at an activity level. The results were considered across the quadruple aims, with each data set contributing to the understanding.

4.8 Critical appraisal of the quantitative methods

To ensure suitable rigor and to assess the extent to which the study had 'addressed the possibility of bias in its design, conduct and analysis', a self-assessment of the study methodology using the Joanna Briggs critical appraisal tool for quasi-experimental studies was applied, answering nine key questions.(45) The answers to these outline the degree of rigour applied in this study, and in doing so provide evidence that the research design will support rigorous synthesis and interpretation of the results of the study. These are presented in Table 16.

TABLE 16:SELF-ASSESSMENT USING A CRITICAL APPRAISAL TOOL FOR QUASI-EXPERIMENTAL STUDIES (45)

	Question	Response
1	Was it clear in the study what was the cause and what was the effect – there being no confusion about which variable came first?	Yes. The cause was the intervention. The effect was uptake of an ACD. The application of eligibility criteria ensured patients were excluded if they had a pre-existing ACD. By determining ACD status before exposure to the intervention [the cause] it was clear that any subsequent ACD was an effect.
2	Were the participants included in any comparisons similar?	Yes. Comparisons were made between an independent control group and the intervention group. These two groups were assessed to be similar for age and gender distribution, pre-existing ACD prevalence and purpose of practice visit. These groups were not specifically matched. The intervention group ACD uptake at the beginning of the evaluation period was compared [to itself] at the end of the evaluation period.
3	Were the participants included in any	Yes, to some extent*. The control group received usual care based on a standard format for conducting 75+

	comparisons receiving similar treatment /care, other than the exposure or intervention of interest?	health assessments. The intervention group received usual care based on the same standard format, with the addition of incrementally stepped exposures, as described. *This response is qualified by the acknowledgement that participants in either group could have been exposed to uncontrolled external influences in their day-to-day life, e.g. death of a family member, unexpected deterioration in health status, or media influences, none of which were controlled in the research design.
4	Was there a control group?	Yes, but there were limitations. Data for the control group were collected retrospectively at the end of the evaluation period as a single cross-section at this point in time Based on the literature findings it was considered unlikely that significant natural change occurred in the control group over the study period although in the absence of certainty this remains a limitation of the study. ACD in the community has been shown to be low in several studies. A prevalence study conducted in Australia in 2014 and repeated in 2019 concluded 'despite long-standing efforts to increase ACP, community prevalence of ACD remains low.'(124) Rate of uptake is further shown in RCT studies in which no or minimal change occurred in control groups during ACP intervention study periods. (122, 123) Based on these findings, and in the absence of baseline control data, the assumption was made that there was likely to be minimal natural change in ACD uptake in the control during the evaluation period.
5	Were there multiple measurements of the outcome both pre and post the intervention exposure?	Yes, to some extent. To show that there was a change in the outcome as a result of the intervention it was necessary to compare the results of measurement before and after the intervention. ACD prevalence was calculated before and after for the intervention group only, and baseline and post intervention health literacy scores were also reported for intervention participants.
6	Was follow up complete and if not, were the differences between groups in terms of their follow up	Follow up was not complete. Participation numbers across steps of the intervention were reported, but if individuals opted not to participate this was understood as not consenting. Follow up for non-consenting

	adequately described and analysed?	individuals was not attempted. If a consenting individual was lost to follow up, an explanation for the loss to follow up was provided.
7	Were the outcomes of participants included in any comparisons measured in the same way?	Yes. ACD prevalence was the outcome indicator compared between control and intervention group. This measure was applied equally for both control and intervention group. Data were collected by audit of the medical record by practice staff for both groups.
8	Were the outcomes measured in a reliable way?	Yes, to some extent. Intervention data were collected and measured consistently across intervention and control groups. Within the intervention group, participant HLQ responses may have been subject to variability leading to lack of reliability.
9	Was appropriate statistical analysis used?	Yes. Details and justification of methods of statistical analysis were approved through an ethics process. The validity of inferences may have been weakened by low statistical power on some measures. This was highlighted where applicable.

4.9 Critical appraisal of the qualitative methods

A critical appraisal of a qualitative study considers the 'fit' of the research question with the qualitative methods used in the study.(142) Methodologically sound qualitative research provides evidence that the findings of the study are valid and this is described in terms of rigour, credibility, trustworthiness, and believability.(143) A critical appraisal tool was used to assess qualitative methods in this dissertation, as shown in Table 17.

TABLE 17: SELF-ASSESSMENT OF STUDY USING THE CRITICAL APPRAISAL SKILLS PROGRAM (CASP) QUALITATIVE ASSESSMENT TOOL

	Question	Response
1	Was there a clear statement of the aims of the research?	Yes. The research question was stated in the introductory chapter and presented in the context of the problem. Aims and objectives to answer the research question were presented in Chapter 2, further informed by the findings of the literature review.
2	Is the qualitative methodology appropriate?	Yes. Within the mixed methods case study design, the qualitative component of the

		study was appropriate to achieve the stated aim of understanding participant and provider experiences of the intervention. Thematic analysis of qualitative data was effective in identifying key themes and issues raised in interviews with participants and providers. [Chapter 5.4 and 5.5] The rationale for the use of this methodology was discussed in Chapter 4.
3	Was the research design appropriate to address the aims of the research?	Yes. The candidate determined that conducting a trial in a busy general practice was a multi-faceted undertaking requiring a range of outcome data to understand effectiveness The research design allowed sufficient flexibility in this context, to be practically applied with resulting data available to interpret the patient experience, and provider experience as meaningful outcome data. The resulting qualitative outcome data when combined with the qualitative data contributed to the overall determination of effectiveness.
4	Was the recruitment strategy appropriate to the aims of the research?	Yes. Recruitment strategy ensured participants all volunteered from an identified target population. The sample used in collecting qualitative data in this study was randomly selected, in advance, based on being a member of the target population attending the group information sessions. Sound reasoning and justification for the sampling was provided in Chapter 4.2. Sample size calculations were conducted during the research design. A degree of selection bias was considered unavoidable. Data sets were drawn from general practice patients who voluntarily participated in a 75+ health assessment as part of their annual cycle of care. This participation in the management of ones' own health care presents a bias. It could be hypothesised that this group was more rather than less inclined to participate in ACP because they were more rather than less involved in managing their health in general.

5	Was the data collected in a way that addressed the research issue?	Yes. There was congruence between the identified issue, the approach to explore the issue and the data collection to determine the outcome.
6	Has the relationship between researcher and participants been adequately considered?	There was strong evidence that the relationship between the researcher and participants was well considered and specifically addressed in the ethics approval process. The researcher remained a third-party observer throughout the evaluation period with the primary relationship existing between the practice team and patients. Research information sheets were provided in a timely manner. Consent forms were explicit providing the option to consent for each section of the study. The ability to opt out at any point was clear.
7	Have ethical issues been taken into consideration?	Ethics approval was granted by the Flinders University Social and Behavioural Research Ethics Committee (SBREC) [Appendix 15] and ethical considerations were outlined in Chapter 4.4.
8	Was the data analysis sufficiently rigorous?	Data analysis demonstrated qualitative rigour. The use of audio recording, verbatim transcription, line by line coding and the inclusion of participant quotes contributed to credibility, trustworthiness, and believability. Description of the process used for thematic analysis provided transparency of process. Observation in the group by an informed insider contributed to triangulation of findings and meaning making using an interpretive approach. Further methodological reflection is detailed in Chapter 6
9	there a clear statement of findings?	Yes. Findings are presented in relation to research aims including limitations of the study.
10	How valuable is the research?	The research adds value by organising the ACP literature to find new meaning through a socio-ecological lens. It contributes knowledge to address a gap in the ACP literature by providing guidance to general

		practices interested in increasing uptake of ACP with their practice patients. Value is a subjective construct, however, patients given the opportunity to consider, document and communicate their end of life wishes are likely to find significant value as a consequence of this research being implemented. It has real life applicability.

4.10 Limitations

The research design was subject to the constraints of real life. The intervention was conducted in the environment of a busy general practice, not a controlled laboratory. As such, it was potentially limited by uncontrolled circumstances such as health care emergencies or severe weather hindering attendance at appointments. Variability in the levels of communication skills, experience and effectiveness of the practice nursing staff was not measured or controlled. This variation may have affected results and remains a limitation of the research design.

By engaging an exemplar practice the baseline ACD rate [27%] was already known to be higher than background levels reported in the literature. It is uncertain what implications this high baseline had on determining further effectiveness.

The study design did facilitate understanding or measure ACD outcome effect at the level of the individual GP-patient relationship when participating in group sessions during the ACP intervention. It is unclear if the relationship between the GP presenting at the group session and the attendee would be strengthened or adversely affected if the GP was not the usual GP.

The evaluation period was time limited to 12 weeks because of practical scheduling constraints. This period coincided with the seasonal demands of winter. Given the target group was people aged over 75 years, this may have resulted in a more limited engagement than if the intervention had been run during warmer summer months. Similarly, the timing of the group sessions was governed by practice scheduling constraints. A lack of flexibility in schedule may have contributed to people being unable to attend at the prescribed times.

This study did not obtain qualitative data from individuals in the control group which may be considered a limitation.

4.11 Summary

In this chapter, details of the study design and methods were presented. A case study design was chosen as the research methodology to answer the research question 'How does a complex intervention influence uptake of ACP in a general practice context?' The theoretical framework was explained in the study schema and methods of data collection and analysis were discussed. A quasi-experimental study approach was outlined with quantitative methods used to explore prevalence data from control and intervention groups, combined with HLQ data and process measures. Thematic analysis of participant and provider interviews was used to gain qualitative understanding. A process of triangulation to make meaning of the collective findings was described.

The ethics of the study were considered before critiquing the rigor of the methods, making explicit the limitations. Based on this critical appraisal, it was concluded the research design would support rigorous synthesis and interpretation of the results of the study to address the research aims. This critique was important in ensuring that the results presented in the following chapters can be understood in context, with adequate information to interpret the transferability of the findings. In Chapter 5, the results are presented.

Chapter 5: Results

Introduction

Research design and planned methods of data collection and analysis were described in Chapter 4. In this chapter, the results of the study are presented in two parts. The quantitative results are presented in Part 1 and the qualitative results are presented in Part 2.

Part 1 Quantitative results

Quantitative data results for process implementation, health literacy and prevalence are presented in the following sections, 5.1 to 5.4.

5.1 Process implementation

A proof of concept trial from inception to completion was undertaken in general practice with the initial implementation period of the intervention occurring over 12 weeks from May to July 2019. To determine the effectiveness of the approach, gaining an understanding of the process of implementation was a critical step. In this section data are presented to determine the extent to which day-to-day implementation of the model of care was achieved. Key outcomes of the implementation process are described.

5.1.1 Step 1

Patient arrival and attendance at their 75+ health assessment was recorded as Step 1. Health care providers screened 123 people who attended the practice for a health assessment to determine eligibility (Table 18). No palliative patients attended during the recruitment period. One male and one female were excluded because of a diagnosis of impaired cognition and a further two males were excluded with impaired cognition *and* a pre-existing advance care directive [ACD]. An additional 13 males and 21 females had pre-existing ACD and were also excluded. A total of 38 people were excluded, leaving 85 people eligible to participate in Steps 2 and 3.

TABLE 18: ELIGIBILITY TO PARTICIPATE BY GENDER

	Arriving for health assessment	Palliative	Impaired cognition	Impaired cognition AND ACD	Total with ACD	Eligible to attend session
Male	61	0	1	2	15	45
Female	62	0	1	0	21	40
Total	123	0	2	2	36	85

5.1.2 Step 2

Eligible individuals were automatically included in Step 2 during the same health assessment visit. In Step 2, health providers discussed advance care planning [ACP] and provided individuals with an ACD toolkit booklet. At the end of this health assessment visit, all eligible patients (those who had been included in Step 2) were given an invitation to participate in a group information session. Those who expressed interest were scheduled into a group information session, and also invited to bring a family member or spouse if they wished. Patients who expressed interest in attending the group information session were provided with a research information pack, including a letter of introduction, a research information sheet, and a consent form. Between Step 2 and Step 3, patients had one to two weeks to review the information before commencement of Step 3.

5.1.3 Step 3

The scheduled group information sessions followed a standard format and ran for approximately one hour. Each session commenced with the screening of a brief animated video providing an overview of ACP and allowing participants to settle in. The nurse practitioner prepared and followed a loosely scripted agenda informed by existing conversation guides, and developed further based on common questions arising in the literature. This was also informed by her extensive professional experience. [Appendix 16].

General discussion covered themes including legal aspects of ACP, underpinning values, and beliefs. A brief review of the ACD template contained in the toolkit was undertaken and people were encouraged to discuss any concerns. The GP presented a medical perspective based on perceived usefulness at end of life, and a period of question and answer provided opportunity for specific enquiries.

5.1.3.1 Participation

Upon arrival at the group information session, patients interested in participating in the research gave their consent. Step 3 invitations and attendance by gender are shown in Table 19. Of the 85 patients invited to participate in Step 3, a total of 19 patients attended. This limited attendance meant that the Step 3 intervention sample size was smaller than the required sample size of 53 participants determined by the power calculation [80%] and therefore study outcomes would need to demonstrate a greater study effect to be statistically significant .

Some patients accepted the invitation and did not arrive for the information session. Females were more likely to do so than males. Of the 14 people who did not arrive, at the information session, nine had indicated they would bring their spouse. Health care providers speculated that there was a relationship between those not arriving and the response received from their spouse to the invitation. This could not be confirmed.

TABLE 19 PARTICIPANT ATTENDANCE FOR STEP 3

Step 3	Invited	Accepted invitation	Arrived at group	% invited who arrived
Male	45	18	11	24%
Female	40	15	8	20%
Total	85	33	19	22%

5.1.3.2 Attendance by spouse

Participants were encouraged to invite a spouse or family member to accompany them to the Step 3 group information session. Of the 19 attending participants, nine people (47%) were also accompanied by a spouse. These additional attendees were not included in the data but are reported for completeness.

Overall, participation and eligibility is detailed at each level and decision point are shown in Figure 4 below.

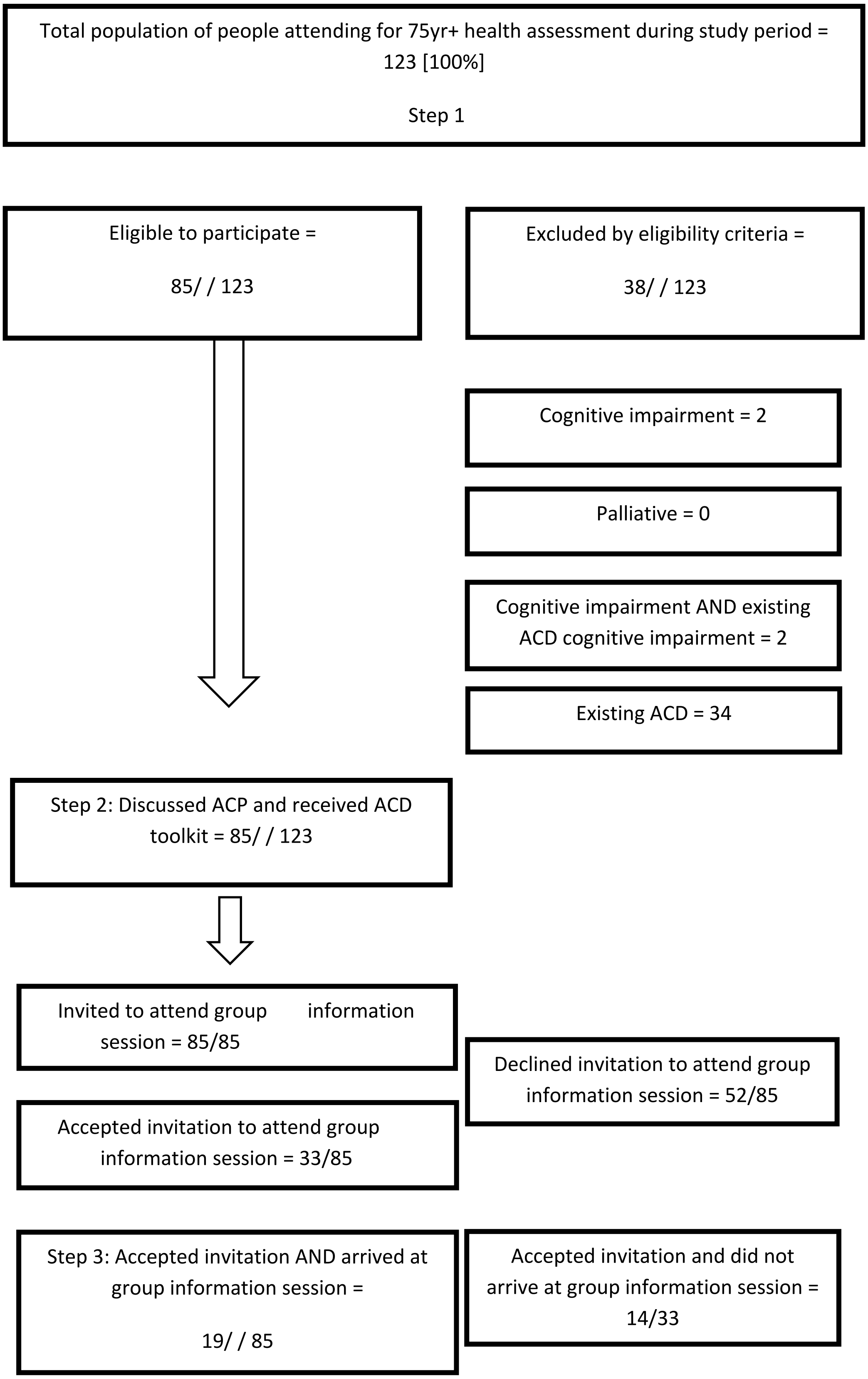


FIGURE 4: PATIENT PARTICIPATION BY STEP OF INTERVENTION

As outlined in Figure 4 above, of the 85 people eligible to participate in Step 3, 52 people declined the initial invitation to attend the group information session, and of the 33 who agreed to come a further 14 people did not arrive for their scheduled group. When combined, this meant that 52+14 =66 of the eligible / 85 (78%) people opted out after Step 2. The 19 people who did attend Step 3 constituted 22% of those eligible to do so. This low uptake was unexpected by practice health care providers.

5.1.3.3 Gender distribution across step of intervention

To determine if gender might be a factor that influenced participation and / or uptake of ACP data, patients were categorised by gender. Attendance data were reasonably equal between men and women. Of the 123 people participating in Step 1, there were 61 females and 62 males. Step 2, had 85 patients, including 40 females and 45 males, while in Step 3 the 19 patients comprised of 8 females and 11 males, as outlined in Figure 5 below. A chi- squared test showed the differences in participant numbers were not statistically different by gender [*p*-value=0.81)

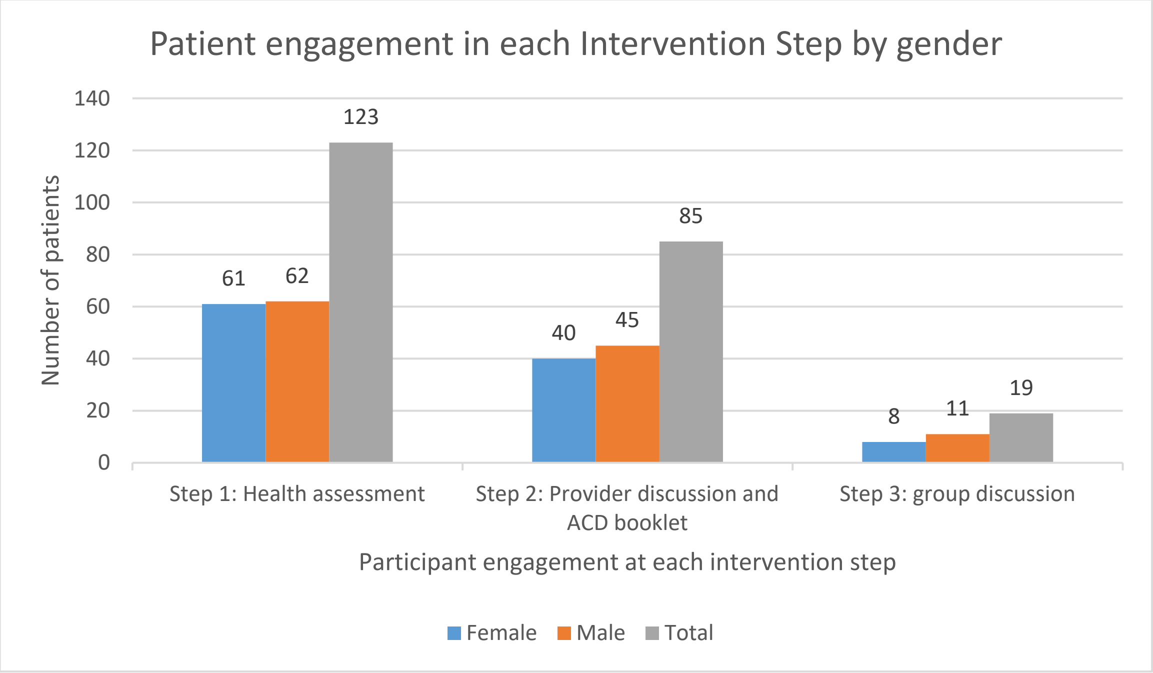


FIGURE 5: PATIENT ENGAGEMENT IN EACH STEP OF THE INTERVENTION, BY GENDER.

