



THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

**An integrated approach to palliative care for frail older people living in the community:
exploring a model of multidisciplinary collaboration.**

Sue-Ann Sonya Carmont

BA (Hons); BA

*A thesis submitted for the degree of Doctor of Philosophy at
The University of Queensland in 2019
Faculty of Medicine*

Abstract

Background: Australia has an ageing population which face an increasing prevalence of chronic health conditions and comorbidities in later life. The population is placing increased pressure on the Australian healthcare system. Frailty is also likely to rise with an increase in the number of older Australians. Frailty is predictive of disability, hospitalisation and death. Palliative care is an approach that improves the quality of life of patients and their families when the patient is diagnosed with a life-limiting illness. Palliative care focuses on preventing and relieving symptoms associated with a patient's illness, such as pain, physical symptoms, psychosocial and spiritual support. As frailty is predictive of death, then it follows that frail patients should be identified and offered palliative care when appropriate. Palliative care is provided in a multitude of settings in Australia including: - hospital, hospice, aged care, and home. However, there is a finite number of specialist palliative care services available. Recently, researchers have been investigating the effectiveness of shared care models and models that integrate primary care (general practitioner) and secondary care (specialist services) to improve patient care and quality of life. However, these models have not been developed nor assessed for a frail older population. To investigate the use of this method for an increasingly aged population, this thesis refined and tested the feasibility and acceptability of a model of integrated palliative care for frail older people in the community.

Method: A two-phase sequential mixed methods design was used. As part of the literature review, a systematic review was conducted and a model of integrated palliative care, engaging GPs and specialist secondary services was identified. Phase 1 was a qualitative study, exploring health professionals' experiences and perceptions of caring for frail older people, of providing palliative care to patients. It also sought the health professionals' views of the model of integrated palliative care that was identified through the literature. The health care professionals were recruited using a mix of purposive and snowball sampling, and comprised of six focus groups involving 12 GPs, four geriatricians, seven palliative specialists, six nurses, and seven allied health professionals. Data were analysed thematically using a framework method. Based on these results, the model of integrated palliative care for frail older people was refined.

Phase 2 used a mixed-methods pilot study with a qualitative and a quantitative component, to assess the feasibility and acceptability of the model of integrated palliative care for frail older people living in the community. This used a pre-post design.

The primary aim of the quantitative component of phase 2 was to provide a preliminary estimate of the effect of the model of care on hospital admissions. To this end, patients and/or carers completed questionnaires at baseline and at one month and three months post-intervention.

The aim of the qualitative component of phase 2 was to explore the experience of participants of the model of care. Semi-structured interviews were conducted with two patients, five carers, two interviews with the patient and carer together, six GPs, three geriatricians, two nurses and four allied health professionals who participated in the model of care. A question guide was developed to ensure consistency. Data were analysed thematically using a framework method.

The data from both the quantitative and qualitative components were integrated to provide a comprehensive analysis of the data to assess the feasibility and acceptability of the model of integrated palliative care for frail older people.

Results: A systematic review identified that integrated multidisciplinary case conference had the most robust evidence and was the most pragmatic form of primary secondary integration. This was the basis of the model of end-of-life care that was examined during the study.

Phase 1 of the study identified four major themes that indicate the complexity of working with frail older people and the challenges of identifying and discussing issues related to palliative care: complex trajectory, constructing the appropriate frame, inclusivity and constraining boundaries. Each of these themes contributed to the refinement of the model identified by the systematic review.

Phase 2 of the study indicated that the patients involved in the pilot study experienced improved mental wellbeing. Carers also experienced improvement in physical and mental wellbeing. Moreover, there was a decrease in the patients' hospital admissions, average days in hospital and emergency department visits. With a small sample size and a pre-post design, these findings cannot be extrapolated or attributed to the model. The model of care was found to be acceptable. However, funding barriers and staff workload pressures reduced the feasibility of the model.

Conclusions: The model of integrated palliative care was acceptable and may provide benefit to frail older patients and their families and would likely reduce hospitalisations. However, workload and paucity of funding create barriers to implementation and reduce the feasibility of the model in the current system. Specific funding allocations to support the model would need to be implemented to ensure success.

Declaration by author

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

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

I acknowledge that an electronic copy of my thesis must be lodged with the University Library and, subject to the policy and procedures of The University of Queensland, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate School.

I acknowledge that copyright of all material contained in my thesis resides with the copyright holder(s) of that material. Where appropriate I have obtained copyright permission from the copyright holder to reproduce material in this thesis and have sought permission from co-authors for any jointly authored works included in the thesis.

Publications included in this thesis

Carmont, S., Mitchell, G., Senior, H., Foster, M. A systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care. *BMJ Supportive & Palliative Care*. 2018;8(4), 385-99. DOI: 10.1136/bmjspcare-2016-001125

Contributor	Statement of contribution
Carmont, S. (Candidate)	Concept and design (80%) Data extraction and analysis (80%) Preparation of draft manuscript (100%)
Mitchell, G.	Concept and design (10%) Data extraction and analysis (15%) Manuscript revision (50%)
Senior, H.	Concept and design (5%) Data analysis (5%) Manuscript revision (30%)
Foster, M.	Concept and design (5%) Manuscript revision (20%)

Submitted manuscripts included in this thesis

No manuscripts submitted for publication.

Other publications during candidature

Peer-reviewed papers

Carmont S, Mitchell G, Senior H, Foster M. A systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care. *BMJ Supportive & Palliative Care*. 2018;8(4):385-99.

Nickles J, Mitchell G, McKinlay L, Waugh MC, Epps A, Carmont SA, Schluter PJ, Lloyd O, Senior H. A series of n-of-1 trials of stimulants in brain injured children. *NeuroRehabilitation*. 2017;40(1):11-21.

Nikles J, Mitchell GK, Hardy J, Senior H, Carmont SA, Schluter PJ, Vora R, Currow D, Yelland M. Single-patient multiple crossover studies to determine the effectiveness of paracetamol in relieving pain suffered by patients with advanced cancer taking regular opioids: A pilot study. *Palliative Medicine*. 2016;30(8):800-2.

Nikles J, Mitchell GK, Hardy J, Agar M, Senior H, Carmont S, Schluter PJ, Good P, Vora R, Currow D. Testing pilocarpine drops for dry mouth in advanced cancer using n-of-1 trials: A feasibility study. *Palliative Medicine*. 2015;29(10):967-974.

Mitchell GK, Hardy JR, Nikles CJ, Carmont SAS, Senior HE, Schluter PJ, et al. The Effect of Methylphenidate on Fatigue in Advanced Cancer: An Aggregated N-of-1 Trial. *Journal of Pain and Symptom Management*. 2015;50(3):289-96.

Sanders M, Calam R, Durand M, Liversidge T, Carmont SA. Does self-directed and web-based support for parents enhance the effects of viewing a reality television series based on the Triple P - Positive Parenting Programme? *Journal of Child Psychology and Psychiatry*. 2014;55(12):e7-e.

Nikles CJ, McKinlay L, Mitchell GK, Carmont S, Senior HE, Waugh MC, Epps A, Schluter PJ, Lloyd O. Aggregated n-of-1 trials of central nervous system stimulants versus placebo for paediatric traumatic brain injury - a pilot study. *Trials*. 2014;13:15-54.

Calam R, Sanders MR, Miller C, Sadhnani V, Carmont S. Can technology and the media help reduce dysfunctional parenting and increase engagement with preventative parenting interventions? *Child Maltreatment*. 2014;13(3-4):3467-61

Hugh EJ, Mitchell GK, Nikles J, Carmont SA, Schluter PJ, Currow DC, Vora R, Yelland MJ, Agar M, Good PD, Hardy JR. Using aggregated single patient (N-of-1) trials to determine the effectiveness of psychostimulants to reduce fatigue in advanced cancer patients: a rationale and protocol. *BMC Palliative Care*. 2013;12.

Nikles J, Mitchell GK, Hardy J, Agar M, Senior H, Carmont SA, Schluter PJ, Good P, Vora R, Currow D. Do pilocarpine drops help dry mouth in palliative care patients: a protocol for an aggregated series of n-of-1 trials. *BMC palliative care*. 2013;12(1):17.

Senior HEJ, McKinlay L, Nikles J, Schluter PJ, Carmont SA, Waugh MC, Epps A, Lloyd O, Mitchell GK. Central nervous system stimulants for secondary attention deficit-hyperactivity disorder after paediatric traumatic brain injury: a rationale and protocol for single patient (n-of-1) multiple cross-over trials. *BMC Pediatrics*. 2013;13:89.

Book Chapters

No publications

Conference Abstracts

Carmont, S., Mitchell, G., Senior, H., Foster, M. (2016). The effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated end-of-life care – a systematic review. International Primary Health Care Reform Conference. March 2016. Brisbane.

Carmont, S., Foster, M., Mitchell, G., Senior, H. (2016). Health professional's perception and experiences of integrated care for frail older people at the end-of-life. International Primary Health Care Reform Conference. March 2016. Brisbane.

Contributions by others to the thesis

The PhD candidate was responsible for the conceptual development and design of the project; gaining ethical approval; participant recruitment; data collection; data analysis and thesis preparation.

The supervisory team, Prof. Geoffrey Mitchell, Prof. Michele Foster and Dr. Hugh Senior contributed to the development and design of the project. Prof Mitchell and Prof Foster contributed to the data analysis of the project. Each of the supervisory team contributed to the critical appraisal of the written work.

To the best of my knowledge, no person who has offered contributions consistent with the above has been excluded as an author. Persons who have contributed to the work but not at the level which constitutes authorship have been acknowledged in text as appropriate.

Statement of parts of the thesis submitted to qualify for the award of another degree

No works submitted towards another degree have been included in this thesis.

Research Involving Human or Animal Subjects

Phase 1 of the research was approved by the Darling Downs Hospital & Health Service Human Research Ethics Committee, reference number HREC/15/QTDD/9 and by the University of Queensland's Behavioural & Social Sciences Ethical Review Committee, approval number 2015000217.

Phase 2 of the research was approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee, reference number HREC/16/QRBW/33 and by the University of Queensland's Behavioural & Social Sciences Ethical Review Committee, approval number 2016000229 (see Appendix A). Research governance was obtained through the West Moreton Hospital and Health Service Research Governance Office, reference number SSA/16/QWMS/6.

Copies of ethics approval letters are included in Appendix A.

Acknowledgements

I would like to thank my supervisors, Professor Geoffrey Mitchell, Professor Michele Foster and Dr Hugh Senior. Each provided their support, expertise and knowledge. They are inspiring individuals and it has been a privilege to work with them.

I would have been unable to complete this research without the support of the staff of the Older Person Evaluation, Review, and Assessment unit at the Ipswich Hospital, the GPs and various health professionals from the greater Ipswich area who participated in the research. I would like to thank all the patients and their families who took the time to speak to me and to those who became involved in the research. I was privileged to learn from you.

I received support and encouragement from my work colleagues and student peers at the Discipline of General Practice which was invaluable on difficult days. It was a joy to share in each other's accomplishments. A special thanks to Lars Erikson for assistance in verifying the search strategy for the systematic review. Thanks to Rebecca from The Expert Editor for providing a professional editing service.

This research was supported by scholarships provided by both the National Health and Medical Research Council Centre for Research Excellence in Improving Quality and Safety in Integrated Primary Care and the Ipswich Hospital Foundation. Without this financial support, this research would not have been possible.

Finally, I would like to thank my family and friends who have supported and encouraged me in this endeavour. I am enormously grateful to my husband Gavin and my children Kiernan and Amelia. You are my always and forever. I am forever grateful to my parents Lorraine and John. They have always believed in my ability to accomplish anything. My brother Kent and the many aunts, uncles and cousins who have always encouraged me, even if they thought it was madness. My friends have remained even when I have been neglectful, encouraged me when I have struggled and laughed with me whenever possible.

Financial support

This research was supported by the National Health and Medical Research Council Centre for Research Excellence in Improving Quality and Safety in Integrated Primary Care.

This research was supported by the Ipswich Hospital Foundation.