Because patients were not asked to give consent to participate in the research until they arrived at the group session, the research design did not enable an understanding of why individuals declined to participate, or accepted an invitation and then did not arrive.

5.1.4 Group information session attendance

Attendance at group information sessions was variable. Sessions were scheduled regularly and frequently throughout the recruitment period. Table 20 below outlines the groups held by date, with participation by scheduled and actual total number attending.

TABLE 20: GROUP SESSION ATTENDANCE BY DATE

Group	Date	Participants scheduled	Participants attending	Non-participating spouse attending	GP attending	Total
1	6 May	5	4	2	Yes	6
2	13 May	6	1	1	Yes	2
3	24 May	3	3	1	Yes	4
4	27 May	0	0			
5	7 June	5	2	1	Yes	3
6	17 June	6	3	1	No	4
7	21 June	2	1	1	Yes	2
8	28 June	2	0			
9	5 July	3	3	1	Yes	4
10	12 July	2	1		No	1
11	19 July*	by request	1	1	No	2

The information session dates and times were scheduled by the general practice to fit into their daily operations in collaboration with the nurse practitioner who was facilitating the sessions. Most sessions were planned for 9.30am, in the morning which was reported to be a difficult time for elderly people to mobilise and attend, particularly in the colder winter months in this regional community. As air temperatures dropped, so did attendance. The high number of scheduled sessions also meant they were unlikely to be adequately filled, because there were insufficient health assessments being conducted to fill the available places. Consequently, participation was reduced at all sessions. Following consultation, the team concluded that the optimal frequency for future sessions would be monthly, with scheduling to occur in the middle of the day for ease of access.

5.1.5 GP participation

A practice GP was scheduled to attend each of the group information sessions for a 15- minute question and answer segment. To facilitate this, a 30-minute appointment time was blocked out of their patient appointment schedules, in advance. Despite this planning, the GPs were only able to attend the group 66% of the time because routine appointments were running late and/or there were emergency presentations taking priority. Participants in sessions where the GP had been unable to attend showed understanding that the absences occurred because of the emergency nature of patient care.

5.2 Health literacy results

The Health Literacy Questionnaire (HLQ) was used to measure pre- and post-intervention scores of participants in Step 3 across five domains of interest. Pre- and post- intervention scores were compared at an individual and aggregated levels across each of the five domains. A summary of means and standard deviations (S.D.) across the five domains before and after participation is shown in Table 21.

TABLE 21: SUMMARY OF CHANGES PRE- AND POST- INTERVENTION FOR MEAN AND STANDARD DEVIATION ACROSS FIVE HLQ DOMAINS.

Domain	Scale name	Mean score before (SD)	Mean score after (SD)	*p*-value
1	Feeling understood and supported by healthcare providers	3.40 (0.61)	3.10 (0.55)	0.96
2	Having sufficient information to manage my health	3.41 (0.55)	3.16 (0.33)	0.96
4	Social support for health	3.41 (0.55)	3.07 (0.52)	0.98
6	Ability to actively engage with healthcare providers	4.17 (0.52)	4.05 (0.48)	0.81
9	Understand health information well enough to know what to do	4.25 (0.73)	4.4 (0.36)	0.19

Normal distribution was confirmed before applying a paired t-test to determine if the aggregated means for each domain were similar before and after the intervention. A statistically significant change in a mean score would suggest an intervention effect. There were no significant differences between before and after scores and hence an intervention effect was not demonstrated. The intervention had 19 participants and there was loss to follow up of two participants, resulting in a final HLQ sample size of 17. The test was only powered to find a statistically significant mean difference if the mean difference between pre- and post-intervention Likert scale scores was in the order of 0.8. Overall, the HLQ data were inconclusive, with a high risk of Type 2 error. The limited numbers lacked sufficient power for interpretation [Appendix 12].

5.3 General Practice level data

5.3.1 Sample demographics

The control group consisted of 235 patients attending the practice for a 75+ health assessment in the six months before the intervention. A chi-squared test of independence indicated there were no statistically significant differences between control and intervention groups for gender and age range as shown in Table 22. There was no overlap in membership between the two groups.

TABLE 22: COMPARISON OF CONTROL AND INTERVENTION GROUPS BY AGE AND GENDER

Factor	Age category in years	Control	Intervention	*p*-value
N		235	123	
Female	75–79 80–84 =>85	48 (42.5%) 37 (32.7%) 28 (24.8%)	29 (46.8%) 15 (24.2%) 18 (29.0%)	0.49
Male	75–79 80–84 =>85	58 (47.5%) 35 (28.7%) 29 (23.8%)	25 (41.0%) 22 (36.1%) 14 (23.0%)	0.57

5.3.2 ACD prevalence

The two groups were compared for ACD prevalence. Change in ACD prevalence in the intervention group was a measure of outcome so the candidate determined it was important to measure ACD prevalence *at baseline* to detect any post-intervention change. In the control group, 65 of 235 (28%) patients had an ACD. In the intervention group before the intervention

36 of 123 (29%) patients had an ACD. (Table 23) The null hypothesis was that there was no difference between the ACD prevalence rates in these two groups. The resulting odds ratio of 1.08 [95% CI 0.64–1.79] was not statistically significant [*p*=0.748]. The null hypothesis was not rejected and the baseline ACD prevalence was considered similar across the two groups.

TABLE 23: COMPARISON OF ACD AT BASELINE

Proportion at baseline					
	Have ACD	No ACD	Total	Prevalence %	
Intervention group	36	87	123	29%	
Control group	65	170	235	28%	*p*-value= 0.748
Total	101	257	358	28%	

5.3.3 Comparison of ACD prevalence in control and intervention groups by gender and age

ACD prevalence in the control and intervention groups was compared by proportion across gender and age. [See Table 24]. In the control group, female ACD prevalence ranged from 20.8% of all females at 75–79 years of age up to 50% of all females in the 85+ age category. The intervention group had a similar spread ranging from 24% in the 75–79 age category up to 55% in the 85+ age category. The numbers were too small for meaningful statistical analysis, but it was noted that there was a pattern of higher ACD levels in the older age categories for females in both groups, but this pattern was not observed in males. Overall, males were less likely to have an ACD in both the control (21.3%) and intervention (24.5%) groups compared with females in the control (34.5%) and the intervention (33.8%) groups. This difference was statistically significant [*p*=0.016].

TABLE 24: PROPORTION ACD PREVALENCE IN CONTROL AND INTERVENTION GROUPS AT BASELINE, BY AGE AND GENDER

Factor	Age category	Control	Intervention	p-value
N		235	123	
		#ACD/# in group (%)	#ACD/# in group (%)	
Female	75–79	10/48 (20.8%)	7/29 (24 %)	
	80–84	15/37 (40.5%)	4/15 (26.6 %)	
	=>85	14/28 (50%)	10/18 (55.5 %)	
Female total		39/113 (34.5%)	21/62 (33.8%)	
Male	75–79	10/58 (17.2%)	3/25 (12.0 %)	
	80–84	9/35 (25.7%)	7/22 (31.8 %)	
	=>85	7/29 (24.1%)	5/14 (35.7 %)	
Male total		26/122 (21.3%)	15/61 (24.5%)	*p*=0.016

5.4 After the intervention

Statistical tests were undertaken to determine any intervention effect. The first considered any change in ACD prevalence. The null hypothesis was that participation in the intervention would not result in a change in ACD prevalence. A statistically significant change in ACD prevalence from before to after the intervention in the intervention group, or a change in prevalence when compared with the unexposed control group would contribute to understanding the effectiveness of the intervention in increasing uptake of ACP in general practice.

5.4.1. Change in ACD prevalence

The Mann–Whitney U test was used to compare the control and intervention groups at the end of the evaluation period. To note, the control group prevalence data was assumed to have remained unchanged from baseline to post-intervention (Table 25). Justification for this assumption was explained in 4.2.1.1.

TABLE 25: CHANGE IN ACD IN POST-INTERVENTION GROUP VERSUS CONTROL

Factor	Has ACD	Control	Intervention	*p*-value
N		235	123	
Baseline	No	170 (72.3%)	87 (70.7%)	0.748
	Yes	65 (27.7%)	36 (29.3%)	
Post- intervention	No	170 (72.3%)	73 (59.3%)	0.012
	Yes	65 (27.7%)	50 (40.7%)	

Of the 123 participants in the intervention group, 50 [41%] had an ACD at the end of the evaluation period which represented an increase of 11% on baseline.

As demonstrated in 5.3.2, there was no statistically significant difference between control and intervention groups at baseline [*p*=0.748], and after the intervention there was a significant difference between them [*p*=0.012]. This finding confirms a statistically significant intervention effect. The strength of the intervention effect was determined by calculating the odds ratio which was found to be 1.79 [CI 1.1–2.9]. This was also statistically significant [*p*=0.012] and indicated that for a person participating in the intervention they were 1.79 times more likely to complete an ACD than for someone who was not offered the ACP intervention.

5.4.2 Change within intervention group

An original hypothesis was that by increasing exposure to the steps of the intervention, developed according to the socio-ecological framework, an accumulation effect would lead to greater uptake of ACD after each step. Prevalence of ACD according to participation in each step of intervention are compared in Figure 6.

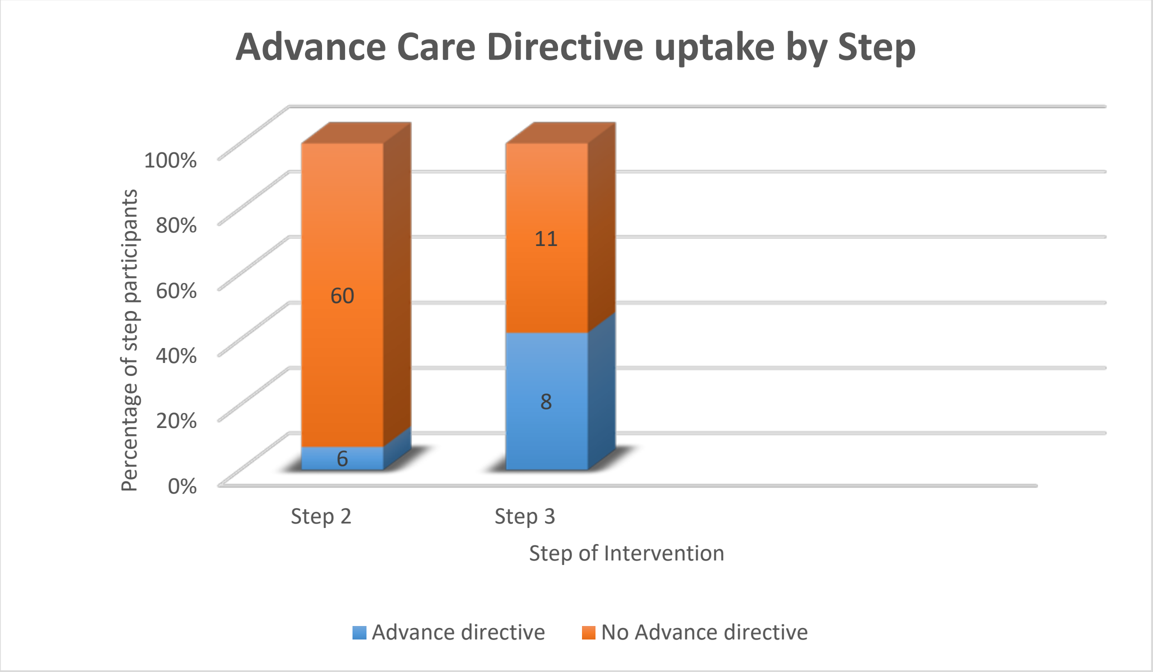


FIGURE 6: ACD UPTAKE BY STEP OF INTERVENTION.

The baseline ACD level in Step 2 was zero because the eligibility criteria applied in Step 1 excluded all patients with an existing ACD. There were 85 patients included in Step 2, of whom 19 continued into step 3. As shown in Figure 6, among the 66 patients who only participated in Step 2, there were six ACDs completed (9%). Among the 19 participants who participated in Step 3, ACDs were completed by 8 of them, an uptake of 41% among the Step 2 plus 3 cohort

5.4.2.1 Comparison of Step 2 versus Step 3

Results of chi-squared test of independence comparing ACD uptake of the 66 people who participated in Step 2 only with the 19 people who continued to participate in Step 3 are shown in Table 26. The value of chi-squared was 11.6879, significant at p=0.001. This demonstrates that participants attending all steps of the intervention were statistically more likely to have an ACD than those who participated in fewer steps.

TABLE 26: STEPS 2 AND 3 ACD UPTAKE COMPARED

Participated in	ACD	No ACD	Row totals	*p*-value
Step 2 only	6 (10%)	60	66	
Steps 2 and 3	8 (41%)	11	19	*p*=0.001
Column total	14	71	85	

When considering cumulative uptake of ACD in response to exposure at successive steps, a linear trend is seen, showing increasing prevalence with increasing exposure to intervention steps (Figure 7). Cumulative prevalence of ACD in the intervention group rose from a baseline prevalence of 36/123 (29%) to a cumulative prevalence at Step 2 of 42/ 123 (34%), and 50/123 (41%) after Step 3.

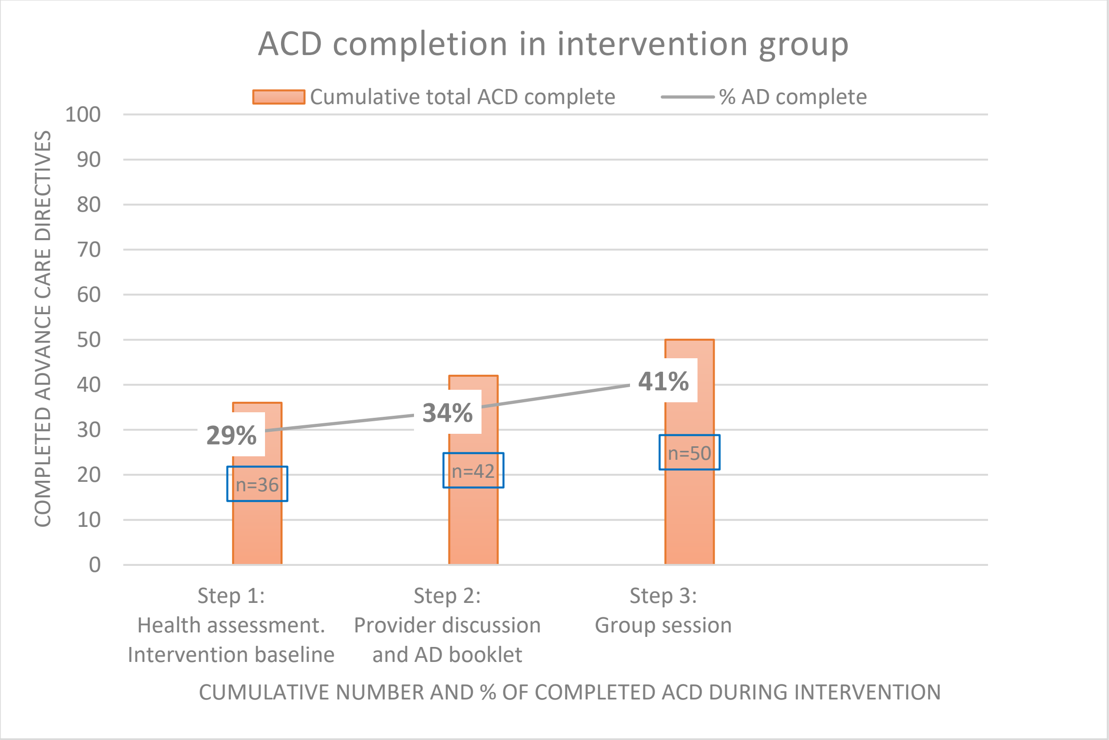


FIGURE 7: CUMULATIVE NUMBER AND % OF COMPLETED ACD DURING INTERVENTION

Patients who participated in more steps of the intervention had a higher rate of ACD than those who participated in fewer steps [*p*=0.001], but results lacked power for the difference from baseline to be statistically significant [*p*=0.061].

5.5 Final survey data

The final telephone survey was conducted 12 weeks after participation in Step 3. Participants' actions are summarised in Table 27.

TABLE 27: SUMMARY OF FINAL SURVEY RESPONSES

Actions	Communicated wishes to next of kin/family	Put my wishes in writing in an ACD	Still thinking about what to do	Loss to follow up
Total	15 of 19 (79%)	8 of 19 (41%)	6 of 19 (31%)	2 of 19 (10%)

There were 17 of 19 participants [90%] available to complete the telephone survey at the end of the evaluation period, meaning two [10%] were lost to follow up. One of these requested to withdraw for personal reasons and the other could not be contacted after three attempts. A total of 15 of 19 participants had spoken to a family member about their end of life wishes, and eight participants had completed an ACD. Seven of these eight participants had also spoken to their family about their wishes. There was a perceived risk that participants would report having completed an ACD to satisfy the researcher. The ACD uptake reported by participants during this telephone survey was consistent with the ACD medical record audit data reported by practice staff and, based on this triangulation, the candidate considered it to be accurate. Individual responses are tabled at Appendix 17.

5.5.1 ACD uptake reported by participants exposed to interview

Of the eight participants who were interviewed, four reported completion of an ACD. This compared with 11 participants who were not interviewed, four of whom had completed an ACD. The numbers were too small for meaningful statistical comparison.

5.6. Limitations

Attendance at group sessions was less than anticipated. 3 of the scheduled eleven group sessions included only the participant and spouse. The research methodology did not accommodate an additional categorisation of 'personal sessions'.

Data for the control group were collected retrospectively at the end of the evaluation period *as a single cross-section at one point in time.* Based on the literature findings, it was considered unlikely that significant natural change occurred in the control group over the study period although in the absence of certainty this remains a limitation of the study. To support the assumption, the prevalence of ACD in the community has been shown to be low in a number of studies. For example, a prevalence study conducted in Australia in 2014 and repeated in 2019 concluded 'despite long-standing efforts to increase ACP, community prevalence of ACD remains low'.(124) Rate of uptake is further shown in RCT studies in which no or minimal change occurred in control groups during ACP intervention study periods.(122, 123) Based on these findings, and in the absence of baseline control data, the assumption was made that there was likely to be minimal change in ACD uptake in the control group during the evaluation period.

A second limitation was the potential distortion of the effect due to the likelihood of volunteer bias. Because participation required consent, it was likely that people who agreed to participate in the study differed from those who declined. There was a likelihood of volunteer bias in so far as those most motivated to complete an ACD would be most likely to engage in the ACD intervention process and most motivated to participate in all three steps.

Similarly, the health literacy levels of those who opted not to participate remain unknown and it was possible that participation was linked to higher or lower levels of health literacy.

It is also possible that confounding bias was undetected in results. It is possible that extraneous uncontrolled variables influenced participant behaviour, for example the effects of the death of family member, or exposure to community ACP initiatives influencing participants to act in one way or another.

Part 2 Qualitative results

Introduction

In this section, qualitative data from a series of semi structured interviews conducted with patients and providers after the evaluation period are presented. A total of 17 semi-structured interviews were conducted with eight participants and nine health care providers. The findings are presented in two parts.

5.7 Patient interviews

Interviews were conducted one week after participants attended an ACP group information session. Three men and five women were individually interviewed, covering attendance at group sessions conducted over 14 weeks (Table 29). Poor audio quality led to one man's record being excluded, denoted* below.

All women interviewed were in the 75–79 years age category while there was one man in each of the three categories. In the following, participants are identified by a code with research ID number, an initial representing their gender^, either M=male or F= female, and their age in years, for example ID100 F: 75.

TABLE 28: INTERVIEWED PARTICIPANTS BY ID NUMBER, GENDER AND AGE

Age in years	75–79	80–84	85 and over
Male	[ID124] M:79	[ID156] M:81	[ID127]* M:85 excluded
Female	[ID176] F:76 [ID170] F:77 [ID 173] F:78 [ID 151] F:78 [ID 128] F:78	0	0

^No participant identified with an alternative gender identity

5.7.1 Interview findings

Thirteen themes emerged from the initial framework analysis. At the individual level these were*: aspects of knowing, things we don't talk about,* and *finding the right time*. At the interpersonal level, the themes were s*pouse, chosen one, family protection, blended family, social support, shared wisdom* and *safety in numbers*. The provider level generated a single theme of *variability of provider opinion*, and the system level themes were *triggers* and *practical advice*. The themes have been described below with participant quotes to emphasise patients' voices.

It is noted that the group of older individuals involved in these interviews was collectively bemused at the notion that their views on ACP would be considered interesting and worthy of research. Despite this apparent surprise, participants appeared to respond in earnest.

5.7.1.1 Individual level

Overall, participants described the intervention process as experientially feasible and acceptable. Individual level themes were *aspects of knowing, things we don't talk about,* and *finding the right time*. Each theme is briefly described herein.

Aspects of knowing

It was common for individuals to explain they had no knowledge of ACP before being invited to attend the information session. It was one of the main stated reasons people chose to engage in the process and this was expressed as a desire to understand more. There was an underpinning element of incredulous disbelief… 'how could I not know?'

> *I learnt about it when I had my health check up at the [general practice] last week. I was so surprised when she [the nurse] gave me this booklet that I knew nothing about it. That was the first time I'd heard about it… [ID 156 M: 81]*

Others suggested some prior knowledge of ACP but described not really understanding what was involved. Among participants who had some knowledge, there was an expressed wish to clarify their understanding and make sure they were taking appropriate steps based on their understanding. Participants appreciated the opportunity to gain better understanding and expressed appreciation for the opportunity to question and seek clarification about things that were not clear to them. Interview participants commonly described that, with knowledge, came the confidence to make a more informed decision. A link was made between having knowledge of ACP and having confidence to take action.

> *I like to know about it so that it gives me confidence about what can be done in the future… [ID176 F 76]*

Things we don’t talk about

Participants were asked how they felt when invited to learn about ACP. Given the interviewed participants were among those who had self-selected to engage in the group session and had consented to be interviewed, a predominately positive response was expected.

> *I was pleased that they [providers] brought it up to me because I didn’t know about it [ACP] and when I found out I thought oh yeah why not… [ID151 F: 78]*

It became clear during interviews that to consider ACP, there was a necessary and direct link requiring a person to consider their own mortality. This notion was more or less abstract for some, giving the impression that the link between completing an ACD and pondering their own mortality had not been fully considered when they agreed to participate. There was common acknowledgement that discussion or thinking about ‘death’ or dying was highly unusual in the day-to-day lives of participants. It was suggested this approach may not be suitable for everyone, with the possibility of triggering emotional responses. One individual described a degree of personal discomfort.

> *I felt funny talking about it, [death] because I think we all feel, uh, dubious, talking about things that we don't want to talk about… [ID128 F: 78]*

Even within the hesitation expressed, there was strong support for ACP discussions to be initiated. When presented with the opportunity to talk about death, perspectives ranged from perceived reluctance to pragmatism. It was noted that most people did not use the word ‘death’, preferring instead to speak around the topic – commonly referring to death as ‘it’. There was an important distinction between speaking about the concept of ACP as an action involving the taking of pro-active steps to consider possible future health care scenarios, and the concept of one’s own impending death. Framing the discussion with an understanding of this distinction was important in avoiding potential for misunderstanding.

> *I appreciated it. I mean, it didn't make me think, for instance, that, "Oh, my God. I'm going to need this pretty soon! It wasn't like that at all… [ID176 F: 76]*

Overall, the interviews demonstrated that it was acceptable to discuss death in this context, and there was an inherent assumption that there was an acceptance and an expectation that ACP discussions should be raised, and would be raised, by their health care provider when the health care provider considered it to be the right time.

Finding the right time

The literature identifies the importance of patient ‘readiness’ to participate in ACP. Agreement to participate and arrival at the ACP information session was one indication of readiness, however, themes arising during interviews highlighted additional considerations. The concept of taking action to write an ACD, and the right time to do so, raised various perspectives on what constituted right timing. None of the participants questioned the construct of ACP itself. That is, they all accepted that having an ACD was akin to having a Will, and now that they knew about it, it was probably something that needed to be done. The question arising was one of timing and activation. Interview participants generally believed that ACDs needed to be done before an individual became unwell. Some expressed feeling a sense of urgency. One couple had already been to their doctor in the week between group session and interview to complete the process. Others described needing more time.

> *I think some people can just go into it and talk about it and you know, act, and others take their time because they need to… [ID128 F: 78]*

It was common for participants to wish to seek advice and consult with family and others before taking action. The next section considers themes arising for participants at an interpersonal level.

5.7.1.2 Interpersonal

Interpersonal level themes included *spouse, chosen one, family protection, blended family, social support, shared wisdom, and safety in numbers.* The following section briefly describes each of these themes. The type and pattern of relationships emerging as I listened to people focused my attention. Every person interviewed considered their ACD *in relation* to another person. The relationship considerations expressed were multifaceted and the following section highlights the main themes.

Spouse

Participants most frequently referred to the spousal relationship in relation to communicating their wishes for end of life care. Those with spouses had generally invited the spouse to attend the group session and experience the discussion. For some, it was identified as part of a pre-existing and ongoing conversation.

> *It really touched on the things that my husband and I had talked about between us and the what-ifs, and it-would-be good-ifs, and that kind of thing…it ticked a lot of the boxes… [ID176.F:76]*

Others suggested preparation of an ACD was an activity to be contemplated together and actioned together.

> *We're going on down and have an appointment with the doctor together…' [ID156 M: 81]*

Another concept arising was the selection of who best to involve in discussion and planning, suggesting there was a theme relating to having a 'chosen one'.

Chosen one

It was common for people to have identified one or more of their children or friends as the 'go to' in the event of a health crisis. In discussion, it was not uncommon for people to have children living both locally and at a distance, including some overseas, but despite any geographical constraints, the chosen one was not necessarily the person who was nearest. It was understood that the chosen one was the person who could best manage the situation. This was the person with whom participants planned to have ACP discussions. There was a sense that not all offspring could cope, either with the discussion of death, and/or the event of death itself.

> *Some of my children might find it too difficult…for example I wouldn't talk it over with my son…I talked to my daughter, and I said, "What do you think about it?" and she said "It's a good idea"… [ID151 F: 78]*

I understood this to be related to a sense of trust that this person was the one who could manage the emotions of the situation and could be relied upon to act according to the wishes of the individual. In addition to identifying a chosen one, a recurrent theme was that by having an ACD the individual was preventing future family disharmony, so this concept was one of family protection.

Family protection

By initiating an ACD, participants described protecting their family from difficult future situations where there may be a risk of disagreement or uncertainty about what was 'the right thing to do'. This also implied the bestowing of a planned measure of protection for the chosen one, in that their judgements would not be called to account by other family members.

> *If she had to make the decisions and then the others could say "Well, why didn't you do x or y or z," or "Why weren't we involved" then that's not fair to pose that onto any of the children… [ID170 F: 77]*

It also implied a more general collective protection for the remaining family. This was protection from disagreement about potential courses of action.

> *If they know exactly what I want, then they can't dispute anything… [ID173 F: 78]*

This was also about making their wishes clear to avoid a sense of burdening an individual with difficult decisions, or resultant guilt from questioning their decision making.

> *I'd rather have something in writing to let my son know what we're thinking about for the future because I don't want him to worry about it… [ID176 F: 76]*

The perceived ability to protect others was described as a key motivation to prepare an ACD.

Blended family

As noted, many of the people interviewed had attended a group information session with their spouse. Of these people, a number described having been re-married in later life, so their current relationship was somewhat reconfigured from what their adult children were familiar with. The extent or relevance of this phenomena more broadly remains unclear, but it is reported here as an emerging theme in the participant group. The unanticipated nuance arising from these step-parent scenarios was the perceived importance of having an ACD, because the stepchildren on both sides of the new relationship were described as presenting unknown challenges to couples. There was a perceived risk that stepchildren would not support the decision-making of the married 'other' in the event of a spouse's impending demise. There was also the sentiment of not wishing to trouble them. The ACD in this blended family scenario was considered a kind of insurance policy, to avoid interference or placing any burden on the other person's children should death occur.

> *I've got step-children and they live overseas and really I don't want to bother them too much and if it's all written down then they can't argue about it...' [ID173 F: 78]*

Social support

Another common interpersonal theme was a sense of wanting to consult and share ACP information with broader family and community members. It was common for people to describe reaching out to others both to receive support or validation in thinking about the ACP experience, or to provide support through influencing others.

> *I already talked to one daughter, and a son and daughter was coming down this weekend for a visit so, we're gonna have a bit of a talk then... [ID156 M: 81]*

One participant spoke of going to tai chi group and talking to the girls, another participant described going down to the Men's Shed and having a discussion with the fellows. The emerging meaning was a sense of people seeking either to influence their community network or alternatively perhaps, to seek reassurance from others that the concept of ACP was somehow valid in the eyes of their social networks.

The final two themes at this interpersonal level involved participants' reflections on the process of attending a group information session, from the aspect of being part of a group. Their experiences of this step in the intervention contributed directly to understanding the acceptability of the approach, informing potential future actions in a general practice context.

Shared wisdom

Whereas the previous theme described participants' actions in sharing their experience among family and others, the focus in this theme was specifically about the shared experience of participation within the group. Participants had an expectation that they would have the opportunity to ask questions and be answered. It was noted that the answer may have come from another group member who was also trusted to contribute relevant advice. Participants related to each other and the experiences they shared. Having other people raise questions was described as enriching the understanding of all.

> *It was interesting to hear what other people had to say and if I wanted to add to their comments, whatever they said, I could… [ID124 M: 79]*

The average group size was quite small so comments arising from this led to a reflection on why group size might be an important consideration. On reflection this was distilled to be understood as looking for safety in numbers.

Safety in numbers

Once in the room, the extent to which individuals felt safe and able to participate varied. The facilitated group process aimed to respect an individual's choice to contribute or not, however small group sizes offered less opportunity for passive involvement. Whilst not a strong theme it was worth noting. Small group sizes were acceptable for some and others described a sense of disappointment and/or potential exposure.

> *I was a little bit disappointed there wasn't many – any more people there… [ID 156M: 81]*

Based on field observations and interview responses the concern was understood as relating to a larger group size providing the opportunity to be heard, to listen or to hide in plain sight whereas smaller groups required more participation from those present.

5.7.1.3 Provider level

The only theme arising at the provider level was *variability of provider opinion*.

Variability of provider opinion

Participants described discussion with their healthcare provider as effectively triggering their contemplation of ACP and reinforcing their decision to act or not. The trusted provider's words provided an endorsement, but participants describe receiving mixed messages from different providers which was confusing. Both nurses and GPs were described as influential.

> *…and she [the nurse] said "You know, it's a good idea," and then she also said that they would like a copy of it so they could put it in the file… [ID170 F: 77]*

Another reported being actively discouraged by her GP who discredited the ACP concept, seeing it as unnecessary. This variability in provider practice and being subject to mixed messages was reported to be confusing.

> *I was sort of put off by my doctor saying I don't need it… [ID176 F: 76]*

5.7.1.4 System level

Themes arising at a system level included *triggers, and practical advice.*

Triggers

Participants understood that receiving an invitation to attend a 75+ health assessment and an appointment reminder were part of a systematically applied process triggered by their age. This was considered acceptable and commonly understood as an appropriate action. The inclusion of an ACP discussion was also supported. This was further understood to mean the perceived responsibility for initiating and triggering ACP discussions lay *with the system,* not the individual. Within a general practice setting, initiation of the ACP discussion was assumed by participants, (even those who did not previously know about ACP) to be the role of the health care provider working within an organised system. Linking the ACP discussion to the 75+ health assessment was commonly agreed as the right thing to do.

> *When you get to that age where you have a yearly health check, that's a good idea to introduce a system to everyone... [ID156 M: 81]*

Additional system level considerations raised by participants related directly to practical matters in seeking advice and clarifying information they had heard during the information session.

Practical advice

The group information sessions were structured to encourage question and answer dialogue with participants able to seek advice. Questions arising during the interview process indicated some participants continued to have a degree of uncertainty about how to proceed and required additional practical advice.

> *So I can get another copy from the internet for my husband, is that right?'… [ID 151: F 78]*

As noted, some participants clearly understood the concept of ACP and had determined to act. Other participants who had made a decision to act and were focused on the required next steps sought advice about practical issues, for example where a completed ACD should be stored, or who should have a copy.

5.7.2 Limitations

The number of participant interviews was limited to eight because of constraints in the candidate's resources for the study. Using the socio-ecological conceptual framework as an analysis framework meant that themes outside of this frame of reference may have required an increased number of participants to be identified by the candidate and reach thematic saturation. It was difficult to engage the more elderly participants in meaningful discussion, and some older individuals became noticeably fatigued during the interview process. Interviews were abbreviated to meet the comfort needs of the participants as required, so deeper inquiry was not always possible.

5.7.3 Summary of patient interviews

Patient experience of the ACP intervention in general practice was described as largely positive. At an individual level, participants described value in the opportunity to gain knowledge of ACP when the time was right. At an interpersonal level, the opportunity to offer protection to loved ones while engaging with spouse and chosen ones was important. Sharing wisdom around ACP was valued and the experience of participation in group interactions was considered acceptable. At a provider level, participants expected that ACP would be initiated by their provider. Concerns raised pointed to opportunities for improvement including reducing variability in practice. At a system level there was support for linking ACP discussions with the 75+ health assessment process.

5.8 Provider interviews

In this section, themes arising from provider interviews about the implementation process of the ACP intervention are reported. Semi-structured Interviews were conducted one week after completion of the evaluation period. Nine health care providers volunteered to be interviewed. Provider quotes have been used to provide clarity, and where quotes are presented the attribution has been coded by role and number, for example RN 1, RN 2. Gender was withheld to preserve anonymity among respondents.

5.8.1 Interview findings

Health care providers described the intervention process as operationally feasible and acceptable. Nine themes were identified including *trust and influence, power,* and *collaboration* at an interpersonal level; *professional motivation, a commitment to quality, and* initiator at a provider level; *the business model, asking the question,* and *resources* at a system level. These are presented briefly in the following section.

5.8.1.1 Individual level

Providers did not focus on individual themes during interview.

5.8.1.2 Interpersonal level

Three themes were understood at an interpersonal level. These were *trust and influence, power,* and *collaboration.* Each theme is briefly described in the following section.

Trust and influence

There was a common view about the importance and strength of the patient–provider relationship. In the group of 75+ patients, relationships were often based on long-standing care relationships between the provider and patient.

> *People engage with their GP, they trust them and they generally trust nurses too, so hopefully they're trusting what we say... [RN1]*

Within these relationships, providers felt they had earned patient trust, which resulted in the perceived ability to inform and positively influence patient behaviour.

> *If the doctors and nurses are endorsing ACD then patients all think it's a good idea too… [RN4]*

Power

Despite the common view of being trusted and having influence, the concept of a power differential between different types of health care providers was raised. Doctors' opinions and influence were reported by nurses to hold more sway with patients than nurses' views.

> *I often refer the patient to talk to their doctor as they see them as a more trusted source of information… [RN3]*

The ripple effects of this within the ACP intervention were observed and reported when nurses described the important role for GPs in reinforcing the key messages they delivered. GPs reported not understanding or concurring with the need for this reinforcing role, expressing surprise that nurses did not seem to command or experience the same level of professional respect. In contrast, one GP described feeling 'not required' when participating in a group session, reporting the nurse practitioner *'had it covered...' [GP2*]. This suggested confidence in the capability of the nurse practitioner, but also lack of awareness about the strength of GP position power in terms of providing endorsement of the activity. The emergence of this theme suggested implications for future team-based approaches involving delegated responsibility.

Collaboration

At an interpersonal level, the concept of collaboration emerged as a strong theme. Most individuals commented on the process flows and dependencies linking their various roles with others. The new model of care relied on a well-functioning team and in this context the team expanded to include an external provider. From administration staff scheduling patients, to nurses conducting better health clinics, to GPs completing the health assessment and followed by a nurse practitioner facilitating group sessions, each role was understood as connected. This external connection was new and highly regarded, demonstrating a willingness for flexibility within the structure of the more traditional practice team.

> *The nurses in general practice were time poor. It would have been hard to run the groups without help so it was great that [name] nurse practitioner was able to come to the practice and run the groups for us. [RN1]*

Having an expert nurse practitioner funded by an external provider come into the practice to conduct the group information sessions was highly valued and contributed a new meaning to the concept of 'team' in this primary care context.

5.8.1.3 Provider

Three themes were understood at a provider level, *professional motivation, a commitment to quality* and *initiator.* These are briefly outlined in the following section.

Professional motivation

Motivation to be involved in the intervention was linked to a provider's sense of professional purpose and their personal values. RNs described their personal experience of caring for patients who did not have an ACD at end of life, and this was described as unfortunate and avoidable. Similarly, GPs in regional settings sometimes held dual positions as visiting medical officers working concurrently in their local hospitals and in general practice. Regional GPs were also likely to provide palliative care services to their patients at home and in the community. In this context, understanding patient wishes for end of life care was described as important so GPs could do their job.

> *When I actually need to use an ACD in a hospital setting, it's really nice to know that people have gone through that process, someone is nominated as an enduring guardian, and someone has had a think about how they want to pursue their end of life care…[GP1]*

The professional commitment to continue to find ways to improve the care being delivered was also important.

A commitment to quality

Several providers described the opportunity to use this ACP initiative as a quality improvement activity working toward the goal of increasing uptake of ACD in their 75+ patient population. Knowing they had been part of delivering a quality service led to personal satisfaction in their day-to-day work and this was cited as a positive factor by several of the nursing team.

> *I've enjoyed the whole process and I personally think it makes a real difference to our patients, so we really need to continue doing it... [RN3]*

Initiator

Providers described overall satisfaction with their experience of this model of care. Some changes in practice had been required but these were not seen as having negative impact on their day-to-day functions. One change described was the provider role of initiating ACP discussion with patients. By including ACP discussion into the 75+ health assessment with resources to support the information flow, the provider was placed in the position of being the initiator of the ACP discussion. Literature suggested this may be confronting for providers, but this was not evident in this trial.

> *I liked this new model of care because it gave the nurses an 'in' to talk specifically about ACP, and this discussion helped some patients to better understand... [RN1]*

5.8.1.4 System level

Three themes emerged at the system level including *the business model, asking the question, and resources.* These are described briefly in the following section.

The business model

Financial viability was commonly referred to as a significant consideration when engaging in new activities. During the co-design process, the decision to align the ACP intervention with the 75+ health assessment was based on a business practicality that required a sustainable way to fund the ACP activity in keeping with day-to-day operations of a small business. Without a practical way to fund the activity it would not be considered.

> *MBS items don’t cover aspects of comprehensive care required by patients attending general practice… [GP1]*

Testing the business model was done by linking the new ACP model of care to the existing 75+ health assessment. Providers determined this was a reasonable step and within MBS guidelines for health assessments.

> *With the over 75 group, you've generally covered the medical stuff in the course of normal consultations, so the loose and non-problem orientated nature of a 75+ health assessment lends itself to talking about life planning documents…[GP2]*

The 'business as usual' considerations covered in standard 75+ health assessments were enhanced by the explicit inclusion of a question to determine whether patients had an ACD.

Asking the question

The decision to systematically ask patients about their ACP status, record the result, and provide access to care based on the response reinforced the provider's role as the initiator, as noted, so this outcome was no longer subject to chance or circumstance.

> *Prior to introducing the model of care, ACP discussion had really been up to the individual doctor to remember do it, to think of doing it, or for the patient to ask…[GP1]*

ACP was understood as being something that not many people knew about and very few thought to ask about. Providers considered it appropriate to introduce the discussion during the 75+ health assessment.

> *It was a natural segue into a conversation that sat well within a 75+ health assessment- patients were already coming in sort of ready to be assessed on their health and life... [RN4]*

More broadly, the visiting nurse practitioner had a responsibility to work towards minimising hospital admissions and early intervention activities in the ageing population. An initiative focused on increasing ACD uptake for this population based in general practice was described as a tremendous opportunity for proactive and early engagement.

> *From my perspective, by 75 you would hope that they had already got one [an ACD] in place, and if they don't have one, then let's have a system to catch them so that they don't miss out on the opportunity to get one ... [NP]*

Resources

During the trial period, patients who did not have an ACD were provided with a copy of the New South Wales Health *Making an Advance Care Directive* (144) booklet to facilitate the discussion.

> *Having the booklet to give people was really useful and I think it answered a lot of their questions... [RN5]*

Nurses expressed value in having a hard copy document to hand to their older patients so they could raise the topic of ACP in a planned and scripted way. The tool was thought to be valuable as a conversation starter and a prompt for individuals when going home to discuss the issue with their families. This ACD toolkit booklet was identified by providers as a key system enabler. The ACD toolkit included a standard template for patient use. The decision to standardise and use a preferred template was reported as a positive step toward creating consistency and familiarity with the ACD format among providers. This familiarity was also seen as potentially useful beyond the practice, if required for reference in hospital care at end of life.

> *You could probably find three or four different ones [ACD templates] in use within this practice so I actually think it was good to use the one that was most familiar to the health department, the one created by the health department. I think it's actually a particularly good document in that it's quite self-explanatory, and it's simple… [GP1]*

The use of this document was not mandatory across GP providers in this practice but making the tool available in the computer system and using it exclusively in 75+ health assessments created the conditions for more widespread uptake.

The group information session was commonly described as a useful resource.

> *I think that for some people the ACD booklet might have been enough – to read the booklet and then complete the ACD, but I think for a lot of people, it was only a guide and I thought they really needed to discuss it to understand more, and the group option allowed for that… [RN3]*

With the provision of additional resources, providers described feeling well supported to perform their roles. Nurses also described a sense of disappointment and puzzlement at what they perceived to be poor patient attendance in the group activity, despite the value the nurses themselves placed on the activity.

5.8.2 Limitations

Practice GPs were involved if one of their patients attended for a 75+ health assessment during the evaluation period. Several GPs were not involved so widespread GP input was lacking. Given the individual autonomy practiced by GPs there remained the potential for continuing variability in ACP practice beyond the evaluation period. Health care providers had insufficient time to complete lengthy interviews with the candidate which were necessarily truncated to match the time available.