Keywords

palliative care, frailty, integrated care, multidisciplinary case

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 111702 Aged Health Care, 60%

ANZSRC code: 111717 Primary Health Care, 40%

Fields of Research (FoR) Classification

FoR Code: 1117, Public Health and Health Sciences, 90%

FoR Code: 1199, Other Medical and Health Sciences, 10%

Table of Contents

List of Tables	xv
List of Figures	xvi
Abbreviations	xvii
Chapter 1 Introduction.....	18
1.1 Rationale for the study	20
1.2 Personal statement.....	20
1.3 Purpose of study	21
1.4 Overview of thesis structure.....	21
Chapter 2 Literature Review.....	23
2.1 An Ageing Population.....	23
2.2 Frailty	24
2.3 Palliative Care	25
2.4 The Australian Health Care System.....	28
2.5 Models of care	29
2.6 Summary	31
Chapter 3 A Systematic Review of the Effectiveness, Barriers and Facilitators to General practitioner Engagement with Specialist Secondary Services in Integrated Palliative Care	33
3.1 Introduction	35
3.2 Methods.....	36
3.2.1 Criteria for considering studies for this review.....	36
3.2.2 Search methods for identification of studies.....	37
3.2.3 Data collection and analysis.....	38
3.3 Results	39
3.3.1 Effectiveness of GP engagement with specialist secondary services in the integration of palliative care	55
3.3.2 Facilitators to engagement of GPs with specialist secondary services in integration of palliative care.....	58
3.3.3 Barriers to GP engagement with specialist secondary services in integration of palliative care.....	63
3.3.4 Process and principles that facilitate GP engagement with specialist secondary services in the integration of palliative care	66
3.4 Discussion	66
3.5 Conclusion.....	69

Chapter 4	Methods.....	70
4.1.1	Overall Aim.....	70
4.1.2	Study design.....	70
4.2	Phase 1: Health professionals' perceptions and experiences of integrated primary and secondary care for frail older people at the end-of-life.....	73
4.2.1	Study Aim of Phase 1.....	73
4.2.2	Study method of Phase 1.....	74
4.2.3	Data Analysis.....	77
4.2.4	Refining the model of care.....	78
4.3	Phase 2: A model of integrated care – a pilot study.....	78
4.4	Phase 2, Part 1: Quantitative component.....	79
4.4.1	Hypothesis.....	79
4.4.2	Study Participants.....	80
4.4.3	Outcome Measures of Phase 2.....	82
4.4.4	Study Measures.....	83
4.4.5	Data Collection and Management.....	85
4.4.6	Adverse Event Management.....	86
4.4.7	Data Analysis.....	87
4.5	Phase 2, Part 2: Qualitative component.....	88
4.5.1	Study Aim.....	88
4.5.2	Study method.....	88
4.5.3	Sampling and Recruitment.....	88
4.5.4	Data collection.....	89
4.5.5	Data Analysis.....	90
4.6	Summary.....	91
Chapter 5	Phase 1. Health professionals' experiences and perceptions.....	92
5.1	Introduction.....	92
5.2	Findings.....	93
5.2.1	Complex trajectory of frail older people.....	94
5.2.2	Constructing the appropriate frame.....	97
5.2.3	Inclusivity of the case conference process.....	99
5.2.4	Constraining Boundaries.....	102
5.3	Discussion.....	107
Chapter 6	Phase 2 Results, Part 1. Insights into the effect of integrated specialist-GP care.....	111
6.1	Recruitment of participants.....	112

6.1.1	Recruitment of patients and carers.....	112
6.1.2	Recruitment of Health Professionals.....	114
6.2	Participants	114
6.2.1	Patients and Carers.....	114
6.2.2	Health Professionals.....	115
6.3	Case conference process.....	116
6.3.1	Outcomes	118
6.4	Patient Outcomes.....	121
6.4.1	Patient Physical Health	122
6.4.2	Patient Mental Health.....	124
6.5	Primary Informal Carer Outcomes	126
6.6	Health System Outcomes	131
6.6.1	Health service utilisation.....	131
6.6.2	Salary cost.....	136
6.7	Individual Patient Examples.....	138
6.7.1	Example 1: Case A.....	139
6.7.2	Example 2: Case B.....	143
6.7.3	Example 3: Case C.....	146
6.7.4	Summary of individual patient examples.....	148
6.8	Sample Size	149
6.9	Discussion	150
Chapter 7	Phase 2 Results, Part 2. Experience of participation in a case conference as a model of integrated palliative care for frail older people in the community.....	153
7.1	Implementation.....	154
7.1.1	Preparation	155
7.1.2	Use of case conference structured proforma.....	158
7.1.3	Care plans created and followed	160
7.1.4	Participants.....	162
7.2	Practicality.....	164
7.2.1	Information Technology	165
7.3	Timing of case conferences	166
7.4	Demand	168
7.4.1	Funding	168
7.4.2	Choice of participants	169
7.5	Acceptability	171

7.5.1	Health Professionals.....	171
7.5.2	Patients and carers.....	174
7.6	Discussion	176
Chapter 8	Discussion and Conclusion	179
8.1	Summary of key findings	179
8.1.1	Impact of a Model of Integrated Care.....	181
8.1.2	Barriers to the Implementation of the Model of Care.....	183
8.2	Implications	186
8.3	Study Strengths and Limitations	187
8.4	Future Research.....	189
8.5	Conclusion.....	190
References	192
Appendices	209
Appendix A	Ethics approvals.....	209
Appendix B	Search strategy for systematic review	220
Appendix C	Information Sheets and Consent Forms.....	221
Appendix D	Mater focus group question guide for phase 1 study.....	241
Appendix E	Semi-structured case review proforma	247
Appendix F	Interview guides for phase 2 pilot study.....	251
Appendix G	Patient example ‘Jane’	258

List of Tables

Table 3.1: Details of studies of GP engagement with specialist secondary services in integration of palliative care	40
Table 3.2: Effectiveness of GP engagement with specialist secondary services in integration of palliative care	49
Table 3.3: Facilitators of GP engagement with specialist secondary services in integration of palliative care	54
Table 3.4: Barriers to GP engagement with specialist secondary services in integration of palliative care	57
Table 3.5: Process and principles to facilitate GP engagement with specialist secondary services in integration of palliative care	62
Table 4.1: Demographic characteristics of health professionals	73
Table 4.2: Demographic characteristics of participants (Interviews n=25)	86
Table 5.1: Participants in focus groups	90
Table 5.2: Themes from analysis of focus groups	91
Table 6.1: Demographics of patients (n=9) and carers (n=7)	112
Table 6.2: Demographics of health professionals that participated in the intervention	113
Table 6.3: Use of structure proforma by section	116
Table 6.4: Care plan action items created and completed (n=9 patients).....	117
Table 6.5: Results of Wilcoxon signed-rank tests for patient outcome measures at one month from baseline	118
Table 6.6: Results of Wilcoxon signed-rank tests for patient outcome measures at three months from baseline	119
Table 6.7: Results of Wilcoxon signed-rank tests for carer outcome measures at one month from baseline	124
Table 6.8: Results of Wilcoxon signed-rank tests for carer outcome measures at three months from baseline	124
Table 6.9: Results of Wilcoxon signed-rank tests for emergency department visits and hospital admissions for the year prior and post case conference	129
Table 6.10: Salary cost of case conference	134
Table 7.1 Topics for analysis of semi-structured interviews	151

List of Figures

Figure 3.1: PRISMA Flow Diagram. Study identification and selection process for a systematic review of general practitioner engagement with specialist secondary services	39
Figure 4.1: Key elements of the development and evaluation process	69
Figure 4.2: Study diagram	70
Figure 6.1: Flowchart for patient recruitment and enrolment	110
Figure 6.2: Functional status of patients as measured by the AKPS.....	120
Figure 6.3: Patient physical health as measured by the SF12	120
Figure 6.4: Patient mental health as measured by the SF12.....	121
Figure 6.5: Patient depression measured by HADS.....	122
Figure 6.6: Patient anxiety measure by HADS	123
Figure 6.7: Caregiver strain index across time	125
Figure 6.8: Caregiver physical health as measured by the SF12 over time	125
Figure 6.9: Caregiver mental health as measure by the SF12 over time	126
Figure 6.10: Caregiver depression as measured by HADS over time	127
Figure 6.11: Caregiver anxiety as measure by HADS over time	128
Figure 6.12: Number of ED visits for 12 months pre-case conference and 12 months post-case conference	129
Figure 6.13: Number of hospital admissions for 12 months pre-case conference and 12 months post-case conference	130
Figure 6.14: Number of ED visits that led to hospital admissions for 12 months pre-case conference and 12 months post-case conference	130
Figure 6.15: Total days in hospital for 12 months pre-case conference and 12 months post-case conference	131
Figure 6.16: Average days in hospital per admission 12 months pre and 12 months post-case conference	132

Abbreviations

AKPS	Australian-modified Karnofsky Performance Scale
AQEL	Assessment of Quality of life at End-of-Life
CASP	Critical Appraisal Skills Programme
CBAs	Controlled Before and After studies
CI	Confidence Interval
DNs	District Nurses
ED	Emergency Department
GP	General Practitioner
GSF	Gold Standard Framework
HADS	Hospital Anxiety Depression Scale
HREC	Human Research Ethics Committee
IQR	Inter-quartile range
ITSs	Interrupted Time Series studies
JBI NOTARI	Joanna Briggs Institutes Narrative, Opinion and Text Assessment and Review Instrument
MCS	Mental Component Score
MRC	Medical Research Council
MeSH	Medical Subject Headings
OPERA	Older Person Evaluation Review and Assessment
PCS	Physical Component Score
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
NZ	New Zealand
QOL	Quality of Life
RCTs	Randomised Controlled Trials
SPICT	Supportive & Palliative Care Indicators Tool
WHO	World Health Organization
WMHHS	West Moreton Hospital and Health Service

Chapter 1 Introduction

In Australia, an increasing proportion, 9 to 15% over the last 40 years, of the population is aged 65 years and over.(1) The number of those in the 85 years and older age group has more than doubled in the last 20 years.(2) Although Australians are staying healthier for longer,(3) those in the older age groups have an increased prevalence of chronic conditions and comorbidities.(3) The hospital expenditure for those aged 65 years and over is higher than any other age group and is increasing.(3)

The incidence of frailty is also likely to increase in Australia due to the ageing population. The incidence of frailty varies depending on the definition used, however, it is up to 25% of those over 65 and living in the community.(4, 5) Frail older adults experience functional decline and are vulnerable to adverse health outcomes, such as disability, hospitalisation and death.(4) However, the health system in Australia does not routinely identify frailty. Overseas research has shown that frailty, identified using frailty screening tools, increases healthcare costs significantly compared to non-frail patients, pre-frail patients, and patients with chronic conditions.(6-9)

The total expenditure on health in Australia has increased 4.8% each year for the last 10 years.(10) Hospitals and primary health care account for 74% of the total health expenditure in Australia.(10) As health expenditure is funded by tax revenue this is an increasing economic cost to those of working age, as population growth is not keeping pace with the rising ageing population. An ageing population, particularly a frail population, presents an increasing burden to health resources. The health system is under pressure to provide efficient and timely care with limited financial resources which are stretched further in each funding cycle.

There is a home care package program in Australia which provides home care services to an older person that enables them to stay at home, rather than entering a residential aged care facility. At the end of 2017 there were over 100,000 people waiting to be assessed for this program, and just over 30,000 were approved in the final quarter of 2017.(11) After a person develops a condition which causes reduced physical capacity, they are placed on a waiting list to be assessed for a package. Access after approval can take between 6-9 months for a medium level package and over 12 months for a high level package.(11) During this time it is possible that the person's health may deteriorate further. This increases the risk of an adverse event such as a fall and subsequent admission to a residential aged care facility – the very event the home support package is supposed to prevent.

Proactive planning may minimise the risk or prevent adverse events. Palliative care really needs to be considered as part of planning for and managing adverse health events.(12)

Palliative care is an approach that provides care for a person with a life-limiting illness and who is expected to die. Palliative care identifies, prevents and relieves symptoms associated with a life-limiting illness, such as pain, physical symptoms (e.g. shortness of breath, vomiting), and provides support to address emotional, social or spiritual concerns. Palliative care is provided across a range of settings: hospital, hospice, aged care, and home. However, in Australia, there is a finite number of specialist palliative care services available and most palliative care is provided to patients dying of cancer.(13) Palliative care services have been found to reduce emergency department visits, hospital admission, length of stay in hospital and reduce the number of tests and treatments administered that are no longer of benefit to the patient.(14-17)

The term palliative care encompasses three types of care: specialist palliative care, palliative medicine and a palliative approach. Specialist palliative care is provided in a specialist setting and comprises multidisciplinary teams with specialised skills, competencies, experience and training in palliative care.(18) Palliative medicine is medical care provided by a specialist palliative medicine physician who has specialised in palliative medicine.(19) A palliative approach aims to improve the quality of life by reducing suffering through identification, assessment and treatment of pain and any physical, cultural, social or/and spiritual needs and can be provided by a number of care providers.(20)

The delivery of palliative care is inconsistent across disease types, with the majority of patients that receive palliative care being cancer patients.(21) However, the World Health Organization(22) and the Prague Charter(23) both state that palliative care access should be universal, available to all patients with a life-limiting illness. To provide universal access there is agreement that palliative care should be community-based.(24) A move to community-based care would result in the majority of palliative care delivered by non-specialists, likely GPs. Research has shown that by involving GPs in advance care planning for patients with complex conditions, access to palliative care can be improved.(21)

The availability of palliative care for all people with varying conditions and in all settings is important.(25) Palliative care cannot remain confined to specialist providers if the expectation is for access to be universal. Palliative care specialists can provide care for patients with complicated

and unstable conditions. However, not all patients that require palliative care require the ongoing involvement of a palliative specialist. Primary care has a critical role to play at the end-of-life and GPs, with established relationships with their patients, are optimally placed to coordinate the care and services required. This may be particularly relevant to frail older people with functional decline over a long period of time.

1.1 Rationale for the study

Researchers have identified that worsening frailty is indicative of a need for palliative care provision, particularly in symptom management.(26) However, current palliative care systems are unlikely to identify those patients dying with frailty.(27) Identifying frail older people and providing palliative care when appropriate may prevent, minimise or relieve symptoms associated with frailty, reduce hospitalisations and reduce the costs of frailty to the health system. Research into frailty and its impact on the health system is in the early stages and has yet to investigate a model to provide palliative care for those frail patients approaching end-of-life.

The effectiveness of palliative care for a number of underlying diseases, including cancer, HIV/AIDS, heart disease, renal failure and other non-malignant disease groups has been confirmed.(28-30) Models of care included home palliative care (community services to support the patient to stay in the home), residential aged care, hospice care, and specialist palliative care, delivered as consultancy services within the hospital and in the home, and in specialist inpatient units. Some models of care are delivered across multiple settings, such as, hospice care and home palliative care. Specialist palliative care provision is oversubscribed with insufficient capacity to meet current demand, creating an access problem that is likely to rapidly worsen.(31) Shared care and models that integrate primary care (general practitioner (GP)) and secondary care (specialist services) to improve patient care and quality of life have been suggested as a way to increase capacity, best utilising the different skill sets of different providers and in different disease settings. However, these models have not been developed and assessed for a frail older population. This thesis aims to develop and test the feasibility of a model of integrated palliative care between age care specialists and GPs for frail older people in the community.

1.2 Personal statement

The researcher has had a strong interest in palliative care and primary care research for over ten years. The focus of the research has been on the integration of palliative care across the health

settings in Australia, with GPs being an integral part of the provision of palliative care. Although palliative care is not yet universally accessible to everyone with a life-limiting disease, there seems to be one area that was overlooked in the palliative care research, that of frailty.

1.3 Purpose of study

The purpose of the study is to develop, and pilot test a model of integrated palliative care that engages GPs with specialist secondary services in the provision of palliative care for frail older people living in the community. This may reduce health service utilisation and improve outcomes for patients.

1.4 Overview of thesis structure

The thesis comprises eight chapters: -

- Chapter 1 provides context for the thesis and presents the aims and the thesis structure.
- Chapter 2 provides a comprehensive background on frailty and palliative care and a comprehensive review of the literature on the provision of palliative care.
- Chapter 3 presents the results from a systematic review the aim of which was to identify the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in the provision of integrated palliative care.
- In Chapter 4, the method is described for a two-phase sequential design, which builds on the findings in the literature. The first phase is a qualitative study aiming to refine and implement a model of care identified in the systematic review. The second phase evaluates the feasibility and acceptability of the model, using both a quantitative and a qualitative component.
- Chapter 5 presents the findings from the first phase of the research. This phase explored health professionals' experiences of working with frail older people and with patients with palliative and supportive needs. These experiences informed the design and implementation of an integrated model of palliative care for frail older people at the end-of-life in their local context.
- Chapters 6 and 7 present the results of phase 2 of the study, a pilot study of a multidisciplinary case conference as a model of integrated palliative care for frail older people. Chapter 6 presents an estimate of the effect of the multidisciplinary case conferences on health service utilisation and patient and carer outcomes, including health-related quality of life, stress and anxiety. Chapter 7 reports the findings of a qualitative exploration of the

feasibility and acceptability of the integrated care model through the experiences of participants.

- Chapter 8 discusses the key learnings in the context of the relevant literature, the implications of policy and practice, the limitations of the research design and the directions for future research.

Chapter 2 Literature Review

2.1 An Ageing Population

The United Nations has identified that population ageing is taking place in nearly all countries, due to a declining birth rate overall and an increase in life expectancy.(32) In more developed regions, as defined by the United Nations, Europe, Northern America, Japan, Australia and New Zealand, the birth rate has been stable since the early 1990s at 1.7 children per woman and life expectancy is expected to continue to rise. In less developed nations, the birth rate is currently 2.7 children per woman and is expected to drop to 2.3 by 2050, while life expectancy continues to rise.

In the last 60 years the percentage of the world's population over 60 has increased from 8 to 12% and it is expected to increase to 20% by 2050.(32) In the more developed regions, this population is even greater with 24.6% of people over 60 which is expected to increase to 32.9% by 2050.(32) With an increasing percentage of the population in retirement, the public costs of increased ageing will shift onto a smaller percentage of tax-paying citizens. This will occur in the less developed regions as well with 10.4% of the population over 60 in 2017, with the expectation that this will rise to 19.5% by 2050.(32) Governments around the world are looking at this issue and working towards preparing for the impacts of an ageing population on health care, social services, housing, transport, financial support and attitudes to and expectations of ageing.(33-37)

In Australia, over the last 20 years we have seen the proportion of children aged 14 and under decrease from 21.7% to 18.9% of the population, our 15-64 year age group has remained stable at 66.7% of the population, our over 65s age group increased from 11.6% to 14.4% and our over 85s age group doubled to 1.9% of the population.(38) Although our working-aged population (15-64) and non-working aged population has remained stable over the last 20 years, this is not expected to continue. It is expected that the birth rate will remain stable but the proportion of the older age groups will increase as life expectancy continues to improve. By 2050, 22.6% of our population will be over 65 and 5.1% of our population will be over 85.(39) The percentage of our population at working age will drop to 60.2%. It is estimated that by 2050, there will be just two tax payers per pensioner to contribute to government revenues, down from seven today.(39)

Currently in Australia just under one-quarter of government spending is on health, age-related pensions and aged care, however this is estimated to increase to close to half of all government

spending by 2050.(39) The government has introduced compulsory superannuation as a way to encourage self-funded retirements. Policy changes have been introduced to encourage later retirement and partial retirement, all aimed at reducing spending on pensions. Health spending is expected to increase as we can expect to live an average of 72.6 healthy years and approximately 7.9 years in less than full health due to disease and/or injury.(40) In comparison to other countries, we are in the top 10 for healthy life expectancy but even so, we expect health spending on those over 65 to increase by a factor of seven and by a factor of twelve for those over 85.(39) Those aged over 65 account for 20% of emergency department presentations, 42% of same-day hospital admissions, 41% of overnight hospital admissions and 30% of GP or family physician visits.(37)

In addition to an ageing population, we are seeing an increase in the prevalence of many chronic conditions.(41) Coronary heart disease, cancer, diabetes, hearing loss, chronic obstructive pulmonary disease, dementia and arthritis are the leading causes of illness in Australia in the over 65 population. These conditions include some of the leading causes of mortality.(37) Currently, in those aged 65-85, 55% of the age group has multiple long-term co-morbidities, increasing to 65% in those over 85.(42) With an ageing population this has increasing implications for our health system. We will need the most effective model of care possible to improve health outcomes, as well as to minimise the rate at which costs in the health system rise.

2.2 Frailty

Frailty can be considered as a syndrome of functional decline and vulnerability to adverse outcomes. However, there is no agreed definition of frailty(43-47) with the definition used being dependent on the screening tools used and the biases inherent in choosing those tools.

There are two main approaches to frailty, - the phenotype approach pioneered by Fried and colleagues(4, 48) and the index approach used by Rockwood and colleagues.(49-53) The phenotype approach(4) considers frailty as an accumulation of physiologic deficits which results in decreased resistance to stressors. The phenotype approach of measuring frailty distinguishes frailty from disability and cognitive decline. Frailty is indicated by weight loss, low energy, physical weakness, a decline in the ability to walk, and low activity. Fried and colleagues(4) proposed that these factors are interrelated in a cyclical nature, with a decline in one body system related to declines in another. Fried and colleagues(4) found that the presence of at least three of the following criteria indicates frailty; weight loss, weak grip strength, slow walking, self-reported exhaustion and physical inactivity. They also found that those individuals with one or two of the indicators had

increased risk of becoming frail over a three-year period, compared to those individuals who did not have any indicators.

The index approach uses a cumulative count of health deficits which can include physical deficits, cognitive deficits, disabilities and diseases. This means that unlike the phenotype approach, the index approach sees functional decline, disability, comorbidity and cognitive decline as indicative of frailty.(54-56) A predefined list of deficits are measured, and the Frailty Index is calculated by dividing the number of deficits identified by the number of deficits measured. The index can be built from any sufficiently large set of age-related deficits, when differing health deficits are considered, accumulation of deficits results in similar frailty scores.(57)

Researchers have found that the Frailty Phenotype and the Frailty Index measures are comparable,(58, 59) with the phenotype approach resulting in a lower incidence of frailty than the Index approach.(58) However each approach is distinct, with the phenotype indicating the absence of physical or physiological conditions and the index approach measures an accumulation of deficits. Cesari and colleagues(60) argue that the measures are complementary, with the phenotype measure of frailty useful at first contact with a patient as an initial risk assessment. The Frailty Index measure is routinely completed as part of a comprehensive geriatric assessment of a patient, or shortly after the assessment and it provides information for continuous follow-up of a patient. The choice of measure should, therefore, be based on the reason for measuring frailty.

Depending on the scales used, the incidence of frailty in the community ranges from 7% to 26%.(4, 5, 61, 62) Frailty has been found to be predictive of falls,(4, 63) disability,(4, 61, 63) hospitalisation(4, 61, 63, 64) and death,(4, 53, 63, 65) thereby increasing the demand on health services and carers alike. Canada is the only country where frailty is recorded as a cause of death. (66) Of the 18,000 that died in hospital in one year, 30.2% died of frailty.(66) As frailty is predictive of increased hospitalisation and mortality and there is a large number of people in the community that are identified as frail, an opportunity is probably being missed to provide palliative care to those people, unless it is routinely identified and acted upon.

2.3 Palliative Care

With increasing multiple long-term comorbidities as our population ages our health service will increasingly need to provide care for those patients who cannot be cured but require treatment for

symptoms caused by the disease or diseases. Palliative care is the term often used for care at the end-of-life.

The World Health Organization (WHO) defines palliative care “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”(22)

This definition of palliative care is comprehensive, noting early identification, affirmation of life, relief from pain, quality of life and that it can occur in conjunction with other therapies intended to prolong life. This definition was updated after the conclusion of this study to include the following:

- “should be applied by health care workers at all levels of health care systems, including primary care providers, generalists and specialists in many disciplines and with various levels of palliative care training and skill, from basic to intermediate to specialist;
- encourages active involvement by communities and community members;
- should be accessible at all levels of health care systems and in patients’ homes; and
- improves continuity of care and thus strengthens health systems.”(67)

The National Health Service in the UK has a similar, if simpler definition that focuses on relieving pain and distressing symptoms, providing support, early identification and providing care in conjunction with other therapies to prolong life.(68) The Australian Government's Department of Health definition is similar again, but does not mention early identification or the use of palliative care in conjunction with additional therapies to prolong life.(69) The Queensland Government's definition is more limited again, defining palliative care as care for the terminally ill and only focuses on supporting and improving quality of life by relieving the symptoms of the illness.(70) Once again there is no mention of early identification or provision of other therapies to prolong life. This indicates that Australia's health service focusses on care later in the disease progression and after all other treatment options are exhausted. This downplays the role of palliative care in conjunction with life-prolonging treatments, in other dimensions of the patient's life, psycho-social, spiritual and practical help, and it does not acknowledge that palliative care encompasses the patient's family and friends. For the purposes of this thesis the WHO definition of palliative care will be used as it is the most detailed and encompassing of the definitions.