5.8.3 Summary of provider interviews

The model of care was described as feasible. At an interpersonal level, the concept of teamwork through collaboration was explored. The opportunity to better understand the dynamics of patient–provider relationships and power differentials within the practice were noted. At a provider level, a sense of professional purpose was linked to a commitment to quality improvement. At a system level, a number of system enablers were identified including linking the approach to a business model, asking the question and identifying resources to support knowledge, standardising and systematising the approach with suitable tools available to support the process.

5.9 Summary

Chapter 5 was presented in two parts. In Part 1, control and intervention groups were demonstrated to be comparable prior to the intervention. A patient attending a 75+ health assessment during the evaluation period was 1.79 [C.I 1.1-2.9] [p=0.012] more likely to initiate an ACD than a patient attending the practice for a 75+ health assessment in the previous six month period. Within this overall measure, the results show that patients exposed to more steps of the intervention had a greater uptake of ACD than those exposed to fewer steps. Health literacy results did not change during the evaluation period and did not explain the influence of the intervention.

In Part 2, qualitative interviews with participants and providers were reported. A total of 13 themes were understood at participant level and nine themes arose in provider interviews. The themes arising in participant interviews pointed to how individuals work through the decision whether to take action over an ACD. This was seen to include reflections on how infrequently participants talked about death and ACP, who they needed to involve in ACP discussions and who and when they engaged their spouse, chosen one, family members, friends and peers.

Participants also described how they were influenced significantly by the variable opinions of their GPs, and how incorporating ACP prompts and discussions within general practice +75 health assessment was experienced. Their experience of the intervention resulted in many seeing a clear way forward to initiate their own ACD.

Providers reflected on the congruence of the intervention aligned to their professional and personal values and the importance of teamwork and collaboration. ACP resources were identified as key enablers. Both participant and provider experiences of the ACP intervention in general practice were described as experientially and operationally feasible.

Having completed the presentation of the quantitative and qualitative results in this Chapter, Chapter 6 will discuss these findings in relation to the research aims. A reflection on key methodological considerations and the impact on the potential for transferability will be explored.

Chapter 6: Discussion

Introduction

The findings of this original research have been presented in Chapter 5 and in this chapter, the findings are considered, presented in four parts. In Part 1, the research findings are considered in relation to the aims and objectives of the case study. In Part 2, there are methodological reflections about the co-design and implementation process. The transferability of a model of care relevant to broader general practice settings is discussed in Part 3, while in Part 4 the study's contribution to the literature is evaluated and future research opportunities to progress this important work are identified.

6.1 Research findings in relation to study aims

The purpose of this intervention was to translate key themes arising in the ACP literature into a practical solution aimed at increasing patient uptake of ACP in general practice. The primary question was 'how might a complex intervention influence uptake of ACP in general practice?' To answer this question, four key aims were defined. These aims were a) co-designing a socio-ecologically engineered approach to ACP in general practice; b) determining the perceived feasibility of ACP intervention in general practice; c) determining the patient experience of ACP intervention in general practice; and d) determining the effectiveness of a socio-ecologically derived model of care in general practice. Five data sets were identified to support this analysis, with outcomes reported in Chapter 5.

In 6.1 the candidate considers the results, triangulating and interpreting the findings to demonstrate how these addressed the four study aims. This is achieved by posing questions relating to the four aims.

6.1.1 Aim 1: Was a socio-ecologically engineered approach to ACP designed and then successfully implemented for a trial period in general practice?

Co-design and implementation of a new approach to ACP was based on literature review findings [Chapter 2]. It was understood that design of a complex intervention would likely benefit from consideration of known barriers and enablers operating at various socio-ecological levels of influence, and that the ways these barriers and enablers interact should be factored into intervention design. To build this approach into the intervention design, the candidate started by reviewing previous interventions and cataloguing ACP barriers and enablers into conceptual levels of influence, to identify what strategies worked for whom and in what circumstances.

By applying a socio-ecological lens to the existing ACP literature the candidate identified actions to enhance effective ACP in this general practice context. These actions were understood as addressing known barriers and/or strengthening identified enablers. When applied in this general practice context at the **individual** level, lack of patient knowledge was widely identified as a significant barrier [see Table 5 – barriers] and this was linked to the concept of low health literacy.(93) The intervention required mechanisms to increase patient knowledge about ACP and these were built in to the intervention design across multiple levels, informed by the evidence including provision of written information,(82) ACP discussion with a trusted provider,(95) and participation in a group setting with interpersonal exchanges.(89) At an **interpersonal** level, relationships between patient and provider (58) were noted as important, but more important was the relationship between patient and family, which was commonly described as a barrier.(55, 98) It was decided to include the option of involving families by extending the group information session invitation, but family participation was not mandated. The inclusion of providers in the delivery of ACP messages during steps of the intervention was strategically designed and based on documented high levels of provider trust, and this being a known enabling factor.(24, 60, 88, 95) At a **provider** level, GPs and nurses were understood to be busy managing competing demands on their time and attention, but often working in a team-based environment with clear roles and responsibilities and various arrangements for delegation. The intervention design was adapted to work within the actual practice constraints identified in the co-design process. At a **system** level, multiple systems supported day-to-day practice functions through scheduling, billing, recall and reminder, IT systems, medical record and data management and general coordination.

The intervention design built on findings from existing intervention studies. It was heavily influenced by the work of De Vleminck et al. (96, 97, 145) in which four key components were hypothesised to underpin successful ACP interventions. These were 1) skilled ACP facilitation, 2) targeting of specific populations, 3) a structured ACP discussion including a prompt, a conversation guide, and a template, and 4) opportunity to complete the ACD document. Variations of these four components were observed in the literature, with the inclusion of group facilitation, (89) the incorporation of additional system enablers such as prompts and reminders, (93) and complex interventions applying various combinations of these components.(90) De Vleminck's study was the only one in which a methodological framework was identified.(60)

6.1.1.1 The value of a theoretical framework

By applying a socio-ecological framework, the candidate was able to source evidence from numerous studies, and map and bundle relevant actions into a flexible but strategically engineered ACP intervention, to generate maximum effect. Each individual component of this intervention had been implemented previously, but the actions had rarely been described in combination. Most notably, the *interaction* of components working together and across levels of socio-ecological influence had not been previously considered in ACP intervention design. Understanding the conditional relationship or links between ACP actions when planning the intervention is understood to have enhanced intervention outcomes. Causal mechanisms were considered and included in the intervention design [Table 9].

The concept of **accumulation** was included. An **accumulation strategy** was intended when each intervention made a discrete contribution to the outcome (50, 51). Actions known from the literature to be effective on their own were combined to have greater impact. This was seen, for example, by the inclusion of patient reminders to attend appointments which resulted in high attendance rates at health assessment appointments (90) and by the provision of written ACP information during the health assessment appointment (97) resulting in patients' describing an increase in access to ACP knowledge. The reminder contributed to the attendance rate which contributed to enhanced knowledge.

In addition to accumulation, the concept of **amplification** was also applied. When considering the mechanism of amplification, one action was intended to increase a participant's receptivity to another action.(51) In the intervention design, amplification strategy was intended at individual, interpersonal and provider levels. For example, the themes of power and trust suggest that health care providers have a meaningful influence on patient behaviour, so providers initiating discussion of ACP as part of the 75+ health assessment, after participants had been given the ACD booklet was likely to have had an amplifying effect. The impact of amplification was also noted during participant interviews when participants described the value gained in listening to other people's stories. Shared wisdom from the group session amplified social support sought by individuals considering ACP.

Convergence strategy involves **elements at different levels mutually reinforcing each other by changing the patterns of interaction**.(51) During the intervention, patterns of usual interaction were changed by the introduction of the group session. The effect of the group setting, described by participants during interview, had a reinforcing effect in so far as participants described how ‘safety in numbers’ and ‘social support’ allowed for discussion of death acknowledged as ‘things we don’t talk about’.

Finally, an effective **cascade strategy,** in which, actions at one level directly enabled actions at other levels was important.(51) Evidence of cascade strategy was seen in complex interventions reported in the literature (93) and factored in to the intervention design. Cascade strategy was intended with strong practice leadership sending a clear signal to staff about the importance of the ACP initiative. By communicating the plan, setting and sharing the vision, providing the resources and allocating responsibility the management team enabled action by the practice team. With reinforced role clarity at the provider level, with provider as initiator, individuals were engaged in ACP discussions, triggering consideration of ACP at an individual level. Cascade strategy contributed to an enabling practice environment.

The final ACP intervention design was determined by the health care providers. Within the bundle of actions described, there was opportunity to tailor a preferred approach determined by the day-to-day realities of the busy general practice.

6.1.1.2 Implementation

To introduce the changes required when initiating the intervention, the management team had to demonstrate effective leadership. This was done through proactive planning to ensure sufficient time was available to embed and familiarise staff with the concept. According to provider interviews, the allocation of clear roles and responsibilities for staff created accountability for the actions in day-to-day practice. Communication [with the practice team] through existing practice communication channels was used by practice management to share and establish a collective goal of improving ACP uptake. This sense of shared purpose was implicit and understood through thematic analysis of provider interviews. Forward planning was done to ensure logistical requirements were met. Resources such as group meeting rooms, an online appointment calendar and ACD toolkits were made available. The intervention process was supported by engaging an external provider to contribute expertise to group facilitation. GP time was quarantined to allow doctors to attend the group sessions.

In addition to operational considerations described above, the intervention relied on eligible patients being receptive to the provision of ACP information.(146) Participation was contingent on patients signalling readiness to engage. As previously reported, two-thirds of eligible patients declined further participation when invited. This rate was higher than anticipated based on other studies in which the percentage of people declining ranged from 12% to 50%.(88, 109) A number of planned group information sessions were cancelled or rescheduled because of patients' inability to attend. Patient feedback on cancellation suggested a range of factors contributed to this, including lack of transport, reliance on a third party who was unavailable, unanticipated ill health, hospitalisation, or other family situation. It was understood from these results that future ACP sessions involving groups of vulnerable older people were likely to be subject to some fluctuation in attendance rates and would require a system with inherent flexibility to respond and accommodate future participants.

Overall, the resulting intervention design was based on socio-ecologically engineered actions, using accumulation, amplification, convergence and cascade strategies to successfully implement the model over the evaluation period as planned. The aim was achieved. The candidate determined from data that implementation of the intervention using the planned process had occurred. Interpretation of further data detailing patient and provider experience would now be based in an understanding that the process, designed around socio-ecological principles, had supported the intervention in the manner intended.

6.1.2 Aim 2: Was the approach determined to be feasible?

Co-design of the intervention involved collaborative discussion at a strategic level with practice management. To be feasible, the intervention was required to work operationally, experientially, and financially. As described in 6.1.1, analysis of the process data indicated the intervention had been successfully installed and operated soundly. The candidate analysed qualitative data from provider interviews to understand if there was provider confidence in this approach being an operationally functional process, and to determine their experience of participation.

Providers described the ACP intervention in general practice as experientially and operationally feasible. The model of care was acceptable to nursing staff who reported having a sense of purpose and perceived value participating in the activity (theme commitment to quality). The intervention was said to align with their personal beliefs and reflected their professional motivation. This translated into a health provider team who were happy to be involved in something they considered to be worthwhile. Operationally, GPs did not report significant changes in their day-to-day practice. Nurses described feeling well supported by the additional resources available which were used to explain and discuss the concept of ACP with their patients. The provision of external group facilitation by the nurse practitioner was described as a significant operational enabler both in terms of time saved and clinical expertise shared. To note, during the evaluation, there was a substantial decline in participation between health assessment attendance [Step 2] and group information session attendance [Step 3] of the intervention. Participation in the group information session required a subsequent visit to the practice. This was logistically more demanding for both patients and providers, and therefore less operationally feasible.

Financial feasibility of the intervention was also an important consideration from a provider perspective during the design phase. As noted previously, there was no specific MBS item number to cover the cost of the nursing or medical time, but by linking the ACP activity to the existing 75+ health assessment, some components of the approach [Step1, Step 2] could be funded through the existing health assessment MBS item number. There was no readily available business model to cover the group information sessions [Step 3]. These sessions were only viable by using existing practice infrastructure and being facilitated by an external provider at no cost to the practice.

The intervention linking ACP to 75+ health assessments supplemented by an associated group information session through appropriate external support was considered an acceptable cost neutral approach. In this way, the intervention was feasible but a cost–benefit analysis was not completed.

6.1.3 Aim 3: What was the patient experience of the approach?

In determining patient experience the candidate focused on ‘what mattered most to patients’.(147) Patient experience of the ACP intervention in general practice was described as experientially feasible and acceptable by the patients who opted to participate. The experience of a larger group of patients who declined to participate was not collected as part of the study. Future research design would aim to include a mechanism to capture the views of those who declined to participate. As a proxy indicator, there were no patient complaints received by the practice in relation to the intervention.(148) Participating patients thought it was a good idea to link the ACP discussion to a routine health assessment. The intervention approach used by providers during the 75+ health assessment clearly allowed patients the choice of whether to participate. The patient–provider relationship was acknowledged as an important conduit for the initiation of ACP discussions that would otherwise be unlikely to occur. Participants viewed providers as a trusted source of knowledge about health care choices at end of life and had an expectation that providers would initiate ACP discussion as part of a systematic approach to care.

As outlined in 6.1.1, the intervention was engineered to leverage causal mechanisms that mediated and moderated an individual's response to a given stimuli.(51) Individuals attending a group information session were exposed to multiple stimuli. Participants in group information sessions received factual ACP information delivered by a trusted healthcare provider. When considering this information, discussion with and between other participants in a group social context permitted and reinforced the concept of talking about death, generally understood as something not routinely spoken about. For participants accompanied by family members/spouses this discussion was more personal and less hypothetical. The opportunity to ask questions, listen to questions asked by others and/or seek clarification about various points created a layer of mutual understanding and social reciprocity, valued as shared wisdom. Participants acknowledged there was a relative silence or inability to discuss end of life issues openly in their day-to-day lives. There was general appreciation for the opportunity to discuss ACP, while exploration of their concerns in the group setting was described as acceptable. General practice was seen as an appropriate place to contemplate future needs for end of life care.

6.1.4 Aim 4: Was there a change in uptake of ACD as a result of the intervention?

A patient attending a 75+ health assessment during the evaluation period was 1.79 [CI 1.1–2.9, *p*=0.012] times more likely to initiate an ACD than a patient attending in the period six months before the intervention. Within this intervention group result, participants who were exposed to more steps of the intervention had a greater uptake of ACD than those exposed to fewer steps. Most notably, eight of 19 [41%] participants who attended a group session completed an ACD. This outcome had an even stronger informal association because attending spouses were also known to have completed ACD documents, although they were not included in the data. It is also of note, but was not measured, that a number of participants described sharing the information more broadly through their social and family networks, contributing to the community knowledge base, and potentially influencing the readiness of others to act in future. The extent and impact of community diffusion was not quantified in this study.

Given the preparation of an ACD is a ‘one time only’ action (it may be updated if circumstances change), any activity that effectively stimulates uptake of ACD contributes to an overall increase in practice ACD prevalence. This intervention resulted in ACD uptake in the eligible group that was higher as a result of the intervention than if no intervention had occurred. The implication here is that systematic inclusion of ACP activities in routine 75+ health assessments will contribute to increasing practice prevalence of patients with ACD over time.

6.2 Part 2 Reflections on case study methodology and implementation

In this section, lessons learned during the co-design and implementation process are considered, highlighting what went well and aspects that were more challenging than anticipated.

6.2.1 Negotiating aspects of ethics approval

One of the notable gaps in the literature was the lack ACP intervention trials based in general practice so the candidate sought to involve a general practice in the co-design of the intervention approach. At the intersection of finding a shared agreement for practical implementation of an ACP intervention in a busy general practice and achieving research ethics approval, unanticipated barriers to participation emerged. While it was understood that it may be standard practice for GPs and nurses to influence the behaviour of patients with regard to their health, the ethics committee advised that ‘influencing’ approaches used in clinical settings did not translate into appropriate recruitment strategies for research projects. Understandably, exerting undue influence on a patient by repeated reinforcing of a health message was seen potentially badgering, but health care providers argued that they leveraged their influence with patients respectfully on a daily basis to inform and encourage them to adopt healthy behaviours across many areas, including, for example, smoking, diet, alcohol consumption and exercise. Navigating an approach to patient recruitment for busy clinicians while avoiding a perception of undue influence for patients was challenging. Frustration was voiced by providers who felt they had somehow been perceived to be operating in an unethical manner, and this presented a barrier to practice participation. To constrain the reasonable influence a provider was able to apply, in seeking ethically to recruit individuals into an activity that was viewed as beneficial, was considered by providers to be counterproductive and counter intuitive. A satisfactory solution was negotiated as detailed in Chapter 4, resulting in practice agreement and attainment of ethics approval, and the subsequent conduct of the intervention proceeded. The process highlighted one of the challenges when seeking to study in real time at the interface between research and application in this general practice setting.

6.2.2 The assumption of a willingness to change

When considering the co-design and implementation of an ACP intervention, the candidate had an inherent assumption about the practice's willingness to adopt change. How change could be orchestrated within a complex system had been described (60, 149), and the levers needed to make change and do something differently to get from 'here to there' were identified in the co-design process [Chapter 3]. With a complex intervention, the system including its dependencies, e.g. provider behaviour, routines, and processes, would need to be positioned for change. The ACP literature provided examples where passive inaction or failure to adopt change was a barrier to effective implementation.(25, 97) Conversely, positive provider attitude was a known enabler.(29) The challenge for any practice considering implementation of a systematic approach to ACP would be to assess and determine their practice state of readiness to change. Determining a practice's cultural readiness for change was beyond the scope of this dissertation but it is mentioned here as an important consideration for any practice considering significant change.(150) Analysis of provider interviews in this practice found a strong sense of purpose and a shared commitment to providing quality care for patients, which were understood as strong motivators for engagement.

When reflecting on the level of engagement in the patient population, the concept of *readiness to change* was identified in the literature as the *stage of change.*(29) Based on the trans-theoretical stages of change model, some scholars described tools and tests to measure a patient's readiness to participate.(56, 80) Inclusion of these tools as a step in the intervention was considered during the design process, and there was agreement about the merit of understanding patient readiness to engage in ACP discussion. Ideally, this would occur before the initiation of ACP discussion during a consultation. However, the process involved in issuing questionnaires to patients on arrival for completion in the waiting room and supporting elderly patients through the process of answering questions on paper or digitally on a tablet was unacceptable to busy administrative staff. The practice team determined that in their operational context, it was preferable for the nurse to ask patients about ACP during the 75+ health assessment consultation, and that by using this approach, the patients' self-determined response was itself an indication of readiness to engage. The findings indicated a significant number of patients opted not to engage during the evaluation period. According to the trans-theoretical model, this pre-contemplation stage may be subject to change over time (151) so the importance of a universal and systematic inclusion of ACP discussion every year to identify and provide options if and when a patient moved through the stages of change was considered to be a practical approach. As previously discussed, the stepwise structure of the intervention provided patients with the flexibility to participate in none, some, or all of the individual components of the model. In this way, patients were provided with the opportunity to respond according to their readiness to do so.

6.2.3 Business as usual

ACP research evidence did not provide adequate guidance to inform systematic approaches to ACP initiatives, and existing general practice contribution to the ACP literature was sparse.(104) The model of care presented in this ACP proof of concept intervention was designed in a large, regional general practice based on an amalgamation of evidence-informed approaches from the literature. Research conducted in real life settings has been described as a major challenge where there is 'tension between capturing the contextual variables' versus 'what can be realistically conducted within a controlled experiment'.(152) This intervention was conducted in a busy general practice environment, not a controlled laboratory, and as such, implementation had the potential to be limited by uncontrolled circumstances e.g. health care emergencies. In this exemplar practice the candidate sought to determine the effectiveness of the approach in increasing uptake of ACP, integrated into *business as usual* and with sufficient flexibility to transfer to other practices.

What was *business as usual*?

It was understood that general practices in Australia operate with varied and unique ownership and management structures, with different business models and approaches to billing and delivering care.(153) Business as usual was therefore understood to be subject to wide variation. The financial arrangements supporting the ACP model of care were a primary consideration in intervention design. As previously described, patients attending general practice are billed for the services provided. Through the Federal government's Medicare system, their bill for each attendance is subsidised (for most people) or fully reimbursed (for most low socio-economic status and elderly people). This reimbursement is based on a set of agreed activities (MBS item numbers) with a schedule of fees payable. ACP is not specified in these agreed activities, does not have an item number and no specific reimbursement is available.(63) Previous studies have identified lack of Medicare payments specific to ACP as a barrier to practice involvement.(63,

81) Others have suggested the inclusion of ACP as a component of routine health assessments as a practical option.(37, 24) This intervention was aligned with the 75+ health assessment for billing purposes and found to be consistent with the MBS intent which requires health assessments to meet a number of specific criteria. Relevant here were 1) recommending appropriate interventions; and 2) providing advice and information to the patient.(154)

Aligning the activity to a 75+ health assessment was not a complete solution to the funding issue. The MBS descriptor did not adequately cover all components of the model of care being implemented. As discussed, access to the MBS funding stream to make the activity sustainable in a fee for service environment covered Step 1 and Step 2 of the intervention. Step 3, the group information sessions, did not fit the MBS criteria. In this intervention, the cost of Step 3 was avoided by accessing external facilitation. Provider interviews highlighted the importance of this arrangement, which was necessary to overcome the identified practice limitation of insufficient workforce capacity, linked to lack of funding for this activity. Identifying and establishing collaborative ACP partnerships for facilitation was a key step when planning group information sessions in this current funding environment.