The roots of Palliative care can be traced back to some of the first hospices for the dying, set up in both France and Ireland in the early 1840s.(71) These were set up by religious organisations and cared not just for the body but also the soul. They were called hospices after the medieval hospices that provided food and lodging to travellers passing through a region, providing a place for the soul to lodge on their way to God.(71) However, it should be noted that religious groups provided care for the poor, abandoned and dying previous to this, notably the Daughters of Charity which was founded in 1633.(71, 72) Dame Cicely Saunders invented the modern hospice movement, opening the world's first modern hospice in London in 1967.(73) She initiated regular pain treatment instead of relief when the pain was too severe and insisted on treatments with scientific rigour. She believed that the dying deserved dignity, respect and compassion.

The term palliative care arrived in medical and research journals in the mid-1970s. In 1977 Dr Shephard reported on an international seminar, with 300 attendees interested in the practical aspects of care and management of dying patients, where they constructed a list of symptoms to control. They also generated the theoretical and research basis for the study of palliative care.(74) Early papers included the proposed creation of palliative care units(75, 76) and descriptions of their working units and multidisciplinary teams.(77-79) The majority of early palliative care publications originated from Canada and this continued to be the case until the early 1980s.

Palliative care research started to focus on late stage cancer in the late 1970s and a basic search of online databases shows that about half of all research in palliative care has a focus on cancer. Perhaps this is because in Australia half of men and one-third of women will be diagnosed with cancer before the age of 85.(80) Cancer is a feared diagnosis because of how it progresses and the distressing symptoms that arise from it. (81) Although many will have a good prognosis, cancer accounted for 30% of all deaths in Australia in 2010, second only to cardiovascular diseases.(80) Australia has a slightly lower rate (per 100,000) of cancer mortality than North America, Europe and New Zealand.(82)

Australia in 2009-2010, 59% of all palliative care hospitalisations were cancer-related.(83) It has been proposed that the reason that the majority of palliative care services are provided to cancer patients is the recognised time-limited and consistent disease pathway and decline for cancer patients.(83) This means that much of our evidence for palliative care is built around palliative care for cancer. However, there is research in palliative care in non-malignant (non-cancer) disease groups, such as, HIV starting in the early 1990s,(28, 84) heart disease in the mid-1990s,(29, 85, 86) degenerative neurological disease,(87-89) and renal failure.(30, 90)

The benefits of quality palliative care have been well established. Palliative care reduces symptoms of advanced disease (for example, pain, fatigue and dyspnoea), supports decision making about appropriate care and improves patient and family quality of life. Moreover, studies show it is more cost-effective to provide palliative care than to treat a patient in an acute hospital setting.(14, 77) The introduction of early palliative care has been shown to improve prognosis, quality of life and symptom management in advanced lung cancer.(91)

Ideally, based on the WHO definition of palliative care, it should be routinely available to anyone with a life-limiting prognosis at the earliest possible stage. However, in a health system that is under budgetary pressure from an ageing population and increasing co-morbidities, which model of care will provide the increased access, provide the best patient outcomes and in the most cost-effective manner?

2.4 The Australian Health Care System

Australia has a universal health system which provides citizens and permanent residents with free public hospitals, subsidises primary care services delivered by a GP, medical specialists, allied health services and nursing services. The state governments are responsible for the delivery of

public hospital services, preventive health programs such as immunisation, and emergency services such as ambulance transportation. The federal government is responsible for primary health care, pathology, radiology and specialist consultations. However, a co-payment, or contribution is often required from the patient for specialist consultations, primary health care and some radiology services. There is also a private system of health care in Australia, whereby private insurance contributes to the cost of care in a private hospital. These costs are also subsidised by the federal government. This approach to funding health care has resulted in a fragmented system with poor collaboration between the different health care providers.(92) Research has also suggested that the division of funding across different levels of government leads to duplication and waste and enforces division between the different providers of healthcare.(92)

The number of deaths in Australia will rise rapidly over the next 50 years with more people dying with multiple long-term comorbidities.(3) An increasing proportion of health funding will be required to provide palliative care that meets the needs and expectations of patients and their families. The present national cost of hospital services in the last year of life has been estimated to be \$2.4 billion.(3) This cost is expected to rise rapidly and will add huge pressures to the health budget. This is similar across all developed countries.(93) There will be increasing pressure on all areas of the health system, emphasising the fragmented nature of health services. This fragmented nature of service provision for end-of-life care has been acknowledged as a barrier to providing quality end-of-life care.(94)

2.5 Models of care

Davidson and colleagues define a model of care as an overarching design for a health care service, the provision of which is shaped by theory and consists of defined core elements.(95) The World Health Organization has documented the key elements to provide palliative care.(67) Models of palliative care have been developed using these key elements. They are complex and often ill-defined in the literature. They vary depending on the number of groups involved in the provision of care, the number and degree of difficulty in the behaviours required by the model, the degree of flexibility allowed by the model and the number and variability of the outcomes.(96) Furthermore, models reflect differences in cultures, religious beliefs, health frameworks and the available resources.(97) Models of palliative care are generally viewed according to: 1) who provides the treatment; and 2) where the treatment is provided. This is a simplistic breakdown of complex field.

Brown and colleagues(98) have conducted a review of the literature and have identified four different models of palliative care based on who provides the palliative care. Low engagement models have no physician input in the provision of palliative care. Generalist models have physicians that provide palliative care, but the primary focus of their practice is not palliative medicine. These physicians may be GPs, oncologists, surgeons, cardiologists or psychiatrists. The generalist/specialist palliative model involves consultative palliative care. Both the generalist and specialist palliative care physician provide parts of the care, and the latter often leads the caring team. The final model is the specialist palliative care model where care is provided only by the specialist physician and the specialist palliative care team.

The setting in which palliative care is provided is often used to identify models of palliative care.(96, 99, 100) Four models are described in the literature. Home-based palliative care(15, 101, 102) is where palliative care is delivered in the patient's or the carer's home. It is often delivered by community-based providers, some with input from GPs when required. Secondly, specialised palliative care(96, 99) is provided as an inpatient in a palliative care unit or in a hospice, staffed by nurses and physicians with specialist palliative training. The third type of care occurs in outpatient clinics.(103-105) A patient attends a clinic and has access to specialist consultations and a multidisciplinary team which can co-manage the patient's needs. The final model of care identified by setting is the multidisciplinary team approach(96) which differs from the outpatient model in that it originates from a hospital-based team, and comprises a dedicated multidisciplinary team that works in the community, visiting the patient at home, in residential care or hospice care. All the models, except for the home-based model have the input of a specialist palliative care provider.

Home-based and multidisciplinary team models of palliative care delivery could also be considered to be shared care models. Shared care models are varied, with different structures and composition, as well as different providers and settings, but the providers share a common goal of using their skills and knowledge to plan and provide palliative care.(106) Whatever model of palliative care is used, they all provide some benefit to the patient and their caregiver with no evidence of negative effects.(96) Benefits range from improved functional status,(107) pain management and symptom control(101) to reduced total healthcare costs(96), which is mainly achieved through reduced hospital admissions.(16, 96, 108)

However, in Australia, there is a finite number of specialist palliative care services available. Most specialist palliative care services are provided through either the hospital system or through hospice

services. Most specialist palliative care in Australia is provided to patients dying of cancer.(13) Specialist palliative care services are oversubscribed. As a result of the expected increase in need due to the ageing population and multiple co-morbidities, researchers have been looking at shared care models(106) and integrating the care provided at the tertiary and primary levels.(107, 109) It has been argued that many elements of palliative care, such as pain and symptom management, advance care planning and goals of care, can be provided by generalist palliative care providers with some training(67, 110) which would increase the number of patients with access to palliative care. According to WHO, the integration of primary care into the provision of palliative care will improve palliative care.(67) WHO has identified that many of the principles of palliative care overlap with the principles of primary care, including equity, universality, people-centredness, participation, self-determination and care based on scientifically sound and socially acceptable methods. In many areas of the world, health care is fragmented and cannot cope with the demands of an ageing population and the growing burden of chronic illness. This is true of the Australian system which is fragmented, with hospitals funded and controlled by the state governments and the primary care sector funded by the federal government. This creates a disconnected system, with little integration of care. Research has shown that having the GP as part of the multi-disciplinary palliative care team, improves patient care and quality of life.(107, 109)

Any model of palliative care should also be based on the WHO definition of palliative care, provide care early, and by all levels of the health care system.(67) Early identification of patients that require palliative care allows the patient, family and doctors to anticipate future likely symptoms and prepare care plans for the future that are consistent with the patient's goals, values, beliefs and preferences. Early palliative care provides relief from pain and distressing and improves the quality of life of patients and their carers.(67, 111, 112)

2.6 Summary

With an ageing population, Australia is facing increased pressure on its health system from a population with increasing co-morbidities late-in-life. Frailty is a common syndrome in the community and is leading to increases in hospitalisations. As it is not identified as a cause of hospitalisation or death in Australia we can only look at its prevalence overseas, which represents 30% of all deaths in hospital.(66) To increase early care, frail older people should be identified within the community or at admission to hospital and provided with palliative care. This would reduce their physical discomfort, support their decisions about care, and improve their quality of life and that of their family. To prevent overwhelming hospital-based specialist palliative care teams it

is necessary to implement a model that integrates the primary care and the specialist secondary care teams. Chapter 3 presents a systematic review of the effectiveness, barriers, and facilitators to engaging the GP with specialist secondary services in the provision of palliative care.

Chapter 3 A Systematic Review of the Effectiveness, Barriers and Facilitators to General practitioner Engagement with Specialist Secondary Services in Integrated Palliative Care

This chapter presents a systematic review which aims to identify the effectiveness, barriers and facilitators to GP engagement with specialist secondary services in the provision of integrated palliative care. The GP has a critical role in an integrated model of palliative care as they often know the patient and carer well, are experts in generalist care and have knowledge of health and social services in the community. Specialist palliative services have insufficient capacity to meet demand,(31),in particular, patients with non-cancer terminal conditions or those from rural and remote areas. Research has focussed on improving access to palliative care by engaging the GP with specialist secondary services in integrated palliative care.

This review focuses on those models of care where a GP is actively engaged with a specialist service in the provision of palliative care. Seventeen studies were included and there is some evidence that integrated palliative care can reduce hospitalisations and maintain functional status. However, there are substantial barriers to providing integrated care. Principles and facilitators of the provision of integrated palliative care are discussed.

The publication presented in this chapter was accepted and first published online in February 2017 by BMJ Supportive and Palliative Care. Sections, tables, figures, and graphs have been renumbered to align with the thesis document.

Citation:

Carmont, S., Mitchell, G., Senior, H., Foster, M. A systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care. *BMJ Supportive & Palliative Care*. 2018;8(4), 385-99. DOI: 10.1136/bmjspcare-2016-001125

The candidate was the main contributor to the publication. The candidate made a large contribution to the concept and design of the systematic review, with critical review provided by the other authors. The candidate extracted the data and completed the data analysis, with Professor Mitchell also reviewing papers for inclusion, and Dr Senior providing arbitration when required. The candidate completed the drafting of the publication, with input and critical review provided by the other authors.

3.1 Introduction

Palliative care is delivered in a large range of settings including hospitals, hospices, nursing homes, and at home. Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.(22) Generalist palliative care occurs when the patient's general practitioner (GP) applies their knowledge and skills to care for the patient, with referral when necessary to services that may assist. Specialist palliative care, generally from a hospital based service, provides care to the patient and family and/or coordination and information to other health care providers (in hospital, oncologists, other specialist, aged care, hospice, nursing home) to assist them to support to the patient and family.(107) Specialist secondary services, from a hospital based or affiliated service, provide care to patients with a life limiting illness and could be any specialist secondary service, for example cardiac failure clinics, lung health service, respiratory service or palliative care service. Specialist palliative care services have insufficient capacity to meet the demands of caring for all dying people. This results in inequitable service provision, with patients suffering from non-cancer related terminal conditions representing a small proportion of their caseload.(18) Rural and remote patients and those from diverse cultural backgrounds are also underrepresented in specialist palliative care services.(18, 113) Consequently this research has focussed on improving access to palliative care through the integration of primary and secondary specialist services.

Many governments are highlighting the need to deliver integrated care to improve quality, safety and cost effectiveness of care.(92, 114-117) There are many definitions of integrated care and the term is often used interchangeably with integrated care pathways, transmural care, coordinated care, seamless care, case management and managed care.(118, 119) Integration can be used by different people to mean different things, and the meaning changes dependent on whose perspective is paramount.(120) Integration can be defined for the user, the provider, the policy maker and the organisation, among others. Integration can be horizontal, linking similar levels of care, or vertical, linking different levels of care such as primary, secondary and tertiary.(121) Integration of health care services can be thought of as a continuum, ranging from a fragmented health system where information about patients is not shared, to a system where "integrated care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care and rehabilitation, and health promotion".(119) Researchers in England and The Netherlands defined integrated care as "an organisational process of coordination which seeks to achieve seamless and continuous care, tailored to the patients' needs and based on a holistic view of the patient".(117) For the purposes of this review, integration is defined as any organisational process

of coordination which seeks to engage a GP and a specialist secondary clinician and/or service, in the care of a patient at end-of-life.

The GP has a critical role in an integrated model of palliative care as they often know the patient well, they often are the carer's doctor or know the carer, they are experts in generalist care and they are aware of the formal and informal health and social services available in the community.(122)

The aim of the review was to identify the common principles and processes of care models that promote GP engagement in integrated palliative care with specialised secondary services. The objectives were to: 1) evaluate the effectiveness of interventions designed to engage GPs with specialist secondary services in integrated palliative care and; 2) identify the personal, system and structural barriers and facilitators to engaging GPs with relevant specialist secondary services in integrated palliative care.

3.2 Methods

A protocol was developed prior to starting the review. Integrated care in health is complex including different sectors, organisations, care settings, and health professionals including the GP.(123) A wide variety of studies was sought to enable a more comprehensive review. Any study of a service that engaged the GP with specialist secondary services in the provision of palliative care within the selection criteria was included.

3.2.1 Criteria for considering studies for this review

3.2.1.1 Types of Studies

The review included randomised controlled trials (RCTs), controlled before and after studies (CBAs) and interrupted time series studies (ITSs) that evaluated the effectiveness of interventions that engaged GPs with specialist secondary services in the provision of integrated palliative care. Qualitative studies that elicited the views of service providers or service receivers about their experiences of integrated palliative care involving the GP and secondary services and qualitative studies that reported intervention development, descriptions, implementation and process evaluation were included. Mixed method studies were also included. Studies that were in a language other than English were excluded. No date limits were applied.

3.2.1.2 Types of participants

Only studies involving adults (aged 18 years or older) receiving services through either their GP, specialist hospital services or an integrated model of care were included. Specialist secondary services could be any specialist secondary service, if they were providing care to a palliative population. Relevant stakeholders included were GPs involved in providing palliative care, secondary specialist services providers offering care to palliative patients included, but were not limited to nurses, medical specialists and allied health professionals, patients and their families/carers and community-based services.

3.2.1.3 Types of interventions

The intervention was integrated care for palliative patients, including shared consultations, case conferences that involved at least the GP and the specialist clinician and/or secondary services, and/or any formal shared care arrangements between the GP and specialist services. The comparator was standard care or 'care as usual', which may be primary care only, secondary care services only, or a non-integrated approach to care. The World Health Organization's (WHO) definition of palliative care (22) was used to define palliative care to allow for the most comprehensive analysis of the literature.

3.2.1.4 Types of outcome measures

The outcomes were 1) measures of the effectiveness of integrated care including place of death, advance care plans in place, symptom management, hospital admission, length of stay in hospital, depression, anxiety, patient functional status, health related quality of life, carer wellbeing; and 2) an analysis of the personal, system and structural barriers or facilitators to GP engagement with secondary services in that care.

3.2.2 Search methods for identification of studies

3.2.2.1 Electronic searches

The following electronic databases were searched using MeSH (Medical Subject Headings) terms/subject headings for Medline as detailed in Appendix B and modified for each database.

- Medline (1946 – Nov, 2014),
- Embase (1966-Nov 2014), and
- CINAHL (1982-Nov 2014)

3.2.2.2 *Searching other resources*

Additional records were identified through references of included articles, and relevant reviews. A cited reference search for included studies was conducted, as well as 'related article' searches in Medline for included studies. Hand searching of key journals and a search of Government reports, specifically searched by organisation and topic (e.g. World Health Organization and palliative care) and conference proceedings was also conducted.

3.2.3 **Data collection and analysis**

3.2.3.1 *Selection of studies*

Records identified from different sources were imported into one database using reference management software and duplicates were removed. Two review authors independently assessed the titles and abstracts of the identified records. Studies that clearly did not meet the inclusion criteria on review of the title and abstract were excluded, and all possible relevant citations were retrieved. Two reviewers independently assessed the eligibility of the papers for inclusion in the review. Disagreements were resolved by discussion between the two reviewers, with arbitration by a third reviewer when required.

3.2.3.2 *Data extraction and management*

Data were extracted using a standardised form and included participant demographics and health status, setting (location, provider, site), methods (design, data collection, analysis), intervention (context, funding, attributes, duration, configuration), control group comparator intervention (context, funding, attributes, duration, configuration), and outcomes (effectiveness, barriers, facilitators, translation to practice). Disagreements were resolved by discussion by two reviewers and when required by arbitration with a third reviewer.

3.2.3.3 *Assessment of quality*

Two review authors independently evaluated the risk of bias of each included study. Disagreements were resolved by discussion or arbitration by a third person. Each included study was evaluated using the most relevant tool for the study design. Qualitative work was evaluated using the Critical Appraisal Skills Programme, (CASP)(124), which uses 10 questions that considered sampling, methods of data collection, sufficiency of data and discussion of the evidence. Narrative studies were evaluated using the Joanna Briggs Institutes Narrative, Opinion and Text Assessment and Review Instrument (JBI NOTARI) which is a critical appraisal tool with 6 questions focussed on logic, clarity and expertise.(125) Cohort studies were assessed using the Critical Appraisal Skills

Programme,(124) which uses 12 questions that consider validity, results and relevance. Randomised controlled trials were assessed using the Jadad tool which has 5 questions assessing randomisation, blinding and participant tracking.(126) Surveys were assessed using the Critical Appraisal of a Survey which uses 12 questions to assess validity, results and relevance.(127) The quality of the articles was considered and discussed in the synthesis of the data.

3.2.3.4 *Data synthesis*

Studies were grouped according to the type of setting, type of intervention and study design. With few randomised controlled trials included, meta-analysis was unsuitable. A narrative framework (128) was used to describe the findings.

3.3 Results

The search produced 593 records and an additional 31 records were identified through reference list checks. After screening of the studies, seventeen studies were included in the review, as depicted in the PRISMA Flow Diagram in Figure 3.1.(129) Sixteen studies were of a high quality, and one of average quality. Three of the studies were randomised controlled trials. In addition, one cohort study, four surveys, seven qualitative studies and two descriptive narrative studies were identified. A number of studies did not include intervention and control comparisons, instead describing current care within a geographical boundary. All studies involved engagement of general practice with specialist secondary services in the provision of care to palliative patients. Twelve studies were based in metropolitan areas, and five studies included rural areas. Specialist secondary services were palliative care services, a heart failure clinic, a heart failure and lung health service and a respiratory service. Patients were diagnosed with a primary disease including cancer, cardiovascular disease, heart failure, respiratory disease, renal failure and one study included dementia and neurological disease. Interventions included shared care, case conferences, home visits to the patient with both the specialist team and the general practitioner attending and the use of a good practice framework (The Gold Standards Framework). The details of all included studies are listed in Table 3.1.

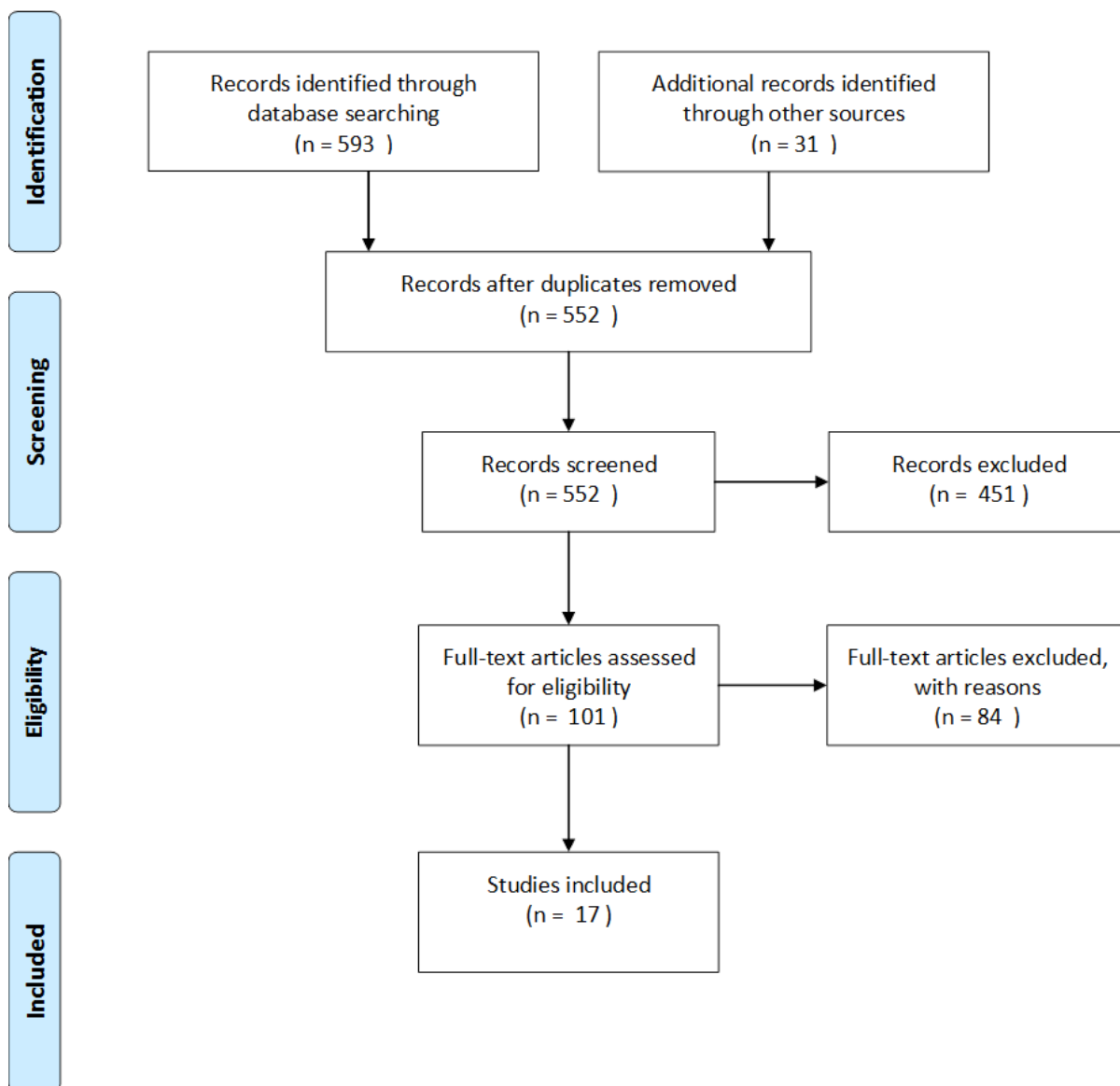


Figure 3.1: PRISMA Flow Diagram(129) Study identification and selection process for a systematic review of general practitioner engagement with specialist secondary services.