This intervention was structured, implemented, and reported in a stepwise fashion allowing future general practices the flexibility to engage with some or all of the individual components of the model, depending on their self-determined capacity to do so. Despite lack of ready funding for the Step 3 group information component, ACP group activities have documented greater uptake in the extant literature,(89, 77) and this was supported by the findings of this intervention. Funding models that provide scope for group interventions are currently being assessed through the Health Care Home trials and if/when introduced, will support full implementation of this ACP approach.

6.3 New guidance for general practice

This section provides guidance from a single case study which could inform ANY general practice considering an approach to increasing uptake of ACP in their practice. Practice providers consider these steps to be transferable to other practices interested in increasing uptake of ACP in their own patient populations.

Preliminary steps

Understanding usual practice approaches to ACP in day to day consultations is an important preliminary step. As described in Chapter 3 and outlined in Table 10, a socio-ecological framework is useful to consider the range of potential strategies for improvement which are able to be tailored to suit practice circumstance. The ACP intervention in this case study resulted in three key ACP steps which were embedded as part of business as usual.

Step 1: Ask the question

All patients will be asked about their ACD status during the 75+ health assessment consultation.

Rationale: Directly asking the patient about their ACD status had resulted over time in an ACD baseline prevalence for the 75+ practice population of 27%. This was a higher ACD prevalence than reported in other general practice locations.(11)

A key consideration in including this step was the need to systematise the approach to overcome any role ambiguity about who was responsible for initiating an ACP discussion. Role ambiguity was widely identified in the literature as a barrier. [See Table 5] Interview findings with participants and providers supported the inclusion of this question. A secondary consideration was ensuring that allocated time was available for any subsequent ACP discussion. Including the ACD question as part of a routine component of a 75+ health assessment ensured scheduled time for any subsequent ACP discussion.

Step 2: Initiate the discussion about ACP and provide consistent, context specific ACP resources

Health care providers will initiate an ACP discussion with all patients who do not have an existing ACD and provide patients with an ACD booklet.

Rationale: The introduction of this step resulted in a 7% increase in ACD uptake in patients attending 75+ health assessments.

A large body of evidence supports that providing patients with information about ACP is an enabler for increasing uptake.(29) Many studies considered the diversity of information sources available, including conversation guides, toolkits, templates and more.[See Table 6] In this setting, located in NSW, it was decided to use the NSW Health document for consistency and familiarity across parts of the health system. Other jurisdictions may have alternative versions. In the context of transferability to other practices, whether 75+ health assessments are systematically planned or opportunistically actioned, the ability to include Step 2 was considered by health care providers to be widely feasible.

Step 3: Facilitate shared wisdom

Host a regular facilitated group ACP information session for practice patients and their partners and family members.

Rationale: Participants attending group ACP information sessions were more likely to complete an ACD, with 41% doing so. Facilitating group information sessions allowed practice patients and their partners or family to ask questions to gain a better understanding of the concepts of ACP.

Both hosting and participating in group sessions required additional actions to be taken by the patient and the practice. These additional actions were achievable in the intervention context, but in determining the future transferability of group information sessions into other general practice contexts the need for internal resource allocation, or external facilitation, would need consideration.

6.4 Part 4: What does this study contribute to the literature?

6.4.1 A useful conceptual framework

Socio-ecological theory has been shown to be a useful framework to navigate and distil meaning from the body of ACP literature. This theoretical framework had not been used previously in this context and its application provided a new approach to seek meaning across this body of work. It provides a relevant conceptual framework for future intervention design. A review of the ACP literature was done to understand how general practice might better support the uptake of ACP. A substantial body of ACP literature was synthesised using a socio-ecological framework to organise concepts and make sense of the findings.(29) With careful analysis, specific ACP actions were identified that were found to be effective at identified levels of socio-ecological influence. When these actions were conceptually linked into a proposed model of care and applied in a general practice ACP intervention, the combined actions suggested a strengthening of effect across all levels. These relationships, described by Weiner et al.(51) as causal mechanisms, were strategically engineered into the design of the intervention. In this way, the application of socio-ecological theory is understood to have resulted in synergy of effect.(50) Determining the effect of each mechanism was beyond the scope of this study and provides opportunity for future research to explore the veracity of the approach.

6.4.2 Building on existing knowledge

This study joins the few ACP intervention studies described in an Australian general practice context. It presents a model of care not previously described in this context and provides guidance for future implementation to support general practices interested in increasing ACP uptake for their patient populations. The genesis of this trial was a realisation that despite extensive evidence and various trials using combinations of evidence, there was no clear guidance for general practice about how to increase uptake of ACP effectively in their practice populations.

6.4.3 Future innovation and research direction

During the intervention, one of the strengths identified by participants was the value of listening to other participants' perspectives and applying their own lived experience to create a shared understanding. Recent studies have shown the growing trend toward peer mentoring and volunteer involvement in ACP discussions, with encouraging results(155). Given successful peer involvement in similar health settings (cancer support, mental health) and based on the findings of this study, it is hypothesised that linking peer facilitators to volunteer with health providers in a general practice setting is a feasible innovation. Models of care involving peer facilitators sharing their lived experience are well established (156) and could be expanded and linked to general practices, working together to facilitate group sessions for interested patient groups. There is merit in future research exploring the role of peer facilitators in this context. Existing community-based organisations may be well positioned to support patients and general practice through collaborative partnerships, where health providers and peer facilitators work together with a common purpose to increase uptake of ACP.

6.5 Summary

Through the research findings, the candidate has demonstrated that the aims and objectives of the study have been addressed. Reflections on implementation including key considerations and limitations provide contextual information for future intervention design. The findings of the study demonstrate a clear contribution to the literature by way of novel application of a conceptual framework, and in new guidance for general practice to improve uptake of ACP. Future research directions have been identified.

Chapter 7: Conclusion

Findings from this case study evaluation present an answer to the question 'How might a complex intervention work to influence uptake of Advance Care Planning (ACP) in general practice?' An approach to ACP that effectively translated complex themes in a way that balanced an achievable, real-time solution in general practice has been presented. An evidence-informed approach to implementing ACP systematically in general practice with the ability to be tailored incrementally according to practice capacity and patient readiness contributes to the general practice literature and provides guidance for interested general practices going forward. A model of care that was stepped, flexible and potentially transferable demonstrated effectiveness in increasing advance care directive (ACD) uptake in this general practice. This study was initiated because the candidate was aware that uptake of ACP was low and general practice lacked support and guidance to participate. Evidence suggested limited ACP was occurring, with the literature detailing many barriers and enablers. It was the view of the candidate that many of the barriers were surmountable with a well-considered process design.

The significance of limited ACP uptake was demonstrated in Chapter 1, in which relevant policy developments over many years were detailed and the increasing relevance and need in the population highlighted. In seeking to develop an evidence informed approach, a critical interpretive synthesis of the international ACP literature was undertaken and presented in Chapter 2. In reviewing the literature, it became apparent that barriers and enablers, factors that mattered to an individual, were distinct from those considerations occurring *between* people, and different again from provider opinions and system issues. This was better understood through the application of a conceptual framework where barriers and enablers were understood to exert influence at different levels across a socio-ecological perspective. Interventions developed to consider the interaction between barriers and enablers operating across levels of influence were by nature complex, but a complex intervention was believed to achieve greater effect in increasing uptake of ACP than business as usual approaches.

By combining the candidate's knowledge of the socio-ecological aspects of ACP with the general practice team's knowledge of functional approaches to delivery of care, a new ACP model of care was designed. This co-design process was outlined in Chapter 3. The practice decided to implement the new model and at the same time, were agreeable to the candidate's involvement in researching the effectiveness of the approach. The case study design and methods were presented in Chapter 4. A mixed methods approach was used where participating patients were exposed to an intervention trialling a model of care, with patients and providers interviewed to determine their experience of the approach. Outcomes were measured at completion and compared with a control group to determine intervention effect. These findings were compared and contrasted, and qualitative data were triangulated to compare process and outcome measures with patient and provider interview data to determine experience and acceptibility.

This study showed that implementation of the model of care was acceptable to providers and suitable for effective implementation. It also highlighted that while many patients opted not to participate, those who participated were pleased with the approach. Readiness to engage was identified as an important consideration underpinning the need for a universal and systematic approach to ensure access to ACP would be available when patients determine their readiness at some future time. Study results showed that patients who engaged with more steps of the intervention had greater likelihood of completing an ACD.

At the time of writing this discussion, the world was plunging into a pandemic crisis with the threat of contagion and the risk (and fear) of death looming large. This study was conceived in simpler times, but upon reflection the purpose remains relevant. Discussion in Australia has focused on preventing contagion, supporting the economy, increasing intensive care ventilator availability, and reinforcing the health care system to avoid death at all cost. At this time, the elderly, vulnerable, and debilitated were said to be most at risk. Extreme measures of life support have not proven to be effective for many. In these unprecedented times, those with an ACD will hope to receive end of life care according to their wishes. In future, establishing effective systems to support patient uptake of ACP in general practice will remain topical. Through this study, the candidate has demonstrated that general practices interested in increasing uptake of ACD in their patient population are able to do so by implementing some or all aspects of an evidence informed model of care.

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Appendices

Summary

Appendix number	Description	Dissertation Chapter / Page reference
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Barriers, enablers and initiatives for uptake of advance care planning in general practice: a systematic review and critical interpretive synthesis

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ABSTRACT

Objectives How advance care planning (ACP) is conceptualised in Australia including when, where and how ACP is best initiated, is unclear. It has been suggested that healthcare delivered in general practice provides an optimal setting for initiation of ACP discussions but uptake remains low. This systematic review and critical interpretive synthesis sought to answer two questions: (1) What are the barriers and enablers to uptake of ACP in general practice? (2) What initiatives have been used to increase uptake of ACP in general practice?

Design A systematic review and critical interpretive synthesis of the peer-reviewed literature was undertaken. A socioecological framework was used to interpret and map the literature across four contextual levels of influence including individual, interpersonal, provider and system levels within a general practice setting.

Setting Primary care general practice settings

Data sources Searches were undertaken from inception to July 2019 across Ovid Medline, Cumulative Index to Nursing and Allied Health Literature, Scopus, ProQuest and Cochrane Library of systematic reviews.

Results The search yielded 4883 non-duplicate studies which were reduced to 54 studies for synthesis. Year of publication ranged from 1991 to 2019 and represented research from nine countries. Review findings identified a diverse and disaggregated body of ACP literature describing barriers and enablers to ACP in general practice, and interventions testing single or multiple mechanisms to improve ACP generally without explicit consideration for level of influence. There was a lack of cohesive guidance in shaping effective ACP interventions and some early indications of structured approaches emerging.

Conclusion Findings from this review present an opportunity to strategically apply the ACP research evidence across targeted levels of influence, and with an understanding of mediators and moderators to inform the design of new and enhanced ACP models of care in general practice.

PROSPERO registration number CRD42018088838

Strengths and limitations of this study

- ► Use of the Joanna Briggs tools for quality assessment provided a rigorous quality assessment process tailored to study type.
- ► Use of a conceptual framework provided a useful structure for critical synthesis of a complex body of literature and provides opportunity for future intervention design.
- ► Studies identified with a focus on advance care planning interventions in general practice were limited.
- ► Lack of consistent terminology may have resulted in not all relevant literature being surfaced.
- ► The study is seeking transferability of international experience to the Australian context and this is uncertain.

INTRODUCTION

Within the Australian healthcare policy framework, advance care planning (ACP) is intended to ensure quality care according to individual wishes at end of life.[1] An advance care plan, sometimes called a ‘living will’ or an advance care directive provides directions describing how an individual would prefer to be treated in the event of a loss of capacity to direct one’s own care.[2] ACP emerged as a rights-based initiative in the USA in response to societal demand for the right to self-determination about medical care at end of life.[1] This concern resonates internationally including in Australia where policies and/or laws have been enacted across all states and territories to support the uptake of ACP.[1–4]

Australia’s population profile is increasingly aged with an increasing life expectancy.[5] For most Australians death will occur ‘at an advanced age following a period of chronic illness and decline’.[6] Associated with increasing age, loss of cognition may limit an individual’s ability to make autonomous decisions at end of life.[7] Advances in medical technology have resulted in the ability of practitioners to intervene and maintain life past what was previously possible, though quality of life resulting from the interventions is not assured.[8] In these contexts, ACP is viewed as an important and emerging issue in the public health domain.[6 7]

Given Australia's ageing demographic profile,[5] and an identified societal concern about quality of life at the end of life,[4 8] combined with a clearly stated policy position, it is difficult to explain why there has been limited uptake of ACP by consumers.[9 10] A 2014 national study identified uptake of ACP in Australia as ~14%.[10] There appear to be significant differences in how ACP is conceptualised in Australia,[11] and uncertainty about where in the system responsibility lies for initiating an advance care plan. Many studies suggest primary care is optimal for initiation of discussions,[12–15] though a 2019 multicentre audit determined ACP in general practice to be as low as 3%.[16]

This systematic review sought to synthesise the published literature to understand how the knowledge, attitudes and practices of clinicians and consumers in general practice are understood as barriers and or enablers to achieving uptake of ACP. Two specific questions guided the synthesis:

1. What are the barriers and enablers to uptake of ACP in general practice?
2. What initiatives have been used to increase uptake of ACP in general practice?

METHOD

Search strategy

Database searches were undertaken from inception to July 2019 across Ovid Medline, Cumulative Index to Nursing and Allied Health Literature, Scopus, ProQuest and Cochrane databases. The selected databases are considered the most useful to identify peer-reviewed articles relating to this topic. The search strategy was developed for Ovid Medline (see table 1) and was modified to suit the language requirements of other databases. It included subject headings and free text words. During the searches, wildcards and * truncation were used to ensure broad inclusion of related search terms. Boolean operators 'OR' and 'AND' were also used. Proximity searching was not used. The search strategy was developed with the expert assistance of a medical librarian. Search terms were determined with the intent of capturing a broad representation of the ACP literature, and then refined to focus on the specific context of interest, thus minimising the risk of incomplete data. Search terms included concepts of ACP, advance care directive or advance health directive or living will; AND concepts of knowledge, attitudes, practice AND concepts of behaviour, engagement, barriers, participation among both consumers, and healthcare providers AND general practice OR family practice or patient-centred medical homes. A review protocol was submitted to PROSPERO available at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018088838.

Patient and public involvement

Patients and public involvement was not sought in the design or undertaking of this review.

Table 1 Example of search strategy—Ovid Medline Search history

#	Searches
1	Advance Care Planning/
2	((advance* adj3 (plan* or directive*)) or living will*) tw, kw.
3	1 or 2
4	Knowledge/ or Health Knowledge, Attitudes, Practice/
5	(concept* or attitude* or belief* or practice* or experience* or knowledg*or uptake* or utilis* or implement*) tw, kf.
6	4 or 5
7	(Consumer Behavior or Consumer Participation or Consumer Health Information or consumer engag* or decision making or consumer uptake or barriers to uptake or consumer concepts or Primary health care* or general practice or family practice or GP or general practitioner or patient centred medical home or patient-centred medical home or health care home or practice nurse or community nurse) tw, kw.
8	Physicians, Family/ or General Practitioners/ or Family Practice/
9	Primary Health Care/
10	*Health Personnel/
11	Consumer Behavior/
12	Consumer Health Information/
13	7 or 8 or 9 or 10 or 11 or 12
14	3 and 6 and 13

Inclusion/exclusion criteria

Determining the most appropriate search terms and inclusion/exclusion criteria required consideration of nomenclature. Nationally and internationally, consistent terminology about research studies in ACP is lacking. It is variously characterised as ACP, an advance (care or health) directive or living will. The search strategy included all derivations.

To identify literature relating to low uptake of ACP required consideration of consumer and provider knowledge, attitudes and practices with regard to ACP. This included studies considering consumer and provider engagement, behaviour and participation.

The review was bound within general practice. General practice in Australia is described by one peak body as an entity that 'provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities'.[17] It was understood from preliminary searches that a substantial body of research about ACP had been generated in countries other than Australia, and within this, there were nuanced differences about how 'general practice' was described.

It was determined not to include or exclude studies based on geographical limits but to filter results based on the description of the healthcare provider and the setting.

Studies from countries describing general practice, family medicine and primary care services sufficiently comparable to the definition of Australian general practice were included. Examples included Canadian family practice and Belgian family medicine each understood to be similar to Australian general practice. In the US general practice differed around type of organisational structure, professional roles and responsibilities, and service descriptors; however, US primary care clinics and family practice outpatient clinics have been described as analogous with Australian general practice.[18]

A further consideration and inclusion was the ‘patient centred medical home’ or ‘health care home’. This emerging model of primary care was thought to be changing the structure of general practice, both in Australia and internationally, and consideration of ACP in this context warranted inclusion in the review.

Studies were included if they met the following criteria: written in English, published in a peer-reviewed journal, primary care research with scope limited to general practice, and adult participants. Studies that focused on acute care, inpatient care, aged care facilities, palliative care or clinical management at end of life were considered out of scope and excluded from the review. Other exclusion criteria included: legal focus, mental health focus or issues for minority groups.

Search results

An online search was conducted in July 2019. A total of 6703 online studies were identified as potentially relevant. At the completion of the database searches identified studies were catalogued in Endnote. Duplicate studies were removed and the remaining 4883 studies were screened by title for inclusion. Of these, 589 studies were considered potentially relevant and screened by abstract. Five hundred and thirty-seven studies were excluded by abstract and a further 18 studies were identified through targeted citation and reference list review resulting in a total of 70 studies for full text review. Year of publication ranged from 1991 to 2019 and represented research from nine countries. The earliest publications came from the USA where the antecedents of ACP originated, and the majority of publications also originated in the USA.

Study selection process

The search process was conducted by one researcher. Studies were reviewed and catalogued by the primary researcher using a template to identify key features of interest relevant to review. The template documented:

1. Type of study.
2. Year and country of publication.
3. Study setting.
4. Barriers identified,
5. Enablers identified.
6. Initiatives identified.
7. Outcomes/recommendations.

A *barrier* was understood to be ‘a circumstance or obstacle that keeps people or things apart or prevents communication or progress’.[19] An *enabler* was understood as a moderating factor to be defined as ‘to make able; give power, means, competence, or ability to’.[20] An *initiative* or *intervention* was defined as ‘a specified strategy or set of strategies designed to change the knowledge, perceptions, skills, and/or behavior of individuals, groups, or organizations, with the goal of improving health outcomes’,[21] and specifically in this case ACP uptake. Studies were accepted when the primary focus of the study included all key search terms and aligned with inclusion and exclusion criteria. The resulting list of studies meeting the inclusion/exclusion criteria was subject to a quality review performed by two researchers.

Quality

The heterogeneity of approaches found within the search literature made it difficult to apply a standardised quality framework; however, the Joanna Briggs Institute provided a suite of critical appraisal tools considered suitable for quality assessment covering a range of methodological approaches.

As noted, a single researcher undertook the initial screening of search results with strict adherence to review protocol and inclusion and exclusion criteria.

Two researchers then independently reviewed all shortlisted papers using Joanna Briggs Critical Appraisal Checklists.[22–26] Tools used included randomised control trial; systematic review and meta-analysis; cohort studies; analytical cross sectional studies; qualitative studies and quasi-experimental studies.

Results were compared and when reviewer findings differed, discussion ensued to reach a consensus understanding and search results were adjusted accordingly. This process was considered important to reduce reviewer bias. Following completion of this process, all studies agreed by both researchers were included in subsequent review and critical interpretive synthesis. The quality assessment resulted in the exclusion of 16 studies. There were quality concerns with three papers and on closer analysis 13 studies were identified as lacking relevance. At the completion of the quality review, a total of 54 studies were included in the critical interpretive synthesis. Results comprised of 8 systematic reviews, 8 randomised control trials, 14 analytical cross section studies, 3 cohort studies, 9 quasi-experimental studies and 12 qualitative studies.

Figure 1 outlines the Preferred Reporting Items for Systematic Reviews and Meta-Analyses framework used to summarise the search process.[27]

Conceptual framework

A socioecological conceptual framework was used to organise the literature. This framework has been frequently applied in health promotion research over the last years[28] and has been found to have applicability to complex health systems.[29 30] The multiple factors that influence health are attributable to *levels of influence*, often depicted as nested concentric circles representing contextual layers of increasing scope. McCormack (2017)

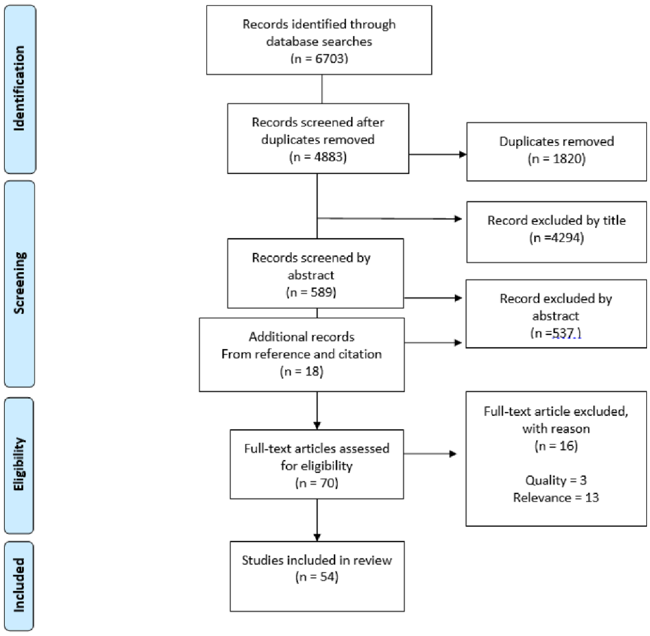

Figure 1 PRISMA flow diagram.[27]. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses

applied this framework in considering the problem of low health literacy and patient engagement in health systems, presenting an argument in support of this theoretical approach. In a general practice setting, individuals as patients bring their own understanding and attitudes when engaging with providers to seek care. The provider is operating within their own frame of reference and within a broader system supported by processes and models of care. Figure 2, adapted from McCormack *et al*,[29] outlines levels of influence depicted from a socioecological perspective appropriate to general practice as the functional system of interest.