Table 3.1: Details of studies of GP engagement with specialist secondary services in integration of palliative care

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
RCTs				
<p>Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the "Palliative Care Trial" (107)</p> <p>Abernethy, Currow, Shelby-James, Rowett, Samsa, Hunt, Williams, Esterman and Phillips 2013</p>	<p>2 by 2 factorial cluster Randomised controlled trial Aim: to improve on current models of service provision</p>	<p>Jadad 4/5</p>	<p>461 participants, 358 assigned to case conferences (167 receiving case conferences). 103 assigned no case conference.</p> <p>Inclusion: New referrals to the palliative care service with any pain in the last 3 months; expected to live at least 48 hours; residing in service's geographic area; Folstein mini mental score 24+;</p> <p>Average patient age of 71, 53% male, 59% married, 94% have caregiver, 91% cancer diagnosis.</p> <p>Setting: - urbancommunity-based, specialised palliative care in South Australia</p>	<p>Control: current specialized palliative care provided by a regional community-based palliative care program</p> <p>Three concurrent intervention in a 2x2x2 factorial randomized study. Intervention 1 is relevant.</p> <p>Intervention: current care + case conferencing (single case conference between general practitioner (GP) and palliative specialist team)</p>

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
<p>Randomized, controlled trial of integrated heart failure management (108)</p> <p>Doughty, Wright, Pearl, Walsh, Muncaster, Whalley, Gamble & Sharpe 2002</p>	<p>Cluster randomised controlled trial</p> <p>Aim: determine the effect of an integrated heart failure management program on quality of life and death and hospital readmissions in patients with chronic heart failure</p>	<p>Jadad 4/5</p>	<p>197 hospital in-patients with heart failure</p> <p>Age range 34-92, 79 female, 70 living alone, 43 patients died prior to 12 month follow up, one other lost to follow up</p> <p>Exclusions: surgical remediable cause of heart failure; consideration for heart transplant; inability to provide informed consent; terminal cancer; and/or participation in any other clinical trial</p>	<p>Intervention: within 2 weeks of discharge attend clinic review; education sessions with cardiologist and nurse; 6 weekly follow up; detailed letter sent to GP with telephone communication with GP if changes to care needed; communication encouraged</p> <p>Control: continued under care of their GP with additional follow up measures as usually recommended by medical team responsible for in-patient care</p>

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
<p>Do case conferences between general practitioners and specialist palliative services improve quality of life? A randomised controlled trial(109)</p> <p>Mitchell, DelMar, O'Rourke & Clavarino 2008</p>	<p>Randomised controlled trial- unit of randomisation was GP/patient dyad.</p> <p>Aim: To test whether case conferences for palliative patients between GPs and specialist teams could improve patient Quality of Life and reduce strain of caring for the primary carers</p>	Jadad 5/5	<p>159 patients: 79 intervention and 80 control.</p> <p>Demographics were similar across intervention GPs: 101 participated. 62 had 1 patient, 26 had 2 and 11 had 3. Intervention and control GPs were similar.</p> <p>Setting: 3 hospital-based palliative care services across 3 hospital sites supporting GPs and home based nurse care</p>	<p>Intervention: GP was encouraged to participate in a case conference with the specialist team to negotiate a treatment plan with the GP playing an active part. Subsequent communication followed normal practice.</p> <p>Control : Normal care</p>
Cohort Studies				
<p>Case conferences between general practitioner and specialist teams to plan end-of-life care of people with end stage heart failure and lung disease: an exploratory pilot study (130)</p> <p>Mitchell, Zhang, Burridge, Senior, Miller, Young, Donald & Jackson 2014</p>	<p>Cohort study</p> <p>Aim: To assess the effectiveness of case conferences between specialist teams and GP in improving patient outcomes for people with end stage heart failure and lung disease.</p>	CASP 11/12	<p>Participants: 23 patients (21 GPs) with a primary diagnosis of advanced heart failure or respiratory failure from non-malignant disease with a life expectancy of less than 12 months.</p> <p>Setting: The Heart Failure and Lung Health service in the West Moreton Health and Hospital Service District, Queensland, Australia</p>	<p>Intervention: Case conference at the GPs office with the GP, palliative care physician and the case management nurse from the heart/lung service. Case conference was guided by a semi structured case conference schedule and a care plan developed including actions and responsibilities.</p>

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
Surveys				
Who is the key worker in palliative home care?(102) Brogaard, Jensen, Sokolowski, Olsesen, Neergaard 2011	Survey and interview Aim: explore who acts as key worker and who ought to act as key worker in views of patients, relatives and primary care professionals.	Critical Appraisal of a survey 10/12	96 terminally ill cancer patients, their relatives, their GPs and their community nurses	No applicable
Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses (101) Goldschmidt, Groenvold, Johnsen, Stromgren, Krasnik & Schmidt 2005	Survey Aim: evaluate a palliative home-care team from the viewpoint of GPs and district nurses	Critical Appraisal of a survey 6/12	GPs that attended the home conference between July 2000-June 2003. GPs were excluded if their patient had been in contact with the department for more than 3 months, did not meet inclusion criteria or had been visited by the home care team prior to the home conference. 213 GPs and 212 were eligible. 82 GPs and 163 nurses received questionnaire and 75 GPs and 148 district nurses completed Q1. 204 GPs eligible for Q2 and 139 DNs ; 143GPs and 101 DNs completed Q2 Setting: Hospital Department of Palliative medicine, Copenhagen, Denmark	Patients are referred to the palliative care home-team. The team visits the patient at home and on the first meeting the patient's relatives, GP, district nurses also attend. The home team visit the patient on a regular basis and propose treatment changes to GPs and nurses.

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
Obstacles to the delivery of primary palliative care as perceived by GPs (131) Groot, Vernooij-Dassen, Verhagen, Crul & Grol 2007	Survey Aim: identify obstacles which hinder the delivery of primary palliative care	Critical Appraisal of a survey 9/12	All GPs practising in 3 regions in the Netherlands were sent a questionnaires (n=320) Setting: 3 regions of the Netherlands	Comparison of services, no control
What information do general practitioners need to care for patients with lung cancer? A survey of general practitioners perceptions (132) Rowlands, Callen & Westbrook 2010	Survey Aim: to establish the patient information needs of GPs within the context of multidisciplinary care	Critical Appraisal of a survey 8/12	All GPs practising in one Australian regional Division of General Practice, excluding specialty clinics (eg skin cancer) - 433 GPs approached Setting: one regional Division of General Practice in Australia	
Qualitative				
Palliative care case conferencing involving general practice: an argument for a facilitated standard process (133) Davison & Shelby-James 2012	Qualitative analysis Aim: raise the understanding of case conferencing for palliative care patients and to recommend improvements to the process	CASP 8/10	17 GP-led case conferences including GP, palliative specialist team, patient/& carer - transcripts of full case conference Setting: - an interdisciplinary, community-based, specialised palliative care service servicing a metropolitan population of 350,000 in South Australia	Case Conference with GP, palliative specialist team and patient/carer

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
<p>Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study (134)</p> <p>Mason, Epiphaniou, Nanton, Donaldson, Shipman, Daveson, Harding, Higginson, Munday, Barclay, Boyd, Dale, Kendall, Worth & Murray 2007</p>	<p>Mixed methods study including ethnographic study and qualitative semi-structured interviews</p> <p>Aim: To identify how care is coordinated in generalist settings for individuals with advanced progressive conditions in the last year of life</p>	CASP 8/10	<p>56 patients and 25 carers participated in interviews. One-off interviews were conducted with 17 clinicians (GPs and palliative specialists).</p> <p>Setting: 3 UK generalist clinical settings - an acute admissions unit, a general practice and a respiratory outpatient service</p>	Comparison of services,
<p>General practitioner, specialist providers case conferences in palliative care (135)</p> <p>Mitchell, Cherry, Kennedy, Weeden, Burridge, Clavarino, O'Rourke & Del Mar 2005</p>	<p>Qualitative semi-structured interviews focus groups</p> <p>Aim: describe the utility and acceptability to general practitioners and palliative care staff of case conferences in palliative care</p>	CASP 10/10	<p>41 GPs who participated in case conferences 16 palliative care staff who participated in case conferences</p> <p>Setting: 3 hospital-based palliative care services across 3 hospital sites supporting GPs and home based nurse care</p>	<p>Intervention: GP was encouraged to participate in a case conference with the specialist team to negotiate a treatment plan. Subsequent communication followed normal practice. Control : Normal care</p>

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
Family physicians and cancer care. Palliative care patient's perspectives (136) Norman, Sisler, Hack & Harlos 2001	Qualitative: semi-structured interviews and chart reviews Aim: To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians (FP) and their perspectives of their FP roles	CASP 8/10	A purposive sampling of 11 men and 14 women Setting: Two palliative care hospital wards in Winnipeg, Manitoba	Analysis of current care program
Communication issues for the interdisciplinary community palliative care team (137) Street & Blackford 2001	Qualitative semi-structured interviews and focus group interviews Aim: examine the communication patters between nurses and general practitioners in providing palliative care	CASP 8/10	40 nurses recruited through presentations in education programmes and distribution of pamphlets. Purposive sampling ensured all the metropolitan hospice and palliative care services were represented.	Analysis of care within metropolitan area.

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
Discovering integrated care in community hospitals (138) Tucker 2013	Qualitative - questionnaire Aim: explore the presence and nature of integrated care in community hospitals	CASP 7/10	48 staff members voluntarily returned questionnaires. Number approached not included, however invitation to participate was purposive. It was found that they were representative of the diversity of hospitals in terms of type, geography and size. Community Hospital Services across the England	Analysis of current care program
Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts (139) Walshe, Caress, Chew-Graham & Todd 2008	Qualitative semi-structured interviews Aim: describe the reasons and influences on the referral decisions made by healthcare professionals providing community general and specialist palliative care services.	CASP 8/10	47 health care professionals (general and specialist palliative care) from three Primary Care Trusts in North West England	Comparison of services, no control

Title, Author, Date	Study design and aim	Study quality	Participants and setting	Intervention and control
Building Primary Care Capacity in Palliative Care: Proceedings of an Interprofessional Workshop (140) Brazil, Howell, Marshall, Critchley, Van Den Elzen & Thomson 2007	Workshop Proceedings Aim: to enhance the capacity of primary care for the terminally ill.	JBI NOTARI 4/5	Setting: Three primary palliative care demonstration projects in Ontario, Canada	Analysis of 3 separate projects to identify and disseminate key learnings.
Palliative Care Partnership: a successful model of primary/secondary integration (141) Stewart, Allan, Keane, Marshall, Ayling & Luxford 2006	Narrative and survey	JB NOTARI 5/6	Setting: mid central health district NZ. Participating organisations: Arohanui Hospice and General Practice teams Participants: 225 patients in 14 months (cancer patients, ,cardiovascular disease patients, respiratory patients, renal, dementia, neurological and other)	To detail the development and implementation of a primary secondary integration project in palliative care

Table 3.2: Effectiveness of GP engagement with specialist secondary services in integration of palliative care

Author	Outcome measures	Length of follow-up	Results
RCTs			
Abernethy, Currow, Shelby-James, Rowett, Samsa, Hunt, Williams, Esterman and Phillips 2013 (107)	Primary : AKPS* Secondary: pain intensity, Brief Pain Inventory, QOL^, Symptoms and hospital utilisation	60 days after randomisation until study exit, mean time from case conference to death or end of study was 152 days	Intervention patients had a significantly reduced number of hospitalisations (1.26 vs 1.7) P=0.0069 compared to controls and maintained performance status - mean daily AKPS* 57.3 ¹ vs 51.7 control, P=0.0368 Intervention patients were better able to maintain their performance status over time when performance status had already declined below 70% on referral (P=0.0425). Benefit was not seen when AKPS* was above 70% on study entry. No significant impact on symptom burden, pain or quality of life.
Doughty, Wright, Pearl, Walsh, Muncaster, Whalley, Gamble & Sharpe 2002 (108)	Quality of Life Time to death or readmission Hospital readmission Hospital bed days Hospital readmission specific to heart failure worsening	12 months	There was no difference between groups for time to death or readmission. The intervention group had significantly fewer admissions each (p=0.015) and fewer bed days per year (p=0.0001). Quality of life measures showed a significant improvement in physical functioning from baseline to 12 months for the intervention group (p=0.015), however no difference in emotional scores between groups.

Author	Outcome measures	Length of follow-up	Results
Mitchell, Del Mar, O'Rourke & Clavarino 2008 (109)	Patient quality of life - 3 measures (AQEL [#] , McGill Quality of Life Questionnaire, Subjective Wellbeing Scale Carer burden - Caregiver Reaction Assessment)	1, 3, 5, 7, and 9 weeks post intervention and then monthly until death, withdrawal or cessation of project.	Substantial patient attrition with time. Two a priori analyses: a. Date of case conference as reference point: Quality of Life was not influenced by the intervention. The intervention group showed a significantly lower carer burden in week 5. b. Time of death as reference point. 1-14 days prior to death and 15-35 days prior to death: there were significant results favouring the intervention group for some physical and mental well-being items. However for more than 35 days prior to death the results favoured the control group.
Cohort Studies			
Mitchell, Zhang, Burridge, Senior, Miller, Young, Donald & Jackson 2014 (130)	Service utilisation - Emergency department (ED) presentations Emergency department discharged to home Hospital admissions Admission length of stay Count of case conference recommendations and rate of adherence to recommendations	Up to 12 months after the case conference	ED admissions fell from 13.9 per annum to 2.1 (difference 11.8, 95%CI 2.2-21.3, P=0.001) ED admission leading to discharge home from 3.9 to 0.4 per annum (difference 3.5, 95% CI 0.4-7.5, p=0.05) Hospital admissions 11.4 to 3.5 per annum (difference 7.9, 95% CI 2.2-13.7, p=0.002) Length of stay 7.0 to 3.7 days (difference 3.4, 95% CI 0.9-5.8, p=0.0007). 67% of recommendations made were enacted. Participating health professionals were enthusiastic about the process
Surveys			

Author	Outcome measures	Length of follow-up	Results
Goldschmidt, Groenvold, Johnsen, Stromgren, Krasnik & Schmidt 2005 (101)		Follow up at one month after home conference, which is held at the start of home care.	More than half had learnt aspects of palliative care from the home conference. 90% were satisfied with home conference. At one month 91% reported improvement in care and treatment of patient because of home care team, more than half learnt aspects of palliative care and 89% were satisfied with level of cooperation. Benefits included improvement in security for patient and relative, pain control, input from specialist in palliative care and improvements in general symptomatology and nursing care. Training benefits were symptom control, patient-centred care.
Groot, Vernooij- Dassen, Verhagen, Crul & Grol 2007 (131)	communication organisation knowledge and expertise integrated care time for relatives	no follow up	Response rate to survey of 62.3% General practitioners (GP) that participated in multidisciplinary case discussions reported fewer perceived obstacles to the delivery of primary palliative care.

NARRATIVE

Stewart, Allan, Keane, Marshall, Ayling & Luxford 2006 (141)	Participation Communication Professional development Hospice Impact Patient impact Linkages	14 months	<p>73% of practices, 62% of GPs and 67% of practice nurses participated. Communication: Communication between services is effective, with participants indicating a sense of partnership</p> <p>Professional development: Training has been extremely useful, with enhanced knowledge, increased confidence and familiarity with hospice staff</p> <p>Hospice Impact: Referrals have decreased however complexity has increased</p> <p>Patient impact: Approx. 60% of deaths occurred in community with less than 5% within the hospital setting. No comparison is provided to general NZ data.</p> <p>Linkages: a strengthening of service relationships has been claimed, with the role of Patient Care Coordinator being responsible for this. No data were provided to support this.</p>
---	--	-----------	--

Qualitative

Mitchell, Cherry,
Kennedy, Weeden,
Burrige, Clavarino,
O'Rourke & Del Mar
2005 (135)

Advantages of case conferences - time effective and efficient; building relationships with specialist teams
Potentially useful exchanges of information
Discharge planning easier and allowed role delineation
Increased specialist team appreciation of patient-GP relationship
GPs willingness to provide after hours care and house calls
Negotiated management plans

Walshe, Caress, Chew-
Graham & Todd
2008 (139)

GSF^{*^} has improved inter-professional communication, a positive impact on previously difficult communication
GSF provides structure, authority and permission to arrange formal meetings and informal communications
Impact of GSF on provision of anticipatory drugs is positive
GSF has adverse effect on workloads.
GSF lead by specialist palliative care practitioners
GSF is adapted over time to suit the professionals involved

1. SE 1.5 vs 2.3; * AKPS = Australian-modified Karnofsky Performance Scale; ^QOL = Quality of Life; # AQEL= Assessment of Quality of life at End-of-Life; *^GSF = Gold Standard Framework

3.3.1 Effectiveness of GP engagement with specialist secondary services in the integration of palliative care

GP engagement with specialist secondary services in the provision of palliative care has a positive impact in some areas (Table 3.2). Although little quantitative work has been completed in GP engagement in the integration of primary and secondary services in the provision of palliative care, studies showed a significant decrease in number of hospital admissions ($P=0.015$;(108) $p=0.007$ (107) $p=0.001$ (142)). Case conferences and shared care were both effective in reducing hospitalisations and in significantly ($p<0.05$) reducing the length of hospital stay.(108, 130) There was some evidence that patient functional status as measured by the Australian-modified Karnofsky Performance Scale (AKPS) was better maintained by patients receiving integrated care when performance status had already declined below a score of 70 ($p=0.0425$). (107) When performance status was measured via self report surveys, significant improvement ($p=0.015$) accrued for those receiving integrated care.(108) However quantitative studies showed no measured improvement in quality of life or symptom burden.(107, 109) A survey of GPs also found improved pain management, symptom control and increased security for patient and family.(101) Surveys and qualitative assessment of patients who experienced GP engagement with secondary services in integrated care at the end-of-life, case conferences, home conferences and a good practice framework, showed improvements in communication,(135, 139, 141) relationships between services,(135, 139, 141) professional development (101, 141) and patient-perceived benefits (pain management, symptom control, security).(101, 135)

Table 3.3: Facilitators of GP engagement with specialist secondary services in integration of palliative care

Author	Outcome measures	Length of follow-up	Results
Qualitative			
Norman, Sisler, Hack & Harlos 2001 (136)		No follow up - one off interviews	Family Physicians are valued in the provision of integrated care if they are accessible and provide emotional and family support and for referral, triage and general care.
Street & Blackford 2001 (137)		No follow up	Strategies that worked included checking if hospital contacted general practitioner (GP), check after hours arrangements of GP, determine client needs and role that palliative care team will play in meeting these, joint decision making, clarification of roles with clients, determine GP/Hospital first contact, regular communication.
Surveys			
Brogaard, Jensen, Sokolowski, Olsesen, Neergaard 2011 (102)	Actual key worker ideal key worker		Patients, relatives, GPs and community nurses (CN) most often saw themselves as the key worker. When asked about the ideal key worker, most patients (29%, 95% CI: 18-42) and relatives (32%, 95% CI: 22-45) pointed to the GP. There was poor agreement between patients and relatives; patients and GPs and patients and CNs regarding who is the key worker.
Goldschmidt, Groenvold, Johnsen, Stromgren, Krasnik & Schmidt 2005 (101)		one month after start of home care	Benefits included improvement in security for patient and relative, pain control, input from specialist in palliative care and improvements in general symptomatology and nursing care. Training benefits were symptom control, patient-centred care.

Author	Outcome measures	Length of follow-up	Results
Rowlands, Callen & Westbrook 2010 (132)		no follow up	GPs would like to receive relevant information regarding their patient from the most relevant professional for that information GPs would like a point of contact so they can initiate contact GPs would like to receive information quickly (between 1-3 days) regarding changes to condition, outpatient consults, admission, discharge and treatment milestones GPS would like information electronically by encrypted email (88%).

3.3.2 Facilitators to engagement of GPs with specialist secondary services in integration of palliative care

Enabling GP engagement in integrated palliative care with relevant specialist secondary services may require **effective communication**.(132, 137) (See Table 3.3) Communication needs to be timely with an appropriate level of detail.(132) GPs indicated that receiving patient information electronically would be useful in enabling shared care.(132) It is also necessary that communication occurs with the most relevant people for the information being involved in the exchange.(132) Another facilitator to integrated care is **clear role definition**. Although roles of professionals may change for each patient, it is important that the roles are clearly defined and understood by all involved.(102, 137) It was suggested that clearly defined roles would also aid communication. The **availability of the GP** to the patient and carer is also important.(136) When the GP is accessible through prompt appointments and telephone contact for medical care and referral and can provide emotional and family support the GP becomes an integral part of the patient's care which enables the integration of primary and secondary care.(136) There is a **family expectation that the GP will be involved**. Even when the family feels that they are the key persons in caring for the patient, they still have an expectation that the GP will be involved in providing medical care and emotional and family support.(102) Finally, to facilitate integrated care the process should be **organised and initiated by the specialist secondary service**.(137) It was found that the most systematic and successful partnerships were established by the specialist service.

Table 3.4: Barriers to GP engagement with specialist secondary services in integration of palliative care

Author, Date	Outcome measures	Length of follow-up	Results
NARRATIVE			
Brazil, Howell, Marshall, Critchley, Van Den Elzen & Thomson 2007 (140)	Structure of care Processes of care Outcomes of care	n/a	Challenges: -financial issues such as funding palliative care specialists -shortage of trained staff -insufficient training opportunities for primary care - lack of infrastructure and technology difficulty providing care over large geographic area
Qualitative			
Davison & Shelby-James 2012 (133)	Camey's ladder of analytical abstraction was applied to the transcriptions	No follow up	The purpose of the case conference was ambiguous with a lack of understanding or description. The person providing the purpose varied. Participant roles in the case conference were ambiguous. Description of roles varied depending on who was providing description. Information was not provided by any service to any other service prior to the case conference, although this had been expected when necessary. Oral history brought to the conference filled gaps and informed decision making. There is no standard membership to the case conference.

Author, Date	Outcome measures	Length of follow-up	Results
Mason, Epiphaniou, Nanton, Donaldson, Shipman, Daveson, Harding, Higginson, Munday, Barclay, Boyd, Dale, Kendall, Worth & Murray 2013 (134)		Ethnographic observations for 22 weeks. Interviews conducted 8-12 week intervals for 5-9 months or until death. Interviews with professionals completed once	<p>Observations: At all sites there were problems with exchange of information between service providers when patients moved between services. Tensions arose between delivery of patient centred care and the need to promote efficiency. There was considerable variability in knowledge of palliative care.</p> <p>Interviews: Patient identification must precede coordination of care. Advanced cancer patients were likely to be identified and receive good coordinated care, Mismatch between policy and guidance around identifying patients for palliative care and the actual practice of identification Palliative care was often thought of when no cure is possible and death is imminent by patients and carers Patients and families showed little understanding of benefits of palliative care GP was sometimes recognised as playing a key role After discharge patients were disturbed by lack of follow up from GP</p>
Mitchell, Cherry, Kennedy, Weeden, Burrige, Clavarino, O'Rourke & Del Mar 2005 (135)			Disadvantages - workload pressure, teleconference format not ideal

Author, Date	Outcome measures	Length of follow-up	Results
Norman, Sisler, Hack & Harlos 2001 (136)		No follow up - one off interviews	Cancer care is organised in either a sequential, parallel or shared manner between family physicians (FP) and cancer specialists. Cancer patients lose contact with family physician because of relocation, distrust over delays in diagnosis, failure to perceive a need, poor communication between specialist and FP and lack of FP involvement in hospital.
Street & Blackford 2001 (137)		No follow up	Issues that impeded communication between palliative care nurses and GPs were networking, case management, multiple service providers, lack of standardised documents and tracking of clients, difficulties in providing relevant practical knowledge.
Tucker 2013 (138)		No follow up	Vertical integration with secondary hospital care was common but considered competitive rather than collaborative
Surveys			
Brogaard, Jensen, Sokolowski, Olsesen, Neergaard 2011 (102)	Identification of Actual key worker and Ideal key worker		Patients, relatives, GPs and community nurses (CN) most often saw themselves as the key worker. When asked about the ideal key worker, most patients (29%, 95% CI: 18; 42) and relatives (32%, 95% CI: 22;45) pointed to the GP. There was poor agreement regarding who is the key worker.

Author, Date	Outcome measures	Length of follow-up	Results
Goldschmidt, Groenvold, Johnsen, Stromgren, Krasnik & Schmidt 2005 (101)		one month after start of home care	Lack of benefits included home-care team not helping when asked, wrong or no change in medical treatment and waiting too long. Confusion over who is in charge of what. Dissatisfaction - organisational issues, communication problems and problems during home conference (eg wrong focus, badly prepared)
Groot, Vernooij-Dassen, Verhagen, Crul & Grol 2007 (131)	communication organisation knowledge and expertise integrated care time for relatives	no follow up	Communication with relatives - over 50% experienced difficulties, more than 80% reported difficulties with bureaucratic procedures in organisations Lack of GP expertise in home care technologies Integrated care - GPs reported obtaining extra care for patient as the most problematic topic.