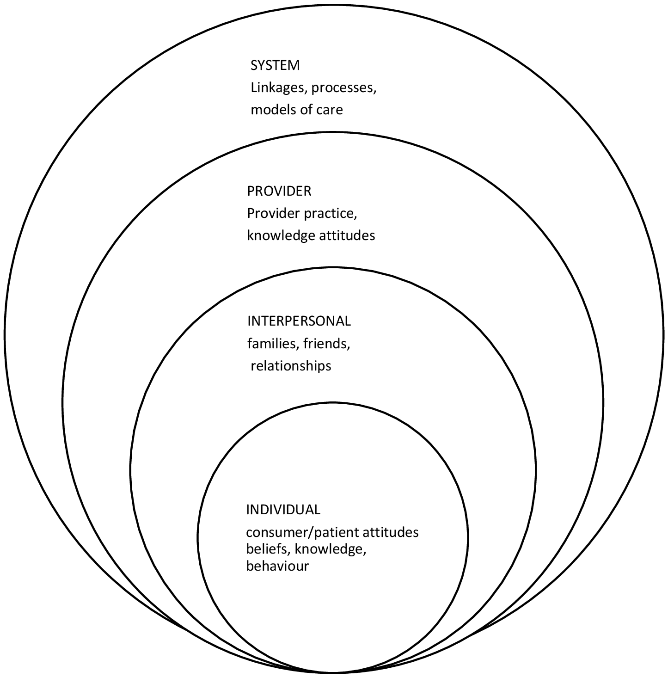

Figure 2 Socioecological perspective for general practice. Adapted from McCormack *et al*.[29]

Each study was reviewed and the barriers, enablers, stated aim and methodology was mapped into one or more of the contextual levels of influence across a socioecological perspective.

A decision matrix (online supplementary file 1) was developed to guide a consistent approach to categorisation of studies across the four contextual levels of influence. A summary of the distribution of studies across socioecological contextual levels of influence is presented in online supplementary file 2.

RESULTS

Synthesising the diverse and disaggregated body of ACP literature was challenging. There was a lack of coherence in literature with regard to the nature and causality of barriers and enablers. Some studies inherently described barriers and enablers as linked and binary, for example—lack of knowledge as a barrier was frequently linked to provision of education as an enabler. Other studies described factors independent of each other in non-binary relationships. Cataloguing these variations was achieved by interpreting the barriers and enablers independently. This resulted in instances of apparent duplication but remained important to capture at each level and is explored further in the discussion. The results of the review are outlined in the following four sections:

1. Critical synthesis of systematic reviews.
2. Barriers to ACP in general practice.
3. Enablers of ACP in general practice.
4. Initiatives/strategies to increase ACP in general practice.

Critical synthesis of systematic reviews

Eight systematic reviews with relevance to ACP in general practice were included, generated from four countries and spanning publication dates from 2007 to 2019. In general, the reviews were quite heterogeneous with one focused on barriers and enablers to uptake of ACP in general practice,[31] one focused on the attitudes of the public and GPs to ACP,[32] and one focused on the effect of structured ACP communication tools.[33] Four studies looked at the efficacy of a range of interventions,[34–37] and the remaining study was a narrative review of other systematic reviews.[38]

In the 2009 review of reviews, Tamayo-Velasquez *et al* reported that most studies, though heterogeneous in approach, had reached very similar conclusions,[38] and subsequent reviews have continued to have largely consistent findings. Common barriers were identified and attributed to lack of patient and provider knowledge; lack of provider skills and experience; patient, family and provider attitudes, and system issues related to time pressure, documentation challenges and mechanisms of information sharing.

A common theme was noted with a number of reviews categorising data across a combination of patient level, provider level and system level findings.[31 32 34] One study,[34] reported interventions at a patient and physician level, and another considered categories of individual autonomy, versus personal circumstance or health system effects.[32] These levels were consistent with contextual levels of influence when viewed from a socioecological perspective, though none of the reviews explicitly linked the described levels to a theory, model or framework.

It was important to observe the described levels in order to understand if interventions described in the literature were targeting specific levels, to achieve their effect. Some studies reported targeting interventions across multiple levels, for example, patient, provider and system, whereas others were understood to be applying multiple interventions within a *single* level for example, mail outs, phone calls, websites aimed at the individual, which was a nuanced but important difference.

As suggested by Weiner *et al*,[30] interventions where multiple level approaches were applied were more effective than single intervention approaches.[34–37] When studies investigated the outcome of combinations of actions in achieving an effect, provision of information alone did not increase ACP completion rates above the background community level.[34] The least successful interventions were mail outs without reinforcement, and one review reported inconsistent findings regarding all types of interventions.[35] The most successful interventions exerted influence over multiple levels and involved direct and iterative patient–healthcare provider interaction over multiple visits. Studies reached similar conclusions in so far as person-to-person interaction was evidenced as a strong enabler when compared with more static approaches.[34 36]

There was some consensus across reviews about the need to better understand barriers to and enablers of ACP.[31 34 37] Some reviews went further to suggest interventions needed to be based on these understandings.[23 24 31 31 31 32 32 32 37] There was general consensus more research was required.

Oczkowski *et al*[33] challenged the quality of available evidence in considering efficacy of documented approaches to ACP in primary care,[33] describing it as low to very low in quality, echoing the findings of an earlier 2010 review.[35]

Analysis of the systematic reviews alone did not sufficiently answer the current review questions. A number of limitations diminished the value of review findings. The inclusion and exclusion criteria of individual reviews were very different, making direct comparison problematic. A number of studies included in the reviews were sourced from non-general practice contexts making more generalised findings not directly relevant.[34–36] These reviews were conditionally included only where general practice findings were explicitly reported as discreet categories.

A number of papers referenced in one or more systematic reviews were also included for individual consideration in the current review because the questions posed were different to the reported aims of the systematic reviews in which the studies originally appeared. Table 2 provides a brief overview of the reported findings of the systematic reviews.

Barriers to ACP in general practice

A barrier is understood in the general practice context as something that limits uptake of ACP. A barrier can have effect at an individual level, at an interpersonal level, at a provider level or a system level. The same barrier can also occur across a number of levels. Table 3 catalogues barriers identified in the literature across four socioecological levels of influence.

Barriers at an individual level

When considering barriers to ACP in general practice from an individual perspective, there were very few general practice studies directly involving patients.[14 39–43] A few studies described patient experience by proxy through opinions obtained from GPs. The most common barrier described at the individual level, largely attributed by clinicians, was patient lack of knowledge and awareness about ACP, including lack of knowledge about clinical considerations at end of life.[44]

Attitudes of individuals about ACP were reported to vary widely. Studies reported the perceived irrelevance of ACP was a barrier, with the relevance of ACP described with ambivalence when associated with an existing state of wellness or absence of terminal diagnoses.[13 14]

Further, an identified lack of trust in the health system with reported concern that an ACP would in some way limit care or negatively impact the individual was reported.[40] The concepts of poor literacy,[45] and poor health literacy,[46] as contributing factors were also noted.

Barriers at an interpersonal level

Barriers identified across the interpersonal level involved the individual in relation with others. Very few general practice studies focused specifically on this interpersonal aspect.[47 48] Many studies described confusion and role ambiguity about initiation of ACP. When considering the doctor–patient relationship a number of studies reported a difference in expectation about whose role it was to initiate the ACP discussion.

Described as a lack of role clarity, this uncertainty in the doctor–patient relationship was understood as a barrier to ACP.[41 42 49–52] A number of studies cited GP concerns about initiating the ACP discussion, not doing so in order to avoid being a source of anxiety or loss of hope. Concern about jeopardising the doctor–patient relationship was a recurrent theme described by a number of studies.

Patient expectation that GPs should initiate ACP discussions,[41 42 51] was understood as a barrier when the GP did not initiate the discussion. Studies found patients were

Table 2 Summary of systematic reviews

First author	Ref	Year	Country	Aim	Studies	Summary of outcomes	Recommendations
De Vleminck *et al*	31	2013	Belgium	To identify the perceived factors hindering or facilitating General Practitioners (GP) in engaging in ACP with their patients.	16	A range of barriers and facilitators were identified and attributed to GP characteristics, perceived patient characteristics and health system characteristics.	Understanding barriers and facilitators, and targeting GP and health system related barriers was considered important for development of interventions aimed at facilitating ACP in general practice.
Durbin *et al*	35	2010	USA	To systematically analyse evidence about the outcome and percent of newly completed AD, focusing on effectiveness of (1) types of educational interventions versus controls; and (2) one educational intervention over another.	16	After examining various combinations of intervention including single approaches, combined approaches and multiple combinations the authors determined the evidence base for effectiveness of specific interventions was weak, with the exception that combined approaches were more effective than single approaches in increasing the percentage of newly completed advance directives.	More research is needed to address the low number of studies looking at specific interventions.
Jezewski *et al*	36	2007	USA	To synthesise the state of the science regarding effectiveness of interventions to increase AD completion rates.	25	Interventions with repeated multiple contacts or stimuli were found to be most effective. Not all intervention designs may be effective across the life span and that 'a single approach' will likely not be effective because the same approach will probably not work for all people.	A knowledgeable person who can answer questions should be an integral component of any intervention. Creative interventions need to be developed that are matched to the individual's needs at a particular point in time.
Oczkowski *et al*	33	2016	USA	To determine the effect of structured communication tools for end-of-life decision making on completion of ACP.	67	Low quality evidence that structured communication tools assist with end-of-life decision making resulting in uncertainty about the magnitude of the effect.	Given the heterogeneity of populations, interventions and effects, more work is needed to guide the selection, adaptation and tailored implementation of tools in local settings and contexts.

Continued

Table 2 Continued

First author	Ref	Year	Country	Aim	Studies	Summary of outcomes	Recommendations
Ramsaroop	34	2007	USA	To systematically review studies designed to increase advance directive completion in the primary care setting.	18	There was increased efficacy in achieving advance directive completion with direct patient to health professional contact with this being a consistent finding among studies. The more effective approaches used iterative interactions over multiple visits. Passive education of patients using written materials alone was relatively ineffective Uptake remains low.	Barriers to completion of advance directives warrant attention in future intervention studies.
Sharp *et al*	32	2013	UK	To investigate attitudes of the public and healthcare professionals to ACP discussions with frail older people.	26	Many frail elderly people would welcome the opportunity to discuss ACP but a significant minority would not. There was no consensus for optimal timing of the conversation. Reluctance of family members to engage is a significant barrier.	Categorised across three levels: health system issues —health providers require support and training to initiate discussions; individual autonomy—raised a number of questions about how to achieve this (inter)personal circumstance—raised a number of questions about how to achieve this
Solis	37	2018	USA	To evaluate strategies used in primary care settings to initiate ACP leading to completion of AD.	12	The use of multipronged approaches was most successful for initiating ACP discussion. Effective interventions included patient education materials, computer generated triggers for providers and multidisciplinary team involvement.	There is a gap in empirical knowledge and this opens an opportunity for more research. Providers should consider increasing ACP discussions with patients and create opportunities to do so more systematically.

Continued

Table 2 Continued

First author	Ref	Year	Country	Aim	Studies	Summary of outcomes	Recommendations
Tamayo-Velazquez *et al*	38	2009	Spain	To identify, appraise and synthesise the results of systematic reviews of the literature that examine effectiveness of interventions to increase advance directive completion rate.	7	Determined that each of the systematic reviews reached very similar conclusions. Passive informative material in isolation does not significantly increase advance directive completion rates. Effectiveness is increased over multiple visits where patients are provided opportunity to interact with an expert in the field and are afforded an individual who will answer any queries.	Further research is required to identify new strategies to increase ACP completion rates.

ACP, advance care planning; AD, Advance Directive; GP, General Practitioner.

willing to discuss ACP when asked. This contrasted with other findings that discussing ACP and end of life preferences was potentially distressing for some individuals who might prefer to avoid the topic as unpalatable or conversely trust in an absolute deity being cited as reason to not need ACP.[39]

One study explicitly studied interpersonal barriers,[39] finding a range of relationship concerns. Poor family relationships were reported as a barrier for some. Not wanting family involved, or not wanting to burden family members was also a consideration.[14] Difficulty conversing with family about ACP and the need for assistance to achieve these conversations was raised. Conversely, studies also identified family members not willing to support GPs in discussion about ACP with patients.[32 44]

Patient preference for informality, choosing to discuss end of life matters privately within the family was more common in more educated people and resulted in lack of formal documentation in the medical record.[13]

Barriers at a provider level

A number of studies focused on barriers to ACP at a provider level, with largely consistent findings, echoing those of the previously reported systematic reviews. GP lack of knowledge, skills and confidence in relation to ACP were most frequently cited. See table 3. Lack of GP knowledge was detailed in a number of studies variously outlining knowledge gaps relating to patient competence, legal considerations, documentation and processes.[53] Time pressure to keep up with busy consultation schedules limited GP's ability and willingness to initiate time consuming ACP discussions during consultations.

GP reluctance to engage patients in ACP discussions due to the complexity of diagnoses,[54 55] doubting an individual's ability to comprehend the issues involved was identified. GPs questioned the efficacy of ACP particularly about application at end of life, and one study described paternalistic views including a sense that the GP knew what the patient would prefer, so ACP was unnecessary.[56]

Barriers at a system level

System level barriers to ACP were commonly considered in the available literature. Common system level concerns included, for example, the suitability of ACP templates[45 57]; or uncertainty about the efficacy of one information kit versus another.[53] Lack of consensus about what information was required in a written ACP including the relative importance of value statements, contributed to a lack of clarity.[45] Difficulties associated with poor system linkages resulting in lack of availability of ACP at point of care were highlighted.[58] Barriers associated with uptake of electronic medical record reminder prompts were identified.[59] Context specific issues were described, for example, lack of suitable funding mechanisms was problematic in some jurisdictions.[56 60] One study suggested that because there was no performance monitoring of providers' ACP activity it was not important. If it was not measured at a system level—it was thought to

Table 3 Key barriers to ACP sorted by socioecological levels of influence and ranked by frequency

Level identified	Barrier	No of studies	References
Individual level	Lack of (consumer) knowledge about ACP	15	14 39 44–46 49 54 56 57 59 62 66 72 79 82
	Attitudes—perceived irrelevance	7	13 14 39 40 44 50 76
	Trust/questions of efficacy	4	40 41 44 57
	Denial/emotions/reluctance	10	14 32 39 40 44 50 54 56 57 72
Interpersonal level	Role ambiguity—GP expectation patient will initiate discussion about ACP	7	13 46 51 56 58 62 83
	Role ambiguity—patient expectation GP will initiate discussion about ACP	5	41 42 49–51 83
	GP—patient relationship	5	44 49 55 57 62
	Concern with family relationships	6	13 14 32 39 44 74
	Preference for informal discussion with family	1	13
Provider level	Lack of (GP) knowledge/skills/confidence	18	14 31 44 46 49 53–56 58–60 63 69 74 77–79
	Lack of time	12	14 39 46 53–55 58 61 66 74 76 79
	Misc concerns including legal uncertainty, prognosis, best time	9	54 55 60 61 68 70 75 78 83
	Doubts about efficacy of ACP	3	44 58
System level	Lack of linkages and mechanism for sharing ACP	5	31 44 54 58 60 80
	Lack of funding mechanisms	2	56 60
	Lack of standard templates, tools, documents, IT systems	6	44 45 53 57–59
	Accountability	1	46

ACP, advance care planning; IT, Information technology.

be not important to the system outcomes.[46] This lack of a reporting for providers was described as a barrier as there was no incentive to drive ACP activity.[46]

A recurrent barrier to ACP across the levels of influence was a lack of shared understanding by providers and patients about whose roles is was to initiate ACP discussions and when ACP was best initiated. Studies report conflicting views. A study by Tierney *et al*[51] sought to explore the perceived barrier about who (patient or provider) should initiate an ACP discussion identifying many arguments in support of broad ranging views.[51] The following studies highlight widely contrasting views.

In a study reported by Emanuel *et al*[50] lack of physician initiative was the most frequently cited barrier to ACP according to patients.[50] Physician reluctance to initiate the ACP discussion was compounded by patient expectation that it was the physician's responsibility to do so,[50] and this is somewhat consistent with findings in a (2015) UK study where 60% of respondents would only talk about ACP if the topic was raised with them.[41] In other instances, patients were reported to have raised the issue themselves.[61] A Canadian study found patients preferred to initiate the discussion themselves and often did so with family or friends in preference to their family physician.[42]

In contrast, Pfeifer *et al*[62] found physicians accepted responsibility to initiate discussions but retained a level of concern about the right time to do so,[62] and this despite evidence that counselling by a clinician was the best catalyst for the completion of advance directives.[59] In a UK study, for a patient, the most important predictor of having completed an ACP was having been asked.[41] GP reported barriers to initiating ACP discussions included concern for causing the patient distress or triggering unwanted negative responses[61 62]; however, at least one study demonstrated significant improvement in patient satisfaction in primary care consultations when physicians initiated discussion about advance care directives. De Vleminck *et al* found GPs deliberated about actively initiating versus passively waiting to discuss ACP and this varied qualitatively according to GP knowledge, experience and communication skills.[63]

Other studies suggested there was a need to encourage more health professional involvement in ACP.[56] Nurse care coordinators have been found to be well positioned to leverage opportunities to discuss ACP with patients in primary care,[14 51 64] but Fletcher *et al*[58] explored the role of nurses and identified the majority of nurse participants looked to the doctor for leadership in ACP (p426) and pointed to lack of role clarity in this regard across providers generally.[58]

Studies described uncertainty about optimal timing for initiating ACP discussions.[62] An emerging consensus was ACP discussion should occur in the community—prior to hospitalisation and before critical situations.[48 60] Concepts about timing varied from routine inclusion of ACP discussion for all patients[65]; when illness became predominant[65]; to passively waiting for the patient to raise the topic directly or listening for patient triggers during consultation as a signal of readiness to participate in conversation.[63]

Barriers were often not considered in relation to their effect on each other. Some barriers were specific and applicable to a particular study modality. For example—studies requiring patients to receive an electronic message relied on the person being able to access the technology. An inability to do so would be reported as a barrier, the barrier being specific and limited to the mechanics of the particular intervention. Other barriers were more complex and multifaceted. In general, lack of patient and provider understanding of roles, lack of knowledge; lack of provider skills and experience; patient, family and provider attitudes, and system issues related to time pressure, documentation challenges and mechanisms of information sharing.

Enablers for ACP in general practice

An enabler was understood as a moderating factor defined as 'to make able; give power, means, competence, or ability to'.[19] An enabler can have effect at an individual level, at an interpersonal level, at a provider level or a system level. The same enabler can also occur across a number of levels. Table 4 provides a summary of literature analysed to identify enablers and locate their influence into one or more of the four levels across the socioecological perspective.

Enablers at an individual level

Studies explicitly outlining ACP enablers at an individual level were not common in the general practice literature. Understanding demographic profiles was suggested as an enabler by a number of studies in which people of an older age group were reported as most likely to engage in ACP discussions,[41 66 67] and expanded by one study which reported people of all ages desired ACP discussion.[50] Studies reported individuals initiating ACP discussion helped overcome GP reluctance to engage in the topic,[63] and suggested that individuals should be encouraged to

Table 4 Key enablers mapped to socioecological levels of influence and frequency reported

Level identified	Enabler	No of studies	References
Individual level	Demographic likelihood (increased age)	3	41 66 67
	Education and public awareness	7	31 43 56 67–70
	Stage of change—readiness	6	15 34 39 43 47 71
	Timing	6	13 31 61 65 67 69
Interpersonal level	Doctor–patient relationship (strength, length of, trust, familiarity)	10	14 15 42 48 49 61–64 67
	Nurse–patient relationship	5	14 64 72–74
	Conversation and deliberation	5	14 43 57 64 65
	Group interaction	2	66 73
	Previous experience with ACP	4	15 31 47 58
Provider level	GP and practice nurse education and communication training	8	14 60 65 69 74–77
	GP or practice nurse initiating the ACP discussion	6	14 46 50 52 63 74
	GP with philosophical agreement to ACP	8	40 42 43 49 55 57 58 63
	GP engagement in team approach	3	60 64 66
System level	IT systems—portals, prompts, decision aids	8	44 46 54 59 63 64 71 80
	Templates	6	57 63 67 70 75 78
	Business as usual processes and protocols	11	13 39 46 50 51 54 56 65 67 69 76
	Models of care—group appointments, nurse led clinics, ACP facilitators	10	14 49 60 64 66 72–74 76 79

ACP, advance care planning.

raise the subject[68]; however, the concept of individual autonomy and empowerment was largely silent in general practice literature.

Studies reported people with higher levels of education were more likely to have engaged in ACP,[13 67] and tailoring ACP discussion and resources to an individual's literacy level was effective.[45] A number of studies reported the need for individuals to access education through public awareness raising activities.[31 56 69] One randomised control trial (RCT) tested approaches to patient education and reported mixed results and ongoing challenges so while potentially useful, was not a panacea.[70]

An alternative approach described an individual's readiness to engage in ACP viewed from the trans- theoretical stages of change approach.[39 71] Described as an iterative process ACP was framed as a behaviour change process which involved the individual through discrete steps.[34 43] Determining the individual's readiness to engage prior to initiating ACP discussions was described as an important step.[39 47 71]

Studies considered if there was an optimal time to initiate ACP discussions referring to time in relation to disease timelines as opposed to chronological time—for example, during first consultation, at diagnosis, in advance disease stages or at end of life. A range of findings included at first appointment,[67] while individuals were healthy,[13] planting the seed for future discussions,[61] and when chronically or terminally ill.[69] In a binary relation, the anxiety of not knowing the best timing was a barrier so understanding the best timing would by contrast, provide clarity and be enabling.

Enablers at an interpersonal level

Studies explicitly focused on ACP enablers at an interpersonal level were least common in the general practice literature though the importance of relational aspects of ACP was evident. The majority of studies identifying interpersonal enablers referred specifically to the importance of the doctor–patient relationship. Enabling factors within this relationship were longevity of the association and high level of trust.[14 42 48 49 61 62 64 67 72] A more recent trend is evidenced in the literature with five studies published since 2016 detailing the role of nurse–patient communication as an enabling factor in uptake of ACP. Other studies found individuals with lived experience of caring for someone else at end of life, or experience with ACP had increased uptake of ACP,[47 58] and this also included GPs with personal experience of ACP.[31] Two studies reported the process of discussion and reflection of values over multiple visits as enabling ACP to be most effective,[14 34] supported by similar findings from others.[43 57 64 65]

Other interpersonal enablers involved participation in facilitated discussions in group settings where group dynamics and the ability to socialise were identified as effective levers.[66 73] One study reported the value of socialisation around ACP discussion in group settings,[66] and another described value in 'learning from the experience and perspectives of others' (p127).[73]

Enablers at a provider level

A number of suggested enablers at the provider level were inter-related. Strong communication skills, confidence, knowledge and positive GP attitudes were described as enablers and achieving this was variously described through provider education and training, skills development, deliberative discussion and the clarification of GP attitudes and roles. The emerging role of the broader healthcare team, with a particular focus on extended roles of the practice nurse was evident in most recent publications.[14 64 72 74]

A number of studies reported recommendations in support of provider training. Within these, the focus of studies varied with training recommendations ranging from the specific to the broad including legal considerations,[75] professional mentorship and observed practice for providers engaged in ACP,[46 60] communication skill training[65 76] and professional development training about ACP.[69] One study reported the efficacy of provider training which was reported to increase GP knowledge and confidence.[77] Positive GP attitude to ACP was shown to increased engagement in ACP discussion.[46 50 52 63]

Enablers at a system level

Many studies included in the review were focused on describing and/or testing enablers at a system level. Among these, the most frequent recommendation was establishing various business as usual approaches to ACP seeking to normalise ACP in practice. Concepts ranged from a general theme,[46 49] to including and specifically targeting all patients of a certain age[13]; to others describing monthly purpose specific clinics[66]; reminders in the medical record,[59] and provision of ACP resources to patients and providers through portals in an automated way.[54]

Systematic prompting of patients and providers with technology reminders and information was found to have some effect. Studies explored timing the prompts preconsultation with mail out,[46] during consultations as screen prompts for providers,[59] and simultaneous prompts for both consumer and provider.[46 68] Studies reported variable degrees of success.[46 59 64 68] and those studies implementing a combination of approaches reported greater uptake of ACP than single step processes.[68]

The importance of ACP resources including templates and standardised documentation was a recurrent theme.[61] A number of studies recommended the need for standardised and improved ACP templates and tools to support discussion in general practice,[57] with testing and development of tools and fit for purpose approaches for target populations. This included one study with findings about efficacy of an ACP template designed for people with low health literacy,[45] another study developed and tested a tool to assess stage of change[71] and a study that found personalised ACPs increased uptake.[70]

Since 1992 when researchers noted the majority of participating physicians had never seen, used or discussed ACP with any patient,[69] there have been many published studies internationally indicating growing physician support for ACP. More recently, most GPs felt ACP was important,[61] citing ACP attributes as safe guarding patient autonomy and conferring peace of mind for the individual and the family.[78] Positive GP attitudes are a known enabler. Practice nurses also reported ACP as beneficial to patients and understood a potential role for nurses in this context.[14 60] Positive attitudes have also been reported in the community with one study describing a majority of patients and healthy people considering ACP as 'meaningful and important' (p1583).[40]

Leveraging enablers alone was not shown to be sufficient to systematically improve ACP. Many enablers were understood to share direct binary relationships with barriers and were described in the context of overcoming particular barriers. For example, if the barrier was lack of knowledge, the enabler was provision of education. If the barrier was lack of knowledge combined with an entrenched or cynical attitude, education alone would be ineffective. In considering the range of barriers, a number of studies explored a range of complex interventions and alternative models of care with a focus on changes to practice processes that enabled alternative ways of working, for example, by role delineation and delegation of responsibility. Alternative models of care were found to be complex enablers with implications across multiple levels of socioecological perspective. Examples included exploring attitudes to nurse led clinics,[60] conducting group appointments[66 73 79] and trialling ACP facilitators in practice.[49]

This section has catalogued a number of known enablers described across multiple contexts and each nuanced to the study environment. An overall observation in considering the body of literature was the need for flexible and place-based responsiveness in the design of interventions. Not understanding the range of barriers at play was understood to limit effectiveness of enablers. One size did not fit all and a single approach was unlikely to work for all.[36]

Initiatives to increase ACP in general practice

This section synthesises current knowledge from intervention studies with a summary provided in online supplementary file 3. Fourteen general practice intervention studies were identified in the review as outlined in online supplementary file 3. Of these, 12 studies were conducted in the USA, 1 in Australia and 1 study was reported from Belgium. Publications spanned a period from 1996 to 2019 with 6 of the 14 studies published after 2016. The studies consisted of six randomised control trials, two mixed-methods studies, a comparison study, a cross-sectional survey, a qualitative study and three studies described as complex interventions.

Intervention studies were only included if the research was undertaken in general practice. Interventions ranged in complexity from simple initiatives focused on one level of influence, to complex multilevel undertakings.

Each intervention aimed to increase ACP and the approaches used were different across the studies. A recent Canadian study (2018) found it was not clear that the assembled body of research had explicitly considered the known barriers and enablers when framing proposed interventions.[44] Two exceptions were found. A study by Miller *et al*[14] explicitly described intervention activities based on and intending to overcome known barriers[14] as did an earlier study by De Vleminck *et al*.[72]

Early research involved interventions with a common focus on prompting and reminding. Patients were prompted by mail outs,[46 70] reminder letters[46] and waiting room questionnaires.[67] Physicians were prompted with scripts and various systems to trigger discussion during consultations.[46 51 68 72] The efficacy of combining various combinations of prompting and reminding was explored in a three arm blinded randomised control trial which sought to test the efficacy of a combination of two simple interventions. Patients with upcoming appointments receiving a mail out of patient information and this was combined with the physician receiving a computer-generated reminder during consultation. Reported findings showed a substantial increase in completed ACPs in one of the three study arms supporting the efficacy of a mail out supported by a physician prompt, with no change between the control and the physician only prompt arms.[68] Subsequent studies commonly included one or more prompts as components of more complex interventions. Another mixed-methods study compared the efficacy of two different conversation guides—based on a determination of the required literacy reading levels contained within the two documents. This was measured by patient and provider experience of use.[53]

Another early study by Tierney *et al*[51] hypothesised physicians feared initiating ACP discussion as it would cause a reduction in patient satisfaction with care. Tierney's study used a physician computer prompt during consultation followed by a postconsultation patient satisfaction survey. Study findings reported patients were more satisfied with their provider when ACP was discussed, so the physician's fears were found to be baseless.[51]

Weiner *et al*'s contention that 'interventions that target determinants at multiple levels and mutually reinforce each other are likely to produce larger and longer lasting effects than interventions that target determinants at only one level' (p34),[30] remains to be seen. Of the one qualitative study[14] and three complex interventions,[46 72 73] only one study systematically and explicitly sought to address barriers and leverage enablers across multiple levels of influence.[72] In this study, by understanding the key barriers and enablers, De Vleminck *et al* determined a structured response which identified four key components underpinning successful ACP interventions.[72] The first key component was described as the involvement of trained and experienced facilitators. This approach was a common feature across complex studies, though the facilitation role varied with involvement of one or more of the patient's physician, social worker, registered nurse or nurse practitioner. Face-to-face facilitation was a known enabler with influence at the interpersonal level. All but two interventions,[54 80] involved discussion with knowledgeable health professionals. This interpersonal influence was further leveraged by Holland *et al*[64] who required individuals to discuss ACP with their families, prior to a second appointment; by Lum *et al*[73] who conducted group appointments to harness the dynamic interaction between participants in facilitated sessions. The importance of skilled facilitation was also noted by Miller *et al*[14] who provided training to the providers to enhance their facilitation skills.

The second key component identified in De Vleminck's (2016) complex intervention, was a selection process to identify eligible patients, considered to be a key underpinning component of ACP interventions. The patient characteristics cited for inclusion on an ACP invitation register in De Vleminck's study were those with poor health and poor prognosis.[72] Demographic targeting of older people was identified as an enabler and advancing patient age was a primary consideration for recruitment in all but three interventions, ranging from 50 years for those with known chronic disease,[51 68] to 65 years,[73 80] 70 years[68] and 75 years.[51] Only one study included all adults older than 21 years.[14 67] Miller was unique in recruiting both opportunistically and by use of the surprise question—'would I be surprised if this patient were to die in the next twelve months?' If the answer was no, ACP discussion was considered indicated.[14]

The third key component suggested by De Vleminck was a structured and patient-centred ACP discussion which was addressed in the 2016 study design by development of a GP prompt, a conversation guide and template for ACP. Similarly, Duffield and Podzamsky[67] employed waiting room questionnaires; Wissow *et al*[46] prepared physician scripts; Pearlman *et al*[70] employed a conversation guide as did Lum *et al*[73] . Holland *et al*[64] sought to evaluate the feasibility of four different tools. Across all studies, a range of tools were suggested as suitable; however, the key point was the value of a structured approach,[64 70 72 73] as a number of tools were reported as moderately effective. Miller *et al*[14] used an ACP workbook and an advance directive template to guide the discussion.[14]

The fourth key component cited by De Vleminck *et al* was the opportunity to complete ACP documents.[72] The provision of an ACP form or template was evident in the majority of interventions.

The majority of intervention studies had a mitigating effect on one or more known barriers at various levels of influence, but no study was seen to mitigate the influence of all barriers, or leverage all enablers. There were examples of studies testing approaches in contexts in which other known barriers might be predictably problematic, but which were not factored into the proposed interventions. For example, testing a GP reminder prompt in the middle of a busy consultation without quarantining time to respond to the prompt, was not found to be an effective mechanism for change.[68] Whereas some interventions had some impact and demonstrated a level of efficacy, to create a synergistic initiative required consideration of all key barriers operating at each level, with a design structured to maximise outcome. The findings of De Vleminck intervention are yet to be reported.[72] The qualitative study by Miller *et al*[14] arguably addressed all four of De Vleminck's key intervention components but reported outcomes as a pilot study suggesting further research was required.[14]

In keeping with complex approaches, a retrospective analysis by Dipko *et al*[66] explored the efficacy of a single face-to-face education session with a social worker in a primary care clinic versus a combination of multiple face-to-face sessions or participation in group education in an elderly population.[66] In this study, the ACP completion rate was positively associated with participation in group education, and higher still in multiple face-to-face sessions. From an efficiency perspective, the study concluded group sessions provided the most efficacy with regard to time, resources and outcomes.[66]

A more recent study[73] tested the feasibility of group medical visits in a patient-centred medical home environment and explicitly noted the importance of patient engagement through group interaction, 'leveraging the group dynamic to transform the typical patient–clinician encounter'.[73] Positive outcomes were reported from participants both in terms of individual uptake of advance directives but also in reported conversations with loved ones. Group appointments were suggested to be an effective forum for knowledge exchange creating an efficient and less stressful situation than one-on-one office visits,[76] and overcoming a number of barriers related to process, time and role responsibilities. This study was one of two reported interventions from a patient-centred medical home perspective and warrants further consideration. This approach leveraged all of the key components identified by De Vleminck and in addition, compressed time demands by using the group approach. The authors recommended more research to understand the sustainable work flows required and to address ongoing barriers.

DISCUSSION

In seeking complementarity or synergy across levels of influence, McCormack *et al* reported that the socioecological model had demonstrated benefit.[29] This was also described by Weiner *et al*[30] noting the potential synergies to be gained using a socioecological approach provided 'compelling justification for multi-level intervention'. However, both acknowledged a lack of theoretical guidance with regard to the optimal design of multilevel interventions.

In seeking to understand optimal design of interventions, Pettigrew *et al* outlined two important considerations. The first was that complexity may be associated with the activities, singular or multiple, which comprise the actions of an intervention.[81] The second consideration was that complexity may be associated with other mediators and moderators operating *between* the actions. Feedback loops occurring between the mediators and moderators have been described as mechanisms of action alternatively known as causal pathways. These pathways have been said to create or limit the effect of an intervention.[81] Many studies in this literature review could be understood with regard to the first consideration—exploring activities, singular or multiple in various combinations. Studies concerned with the second consideration of looking at how or if the various interventions when combined together created or limit their effect were largely silent in the general practice ACP literature.

With regard to this second consideration, an approach to causal modelling was described by Weiner *et al*[30] in which five mechanisms of action were proposed. Each of the five mechanisms—accumulation, amplification, facilitation, cascade and convergence was observable but not explicitly described in the intervention literature. An *accumulation strategy* is at work when *each intervention makes a discreet contribution to the outcome.*[29 30] The interventions occur at different levels of influence and produce an accumulative impact to achieve the desired outcome.[30] It is accumulative because the effect of each intervention is not conditional on the other intervention. For example, in Heiman's RCT, two separate interventions known to have positive impact individually were combined to determine if a greater impact was achievable. The first intervention was the sending of ACP information to individual patients prior to consultation with their GP. The second intervention involved sending a computer prompt to the patient's GP during the consultation. Both actions were independent of the other, each targeting different levels of influence, but together had an accumulative effect resulting in a small but significant overall increase in ACP.[68] Combining interventions in this manner was commonly described in the review literature. The implication for future intervention design is the explicit combination of known enablers across multiple levels will be more effective.

When considering *amplification strategy, the effect of one intervention is conditional on another. One intervention increases the target audience's receptivity to the other intervention.*[30] This mechanism was identifiable in a study by Amjad *et al*[47] where a patient's previous experience of caring for someone at end of life (interpersonal level) was found to directly influence (or amplify) their likelihood of engaging with their own ACP (individual level).[47] Understanding the conditional relationship or links between activities when planning interventions could be anticipated to enhance outcomes but was not observed in most studies.

Where an *intervention clears the way or removes barriers for another intervention,* it is facilitating the outcome. *Facilitation strategy* was commonly described in the body of general practice ACP literature.[30] To illustrate, lack of GP knowledge about ACP was widely identified as a barrier to GP participation in ACP.[30 43 51 53–55 63 67 68 73 74 78 81–83] By delivering GP education, one intervention[77] sought to improve GP knowledge,[77] which in turn would remove the lack of knowledge barrier, and arguably clear the way for improved GP engagement in ACP discussion. Interventions addressing known barriers were demonstrated in the literature but the complexity of association between barriers was often overlooked. For example a study facilitating access to knowledge and resources but failing to quarantine time overlooks a critical barrier. Facilitation alone was demonstrated to be insufficient.

The final two mechanisms were identified in more complex undertakings. In *cascade strategy, an intervention at one level affects the desired outcome in and through one or more levels of influence.*[30] Generally this would occur from higher levels of influence to lower ones. In general practice ACP literature, a number of more complex interventions described a cascade like strategy. For example, Wissow *et al*[46] sought to increase ACP uptake through a multilevel intervention. To make ACP business as usual in clinic consultations the chief of staff provided opinion leader endorsement and introduced top down processes including allowance for structured ACP discussion time during consultation, and provision of ACP tools, templates and scripts. Combined with this, at the provider level, GP training in communication skills, was intended to increase GP likelihood of initiating ACP discussion with their patients. The combined actions cascading from the Director's endorsement down constituted a test case for a multilevel intervention with cascading influence.[46]

Similarly, *in convergence strategy, influence at different levels mutually reinforce each other by altering patterns of interaction.*[30] The extent to which convergence strategy applied in the literature can only be assumed as it was not explicitly noted. In a study by Lum *et al,*[73] the research explored ACP group medical appointments.[73] Using this model of care, system levels changes around scheduling and provision of information was mutually reinforced by planning a multidisciplinary team approach. The doctor–patient–social worker communication at an interpersonal level was reinforced during the group interaction. In this example, there was presumably convergence across several levels including individual, interpersonal, provider and system levels of influence. Convergence strategy was implicit in a number of general practice ACP research studies.[64 67 68 70 73 79]

Future complex intervention design may benefit from consideration of the relationships between barriers and enablers operating at various levels of influence, and factor causal mechanisms into the intervention design. By doing so greater uptake of ACP in general practice may be achievable.

To note, the bulk of ACP literature was generated in the USA and as described in the Introduction section, was included based on criteria to assimilate models of care most consistent with Australian general practice. There were no Australian systematic reviews found and limited general practice literature. In considering the applicability of findings into the Australian healthcare setting the literature presented consistent themes regardless of geographical origin. The authors are satisfied that the findings are relatable.

Limitations

The volume of studies describing barriers and enablers to ACP in general practice was abundant; however, studies focused on interventions in general practice were quite limited.[84 85] Study quality was variable and a number of small scale studies focused on singular aspects of ACP limiting broader applicability. Existing Australian research draws heavily on international evidence to support local findings and a number of authors identified the need for more Australian research to inform policy and implementation.[86–89] The extent to which international ACP evidence is applicable and transferable to a population or place based context within Australia is uncertain.

Lack of consistent terminology was a challenge addressed initially in the formulation of search terms and inclusion criteria, though it is possible that all relevant literature was not surfaced due to complex terminology. By focusing on general practice literature only, it is possible that transferable knowledge from other sectors may have been excluded. The researcher sought to reduce bias by adhering to the study protocol and by using reflexivity to monitor adherence to methods described.

The Australian Medical Association (AMA) argue that as a distinct medical specialty, general practice requires its own specific body of research and that findings from other medical research cannot simply be transferred to general practice.[90] More studies are required to contribute to the available body of general practice research, described by AMA as the missing link in the development of high-quality, evidence-based healthcare for populations. Limited general practice intervention research was available and opportunities to expand the body of ACP knowledge through effective design of complex interventions will make a useful contribution both to increasing general practice research literature and to increasing ACP uptake through general practice.

In this review, the ACP literature was categorised and considered across socioecological levels of influence distilled from the narrative. This approach provided an insight into distribution of research interest across levels of influence. Individual and interpersonal levels of influence were the least researched in general practice and provider and system aspects focused on GPs and processes were the most prevalent. This finding was unexpected when considering the central role of the individual in ACP, and in relationship with their family, in determining values and wishes for end of life care, and the perceived role of general practice in supporting this process.

Not only were research findings in relation to individual perspectives limited, the patient voice was more commonly presented through a provider as proxy. Future studies should seek to engage patients directly.

Conclusion

This review was set against a back drop in which uptake of ACP remained consistently low, despite widespread agreement that it was beneficial, and with general agreement it was best achieved in primary care settings. The review sought to understand known barriers and enablers to ACP, and based on these, to determine what initiatives had been described to increase uptake of ACP. In seeking to understand barriers, enablers and efficacy of interventions, it was useful to understand at which level of influence across the socioecological perspective the interaction was occurring, and in doing so, consider how interventions had been developed to mitigate barriers and leverage enablers targeted for greatest effect.

By stratifying barriers, enablers and interventions into levels of influence, the important relationship between activities operating across levels became evident. Within this complexity, it was understood that some interventions were more effective than others, and combinations of interventions were more effective again. There appeared to be a shift away from considering ACP as 'a singular action' to be achieved or documented, instead to view ACP as a set of discreet steps in a complex process.[43] Interventions targeting multiple levels of influence were said to reinforce each other, and consequently were expected to yield greater and more sustainable effects than interventions targeting only one level of influence.[30]

Findings from this review have identified a gap between historical research approaches which involved asynchronous testing of multiple mechanisms for ACP across all levels of influence, versus the potential for strategically applying the evidence across targeted levels of influence, and with an understanding of mediators and moderators to inform the design of new and effective ACP models of care.

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Co-authorship Approvals for Higher Degree by Research Thesis for Examination

In accordance with Clause 5, 7 and 8 in the HDR Thesis Rules, a student must sign a declaration that the thesis does not contain any material previously published or written by another person except where due reference is made in the text or footnotes. There can be no exception to this rule.

a. Publications or significant sections of publications (whether accepted, submitted or in manuscript form) arising out of work conducted during candidature may be included in the body of the thesis, or submitted as additional evidence as an appendix, on the following conditions:

i. they contribute to the overall theme of the work, are conceptually linked to the chapters before and after, and follow a logical sequence
ii. they are formatted in the same way as the other chapters (i.e. not presented as reprints unless as an appendix), whether included as separate chapters or integrated into chapters
iii. they are in the same typeface as the rest of the thesis (except for reprints included as an appendix)
iv. published and unpublished sections of a chapter are clearly differentiated with appropriate referencing or footnotes, and
v. unnecessary repetition in the general introduction and conclusion, and the introductions and conclusions of each published chapter, is avoided.

b. Multi-author papers may be included within a thesis, provided:

i. the student is the primary author
ii. there is a clear statement in prose for each publication at the front of each chapter, recording the percentage contribution of each author to the paper, from conceptualisation to realisation and documentation, in accordance with the Research Publication, Authorship and Peer Review Policy, and
iii. each of the other authors provides permission for use of their work to be included in the thesis on the Submission of Thesis Form below.

c. Papers where the student is not the primary author may be included within a thesis if a clear justification for the paper's inclusion is provided, including the circumstances relating to production of the paper and the student's position in the list of authors. However, it is preferable to include such papers as appendices, rather than in the main body of the thesis.

A. STUDENT'S DETAILS (to be completed by the Student)

Name: Joanne Risk Student ID: 2110321

Degree: DPH College: Medicine and Public Health

Title of Thesis: Advance Care Planning in General Practice

B. CO-AUTHORSHIP APPROVALS (To be completed by the student and co-authors)

If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

1. **Full publication Details** Risk J, Mohammadi L, Rhee J, et al. Barriers, enablers and initiatives for uptake of advance care planning in general practice: a systematic review and critical interpretive synthesis. BMJ Open 2019;9:

Section of the thesis where the publication is referred to Chapter Two - Literature review

Student's Contribution to the publication:

Research Design 75 %

Data Collection and analysis 90 %

Writing and editing 90 %

Outline your (the student's) contribution to the publication:

A systematic review and critical interpretive synthesis of the advance care planning literature was required to inform the research intervention for the DPH.

I framed and conducted the search, reviewed and analysed the literature. I determined the conceptual framework and applied it to the literature.

I authored the first and final draft, responded to peer reviewer feedback and revised the document accordingly.

☑ I confirm that the details above are an accurate record of the student's contribution to the work.

Name of Co-Author 1: Leila Mohammadi Signed: Date: 25 03/202

☑ I confirm that the details above are an accurate record of the student's contribution to the work

Name of Co-Author 2: Prof Lucie Walters Signed: Date: 25/03/202

☑ I confirm that the details above are an accurate record of the student's contribution to the work

Name of Co-Author 3: Prof Paul Ward Signed: Date: 25/03/202

2. **Full publication Details** ____

Section of the thesis where the publication is referred to ______________________________

Student's Contribution to the publication:

Research Design _______%

Data Collection and analysis _______%

Writing and editing _______%

Outline your (the student's) contribution to the publication:

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3. **Full publication Details** ____

Section of the thesis where the publication is referred to ____________________________

Student's Contribution to the publication:

Research Design _______%

Data Collection and analysis _______%

Writing and editing _______%

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Student's Contribution to the publication:

Research Design _______%

Data Collection and analysis _______%

Writing and editing _______%

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Section of the thesis where the publication is referred to ____________________________

Student's Contribution to the publication:

Research Design _______%

Data Collection and analysis _______%

Writing and editing _______%

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6. **Full publication Details** ____

Section of the thesis where the publication is referred to ______________________________

Student’s Contribution to the publication:

Research Design _______%

Data Collection and analysis _______%

Writing and editing _______%

Outline your (the student’s) contribution to the publication:

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https://www.crd.york.ac.uk/PROSPERO/

PROSPERO

A systematic review: Barriers, Enablers and Initiatives for uptake of advance care planning in general practice.

- Review question(s)*
    1. What are the barriers and enablers to uptake of advance care planning in general practice?
    2. What initiatives have been used to increase uptake and what was the outcome?

- Searches*

Database searches will be undertaken from inception to February 2018 across MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, ProQuest and Cochrane databases. The selected databases are considered the most useful to identify peer-reviewed articles relating to this topic. The search strategy has been developed for MEDLINE and will be modified to suit the language requirements of other databases. It will include Subject Headings and free text words. During the searches, wildcards and * truncation will be used to ensure broad inclusion of related search terms. Boolean operators 'OR' and 'AND' will also used. The search strategy has been developed with the expert assistance of a medical librarian. We will identify and include additional records by reviewing citations and reference lists of relevant papers.

To be considered for inclusion, a record will need to satisfy keywords including advance care planning, consumer and/or provider knowledge, attitudes, practice, uptake; and in the context of general practice, patient centred medical home or family practice.

- Types of study to be included initially*

The following criteria will inform decisions about the type of studies and eligibility of records for inclusion in the review. The rationale for this Records must meet all of these criteria to be included:

- Includes keywords / search terms as stated above– because they define the subject of interest
- English language – because it can be understood by the researcher
- Published in peer reviewed journal as an initial measure of quality
- Primary care with scope limited to general practice as this is the context of the review
- Adult participants as capable adults have autonomy to decide

To ensure a focused review, a number of exclusion criteria have also been identified.

- Reports, gray literature, unpublished works exclude because they have not been through a rigorous peer reviewed process.
- Records that focus on acute care, inpatient care, palliative care or clinical management at end of life – are out of scope because they are not aligned to the study focus of general practice.
- Specific minority group issues are out of scope unless described in a general practice context.
- Euthanasia, legal issues, mental health incapacity are excluded because the scope is limited to general practice and these are broader societal issues.

- Condition or domain studied*

  Barriers, enablers and outcomes of initiatives with regard to uptake of advance care planning in general practice.

  For the purpose of this review, general practice is broadly described as an entity that provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities. (1) The terminology is broadened to include 'patient centre medical home', 'health care home' or 'family practice' to ensure capture of international variations. The review aims to include all who would participate in an advance care planning initiative in this broadly defined general practice setting.

  An advance care plan (ACP) sometimes called a 'living will' or an advance care directive provides written directions describing how an individual would prefer to be treated in the event of a loss of capacity to direct one's own care.(2) All versions of this ACP terminology will be included in the review.

- Participants/population*

  The population for this review will include consumers, patients of, and health care providers operating within a general practice setting.

- Intervention(s), exposure(s)*

  This review will seek to identify barriers and / or enablers to uptake of advance care planning in general practice. Reported consumer and / or health care provider experience, knowledge and attitudes will inform this understanding.

  The review is also seeking to identify reported advance care planning initiatives implemented in a general practice context. The finding and recommendations from these studies will be informative for proposed future initiatives.

- Comparator(s)/control*

  This review is not anticipated to need a control group.

- Primary outcome(s)*

  Type of outcome measures

  This review is seeking to determine current knowledge about barriers and enablers to uptake of advance care planning in general practice, including an overview of what initiatives have been tried in a primary care general practice setting to increase participation and uptake, including the outcome and lessons learned from these initiatives. The table below outlines the definition and priority of these outcomes.

  Catalogue of known barriers to ACP – Knowledge of themes identified in the literature as impeding consumer or provider involvement in advance care planning at an individual and/or system level. This is important to understanding what is hindering ACP and will allow future consideration about which if any of these barriers is modifiable- to improve ACP uptake.

  Catalogue of known Enablers to ACP- Knowledge themes identified in the literature as contributing to/ enabling consumer or provider involvement in advance care planning at an individual and/or system level. This is important to understanding what is enabling ACP and will allow future consideration about which if any of these facilitators can be included in future initiatives to improve ACP uptake.

Catalogue of Initiatives by type and result - Type of general practice based initiatives identified in the literature aimed at increasing participation in ACP. This is important because understanding past initiatives and the success and / or failure of these initiatives is critical to informing new approaches.

Catalogue of recommendations arising from past initiatives is important to provide valuable insight to informing new approaches

- Secondary outcomes*

Findings will allow the exploration any relationship between practice based interventions and identified barriers and enablers in determining feasible and effective approaches to uptake of ACP.

- Data extraction, (selection and coding)

Data management
Data and records will be managed using Endnote software and Excel on a password protected stand alone computer. The endnote library will be shared with the second reviewer. Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] framework will be used as the basis for reporting.

Selection process
Once the database search strategies are complete and identified records have been catalogued in endnote, duplicate records will be removed. A single reviewer will screen records by title and / or abstract to identify studies that meet the inclusion criteria. Records will be reviewed and catalogued by the primary researcher using a standardized template to identify key features of interest relevant to review. The template will document:

- -type of study,
- -year of publication,
- -study setting,
- -barriers identified,
- -enablers identified,
- -interventions identified.
- -target group-size and type of intervention.
- -findings and outcomes of intervention.
- -recommendations.

Two reviewers will be involved in the quality assessment of the full text record review.

- Risk of bias (quality) assessment*

Limiting the search to peer reviewed journal publications will provide an initial proxy measure of quality. It is anticipated that the heterogeneity of approaches within the search literature will make it difficult to apply a single rigorous quality framework however the Joanna Briggs Institute provides a suite of Critical Appraisal tools considered suitable for use covering a range of methodological approaches. These will be used to assess study quality with the specific tool determined by the study type. Two researchers will independently assess the eligible studies for quality criteria based on the appropriate tool. Results will be compared and if / when reviewer findings differ, discussion will ensue to reach a consensus view and search results adjusted accordingly. This process is important to reduce reviewer bias. Following completion of this process, all records agreed by both researchers will be included in subsequent review and critical interpretive synthesis.

Strict adherence to review protocol and inclusion and exclusion criteria will assist in minimizing potential reviewer bias.

- Meta biases – Publication bias is thought to occur when researchers only publish studies with positive findings, or positive findings are more prevalent in the literature. Negative results may go unreported or under reported. (3) Records will be analysed for defined outcomes including from available records describing barriers and failed studies.

- Strategy for data synthesis*

A critical interpretive synthesis will explore the relationships and findings within and between the included studies in relation to the study variables of barriers, enablers, and efficacy of intervention type.

- Analysis of subgroups or subsets*

Given the iterative nature of the review emergence of unanticipated sub groups and sub sets is possible. The data synthesis process will be responsive to emerging data which may involve additional opportunities for analysis.

1. https://www.racgp.org.au/becomingagp/what-is-a-gp/what-is-general-practice/
2. Australia PC. Advance Care Planning Position Statement. 2013.
3. Thornton A, Lee P. Publication bias in meta-analysis. Journal of Clinical Epidemiology.53(2):207-16.

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Author contribution
Jo Risk is primary author with current candidature for DrPH.
Paul Ward is academic supervisor assisting with the quality review and providing academic oversight.
Leila Mohammadi is the medical librarian assisting with the search strategy

Support
No funding has been provided from any source for this study.
Academic support has been provided by Flinders University.

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INFORMATION SHEET
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Description of the study

x Medical Centre is about to introduce group information sessions for advance care planning. To understand what people think about this approach, a research project is being conducted. This study is titled 'Advance care planning in general practice'. This project will investigate the effect of group information sessions on the uptake of advance care planning by general practice patients. This project is supported by Flinders University, College of Medicine and Public Health

Purpose of the study

This study is looking at a way to improve uptake of advance care planning. An advance care plan, sometimes called a 'living will' or an advance care directive provides directions to the family and health care providers of a person, describing how that individual would prefer to be treated in the event of a loss of capacity to direct their own care. Advance care planning is intended to ensure quality care according to individual wishes at end of life but a 2014 estimate showed that less than 2 out of every 10 people had one.

You have been invited to participate in this research because you have expressed interest in attending the advance care planning information session at x Medical Centre.

What will I be asked to do?

Step 1: Questionnaire

You will be asked by the researcher to provide a signed consent form, and then complete a brief survey. This will occur before the start of the x Medical Centre group information session. Assistance will be available to help you read and answer the questions if you wish. The group information session may be audio recorded but this will only occur if everyone attending has consented for this to happen.

Step 2: Telephone interview

You *may* receive a phone call from the researcher one week after the information session. A number of people will be chosen at random, to receive a telephone call one week after the information session. You may or not be one of the people telephoned. This telephone interview will take about 30 minutes and will seek to understand what people thought about the group information session. It will be audio recorded for transcription (typing up). If you are one of the people telephoned, you will be offered the opportunity to review the interview information before it is included in the study.

Step 3: Final telephone interview

You will receive a phone call from the researcher twelve weeks after the information session, to answer a short questionnaire. This may take 15-20 minutes.

The total time involved including all parts of the research is anticipated to be about one hour.

What benefit will I gain from being involved in this study?
You may not gain any direct personal benefit from being involved in the research. Participating in this research will assist doctors and nurses to better understand important aspects of advance care planning, including what works, and what doesn’t and why not.

Will I be identifiable by being involved in this study?
The researcher will know your name. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced you are free to discontinue at any time. Support / counselling may be accessed free of charge by all participants. Please contact the following services available any time day or night to answer your call: Life Line: 13 11 14 Beyond Blue: 1 300 22 46 36

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?
Participation is voluntary. If you are interested in participating, please complete the enclosed consent form and bring it with you to the scheduled group information session. The researcher will be there and is able to collect consent forms from interested people. If you forget to bring your consent form, but wish to be involved, the researcher can provide you with a spare consent form available on the day.

How will I receive feedback?
On project completion, outcomes of the project will be available to everyone through the x Medical Centre website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number No 8288). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

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Participant ID: _ _ _ _ _

CONSENT FORM FOR PARTICIPATION IN RESEARCH

Advance Care Planning in general practice

Full Name: [PRINT] ____

Contact phone number:____

I am over the age of 18 years and consent to participate in the research project on Advance Care Planning in general practice.

I consent to: (please circle):

Stage of Research	
Stage 1: Pre questionnaire	
I agree to participate by completing a brief questionnaire	Yes / No
Stage 2: Telephone interview – One week after information session	
I agree to being contacted by the researcher if I am randomly selected to participate in a telephone interview following the x Medical Centre advance care planning group information session.	Yes / No
I agree to my interview being audio recorded and I understand I will have the opportunity to approve a transcript of the interview before it is used.	Yes / No
To be completed after transcript reviewed: I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained. Participant's signature……………………………………Date…………………..	
Stage 3: Telephone questionnaire – 3 months after the information session	
I agree to being contacted by the researcher for a follow up phone questionnaire approximately twelve weeks after the information session. This call will be audio recorded.	Yes / No
Audio recording	
I agree to the audio recording of the group information session	Yes / No

1. I have read or had the information explained to me.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet for future reference.

4. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While no identifying information will be published; and all information provided will be treated with the strictest confidentiality, anonymity cannot be guaranteed.
    - I understand that <u>only</u> researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that any recording/observation be stopped at any time, and that I may withdraw at any time from the research without disadvantage.

Participant's signature……………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………….……………………................

Researcher's signature………………………………..Date……………………

Flinders
UNIVERSITY

Participant ID: _ _ _ _ _

INFORMATION ABOUT YOU

1. What is your Gender?

☐ Male

☐ Female

☐ Prefer not to say

2. How old are you? ____________________________

3. **Who is your regular doctor?** ____
[if you don't have a regular doctor, go to the next question]

4. Do you have an advance care plan?

☐ Yes – if yes, specify _________________________________

☐ No

☐ I don't know what this is?

5. What is the language you usually speak at home?

THANK YOU FOR COMPLETING THIS SURVEY

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INFORMATION SHEET
Practice Staff Interview

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Description of the study

x Medical Centre has introduced group information sessions for advance care planning. To understand what people think about this approach, a research project is being conducted. This study is titled ‘Advance care planning in general practice’. This project will investigate the effect of group information sessions on the uptake of advance care planning by general practice patients. This project is supported by Flinders University, College of Medicine and Public Health

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What will I be asked to do?

You will be invited to take part in an interview. This interview will take about 30 minutes and will be audio recorded for transcription (typing up). You will be offered the opportunity to review the interview information before it is included in the study.

What benefit will I gain from being involved in this study?

You may not experience any personal benefit from participation in this research. The research findings will determine the efficacy of the x Medical Centre approach to advance care planning. This knowledge may be useful from a professional perspective to inform models of care in future and may be considered beneficial knowledge.

Participating in this research will add to the understanding about advance care planning including what works, and what doesn't and why not.

Will I be identifiable by being involved in this study?

The researcher will know your name however identifying information will be removed, and your comments will not be linked directly to you. It is likely you will be identifiable by people familiar with the x Medical Centre team. You will be provided with an opportunity to review the interview transcript and authorise its use, prior to it being included in the study. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The researcher does not anticipate any risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. If you are interested in participating please contact the researcher via email and you will be contacted to schedule a suitable time for interview.
Jo Risk risk0002@flinders.edu.au
A signed consent form will be sought at the commencement of the interview.

How will I receive feedback?

On project completion, outcomes of the project will be presented by the researcher to the x Medical Centre team and will be available on the x Medical Centre website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number No 8288). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Participant ID: _ _ _ _ _

Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
INTERVIEW

Advance Care Planning in general practice

Full Name: [PRINT] ____

What is your primary role at the practice?
- ☐ General practitioner
- ☐ Nurse
- ☐ Administration
- ☐ Other: _____________________________

I am over the age of 18 years and consent to participate in the research project on Advance Care Planning in general practice.

I consent to: (please circle):

Stage of Research - Interview	
I agree to participate in an interview	Yes / No
I consent to the audio recording and transcription of the interview I, the participant whose signature appears below, have read the transcript of my interview participation and agree to its use by the researcher as explained **Participant's signature……………………….Date……………**	Yes / No

1. I have read or had the information explained to me.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet for future reference.
4. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the interview at any time and am free to decline to answer particular questions.
    - While no identifying information will be published; and all information provided will be treated with the strictest confidentiality, anonymity cannot be guaranteed.
    - I understand that <u>only</u> researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties.

- Whether I participate or not, or withdraw after participating, will have no effect on my role or standing within the medical centre.
- I may ask that any recording be stopped at any time, and that I may withdraw at any time from the interview or the research without disadvantage.

5. I, the participant whose signature appears below, have read the transcript of my interview participation and agree to its use by the researcher as explained

Participant's signature……………………………………Date……………….

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name………………………………………………………................

Researcher's signature………………………………..Date……………………

8288 ETHICS approval notice (5 April 2019)

Human Research Ethics <human.researchethics@flinders.edu.au>
Fri 5/04/2019 9:35 AM
To: Jo Risk <risk0002@flinders.edu.au>; Paul Ward <paul.ward@flinders.edu.au>; Lucie Walters <lucie.walters@flinders.edu.au>

Dear Joanne,

Your conditional approval response for project 8288 was reviewed by the Acting Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.: **8288**

Project Title: Advance care planning in General Practice

Principal Researcher: Ms Joanne Risk

Email: risk0002@flinders.edu.au

Approval Date: 5 April 2019

Ethics Approval Expiry Date: **31 December 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (2007-Updated 2018)* an annual progress report must be submitted each year on the 5th April (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on 5th April, 2020 or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au
Ms Rae Tyler | Monday, Wednesday and Friday mornings	T: +61 8201-7938 | E: human.researchethics@flinders.edu.au
A/Prof David Hunter | SBREC Chairperson	T: +61 7221-8477 | E: david.hunter@flinders.edu.au
Dr Deb Agnew | SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

ACP in general practice

Date of session: ___________________________

Number attending: ________________________

Content	Method	Actioned
What is ACP?	Show video	
Why is ACP important?	Example and discussion	
What are the considerations? Themes: Legal aspects Values and Beliefs Medical History (relevance)	Discussion	
What are people's concerns? Theme: Barriers Fears Opportunities	Question and Answer	
How you get one? Theme: Practical advice	Advice	
What you do with it when you have one. Theme: Who do you share it with?	Discussion	
Who should people talk with about this? Theme: How do you start the discussion?	Discussion	
What are the important next steps for each of them to progress this?	Appreciative questioning	

Comment:

Signature: ____________________________________

Appendix 17

Actions reported by participants at end of intervention, by telephone interview

Number	Communicated wishes to next of kin / family	Put my wishes in writing in an ACD	Still thinking about what to do	Loss to follow up	Interviewed? Y/ N
159	1	1	0	0	N
124	1	1	0	0	Y
156	1	1	0	0	Y
176	1	1	1	0	Y
151	1	1	0	0	Y
149	1	1	0	0	N
150	1	1	0	0	N
120	1	0	1	0	N
125	1	0	1	0	N
162	1	0	1	0	N
128	1	0	0	0	Y
127	1	0	0	0	Y
157	1	0	1	0	N
170	0	0	1	0	Y
173	1	0	1	0	Y
167	0	1	0	0	N
169	1	0	1	0	N
168				1	N
163				1	N
Total	15 of 19	8 of 19	8 of 19	2 of 19	8 of 19