3.3.3 Barriers to GP engagement with specialist secondary services in integration of palliative care

There are five overarching barriers to engaging GPs with secondary services in integrated palliative care: Health System barriers, Communication barriers, Process barriers, Content barriers, and Other barriers (see Table 3.4). **Health system** barriers include, financial constraints for both the GP and the hospital, workload, lack of standardised documents and systems, bureaucratic procedures, professional silos, lack of services and lack of infrastructure.(101, 131, 134-137, 140) **Process** barriers include roles within integrated care not being clearly defined, barriers to sharing information, health professionals' perceived lack of time, ambiguity around who should be involved, and communication and technology issues.(102, 133, 134, 136, 137, 140) **Communication** can be a barrier, with poor communication creating personal issues (trust, poor relationships) between relatives and patients, lack of patient or family understanding of discussions with healthcare professionals, the quality of the relationship between the patient and the professionals, and a sometimes competitive or combative relationship between health professionals.(101, 131, 137, 138) The **engagement** of integrated care can provide a barrier when there is a lack of clarity of purpose (e.g. future planning, acute medical issue), and participants being unprepared, either with not receiving information, or not reading the information prior to the meeting.(101, 133) **Other** barriers documented by health professionals as challenges, include late referral, lack of understanding of patient prognosis by family, medical professionals underestimating the seriousness of the patient's condition and therefore overestimating prognosis.(134, 136)

Table 3.5: Process and principles to facilitate GP engagement with specialist secondary services in integration of palliative care

Author	Outcome measures	Length of follow-up	Results
NARRATIVE			
Brazil, Howell, Marshall, Critchley, Van Den Elzen & Thomson 2007 (140)	Structure of care Processes of care Outcomes of care		Core elements of a model to improve delivery of palliative care include: Integration of the family physician with a palliative care team - Inter professional training - single point of access to specialist team - 24/7 access -adjustment in funding to allow collaborative practices - funding for patients for equipment, supplies & medication - standardised assessment tools -team meetings -practice-based education by a palliative care physician -common patient records - assessing the quality of care provided to patients and families integrating continuous quality improvement
Stewart, Allan, Keane, Marshall, Ayling & Luxford 2006 (141)	Participation Communication Professional development Hospice Impact Patient impact Linkages	Evaluated at 14 months	Communication between services is effective, a sense of partnership reported .Professional development: Training has been extremely useful with enhanced knowledge, increased confidence and familiarity with hospice staff Hospice Impact: Referrals have decreased however complexity has increased Linkages: a strengthening of service relationships has been claimed, with the role of Patient Care Coordinator being responsible for this. No data were provided to support this.

Qualitative

Mason, Epiphaniou, Nanton, Donaldson, Shipman, Daveson, Harding, Higginson, Munday, Barclay, Boyd, Dale, Kendall, Worth & Murray 2013 (134)	Ethnographic observations for 22 weeks. Interviews conducted 8-12 week intervals for 5-9 months or until death. Interviews with professionals completed once	Patient identification must precede coordination of care. Mismatch between policy and guidance around identifying patients for palliative care and the actual practice of identification Palliative care was often thought of when no cure is possible and death is imminent by patients and carers In most cases the family carer or patient was the coordinator of care Patients with a nurse specialist felt better cared for General practitioner (GP) was sometimes recognised as playing a key role but usually only consulted for acute problems After discharge patients were disturbed by lack of follow up from GP
Walshe, Caress, Chew-Graham & Todd 2008 (139)		GSF* has improved inter professional communication, a positive impact on previously difficult communication GSF* provides structure, authority and permission to arrange formal meetings and informal communications Impact of GSF* on provision of anticipatory drugs is positive GSF* has adverse effect on workloads. GSF* led by specialist palliative care practitioners GSF* is adapted over time to suit the professionals involved

*GSF= Gold Standard Framework

3.3.4 Process and principles that facilitate GP engagement with specialist secondary services in the integration of palliative care

The processes and principles of integrated primary and secondary care provide some common elements to facilitate the provision of palliative care. (Table 3.5) Communication is required,(139, 141) providing an equitable status, or an equal respect and authority between all participants. Communication builds partnerships. To adequately provide palliative care, patients at risk of dying need to be deliberately identified.(134) It has been noted that it is easier to identify cancer patients that are palliative, than non-cancer patients.(134) Providing a systematic method of screening patients for palliative needs is the first step. A structure or framework of patient pathways is necessary with built in flexibility for real world adaption.(134, 139, 140) Referral pathways, provision of care after hours, primary contact details and management plans should find a place within the framework. Professional development is a necessary part of integrated care with training improving knowledge and confidence for the care providers.(140) These principles are common across the research and are reflected in the facilitators and barriers that were identified in the provision of integrated palliative care.(143)

3.4 Discussion

The review found evidence that engaging GPs in palliative care with relevant specialised secondary services is effective and provides positive outcomes for the hospital (reduced readmissions, shortened length of stay) and for the patient (pain management, symptom control, functional status). Interventions that used case conferences between specialist secondary services and GPs were effective in reducing hospital admissions and reducing length of stay as well as improving functional status. Specialist secondary services in these case conferences included a palliative service and a heart failure and lung health service. Shared care provided by a heart failure management clinic and GPs provided similar results. Additionally, conferences between specialist secondary palliative services and GPs at the patient's home improved pain control and symptomatology. Integration of GPs and specialist services serving palliative patients are effective.

The health system requires change if GPs are to engage with specialist secondary services to provide integrated palliative care. A common computer system and standard documents would enable services to share information and build care plans. There are many challenges in creating a system to share patient information between services, not limited to interoperability between systems, security, data ownership, confidentiality and privacy and compliance with legislation.(144) Where standardised documentation exists, integration would be unlikely to face as many challenges,

in the first instance. There is a drive to shared digital medical records occurring in many countries including Australia, NZ, Canada and Europe(145-148) and this initiative may facilitate integrated care and overcome these barriers.

Financial challenges need to be solved. Funding for specialist secondary services to provide palliative care, to provide the infrastructure and technology required within the primary and secondary care services to facilitate integration, and to provide training to encourage integration of palliative services should be considered. Excessive workloads(139) were also identified as a system challenge to be solved. Funding for extra staff may solve this issue. Savings found in reduced admissions to hospital and reduced length of admission to hospital by providing integrated palliative care(107, 108, 130) could offset these financial challenges. It may be that more resources directed to this sort of care may generate more demand.

Integrated care should be clearly defined and procedures should be amended to promote integrated care, encouraging sharing of information and files and adjusting workload to support integrated care. However, this review has shown that these changes are yet to occur and that even without these changes to the health system it is still possible to provide integrated primary and secondary care at end-of-life, albeit with considerable difficulties. Factors were identified that will facilitate an effective intervention.

There are limitations within the review. The review used an inclusive definition of integrated care, with coordinated care and shared care models analysed in most articles. A further limitation is that there are relatively few studies assessing the engagement of GPs with specialised secondary services in integrated palliative care. This is an emerging area of research in the last 15 years, with no research prior to 2000 in this area, so this finding is unsurprising.

Further higher-level evidence from randomised controlled trials need to be conducted to assess the effectiveness of different models of GP engagement with specialist secondary services in the provision of integrated palliative care. Qualitative work to explore the process of implementation of integrated models of palliative care across different health care systems would inform researchers and policy makers and facilitate evidence-based practice. The long-term sustainability of an integrated approach to palliative care provision between primary and secondary care has yet to be investigated. Research should also be broadened to include those specialist secondary services that work with palliative patients, such as geriatrics or neurology, which did not appear in this literature

review. This review provides a cohesive analysis of existing work on which to build this emerging field.

3.5 Conclusion

From this systematic review it was clear that few models of care facilitate integration between primary care and specialist secondary services in the provision of palliative care. Further, these do not have robust evidence to support them. However, integrated multidisciplinary case conferences appear the most robust and pragmatic form of integration and this is the basis of the model that will be examined in detail. The following chapter describes the methodology of the research to develop an integrated approach between GPs and hospital-based specialist services to provide end-of-life care for frail older patients.

Chapter 4 Methods

The purpose of Chapter 4 is to discuss the methodology of the study and to explain the methods which were used. The first part of the chapter presents the Medical Research Council's process for the development and evaluation of a complex intervention and how this underpinned the current research. Section 4.2 describes the study design for Phase 1 of the research and sections 4.3 and 4.4 describe the study design and rationale for Phase 2 of the research.

4.1.1 Overall Aim

The aim of the study was to improve the integration between primary and secondary care, through the development and provision of a model of palliative care for frail older people living in the community.

4.1.2 Study design

The study used pragmatism as a research paradigm. Pragmatism views knowledge and reality based on beliefs, habits and experiences.(149) Pragmatism accepts a variety of competing interests and forms of knowledge, concerned with understanding how knowledge facilitates successful action.(150) This research paradigm aims to solve practical problems in real world settings.(149) The current study aims to improve the integration of primary and secondary care for frail older people in a real world setting. Pragmatism focuses on the research question and embraces both quantitative and qualitative approaches,(149) providing a flexible approach to research design. Pragmatism is a common paradigm in health service research.(150, 151)

This project followed the Medical Research Council's process for developing and testing complex interventions(152), namely by developing interventions systematically, using the best available evidence and appropriate theory. This is followed with an evaluation, using a carefully phased approach, starting with a series of pilot studies targeted at each of the key uncertainties in the design, and moving on to an exploratory and a definitive evaluation (Figure 4.1).

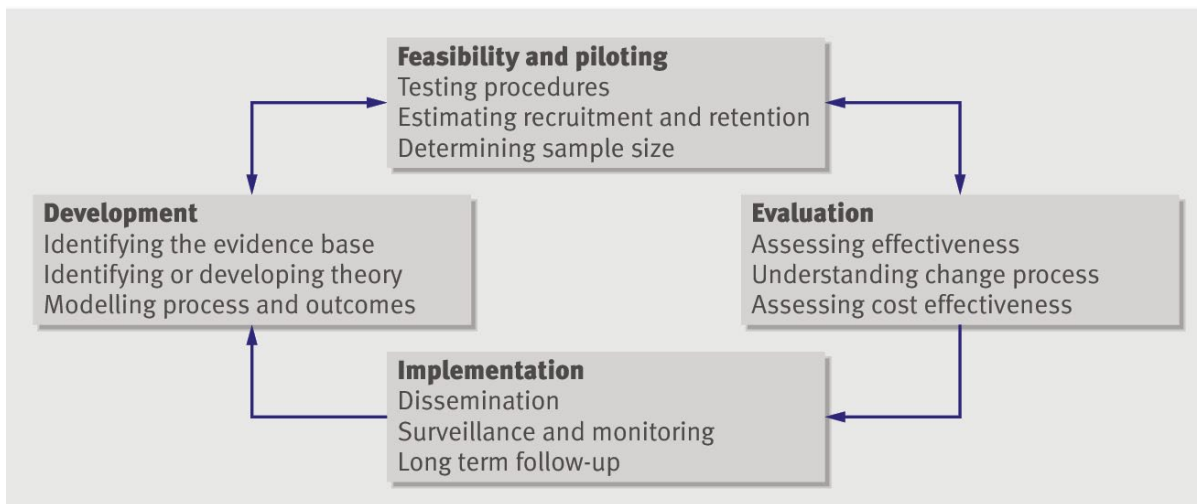


Figure 4.1: Key elements of the development and evaluation process(152)

Source: Craig et al 2008.

This study focused on the development stages of the MRC (Medical Research Council) process, identifying the evidence base by conducting a systematic review of the literature, identifying and further developing a model of integrated palliative care and assessing the model for uncertainties in the design through a pilot study. We employed a mixed-method two phase sequential design with the second phase comprising two components (Figure 4.2). The first phase of the study was a qualitative study, exploring health professionals' experiences and perceptions in caring for frail older people at the end-of-life and in providing palliative care to patients and sought their views on a model of integrated palliative care. This allowed the researchers to explore how an integrated model of care, engaging GPs and specialist secondary services, as identified through the systematic review in Chapter 3, could be refined for the current health system. Phase 2 of the study employed a mixed-methods research design, with two components, to gain a clear understanding of the feasibility of a model of integrated palliative care for frail older people. The first component of phase 2 was a quantitative analysis to provide a preliminary estimate of the effect of the model of care on health service utilisation, patient outcomes and carer outcomes. The second component was a qualitative study to explore the experience of stakeholders participating in the developed model of integrated palliative care for frail older people. Using both qualitative and quantitative methods will provide a rigorous evaluation of the implementation of a new integrated model of palliative care for frail older people at the end-of-life.

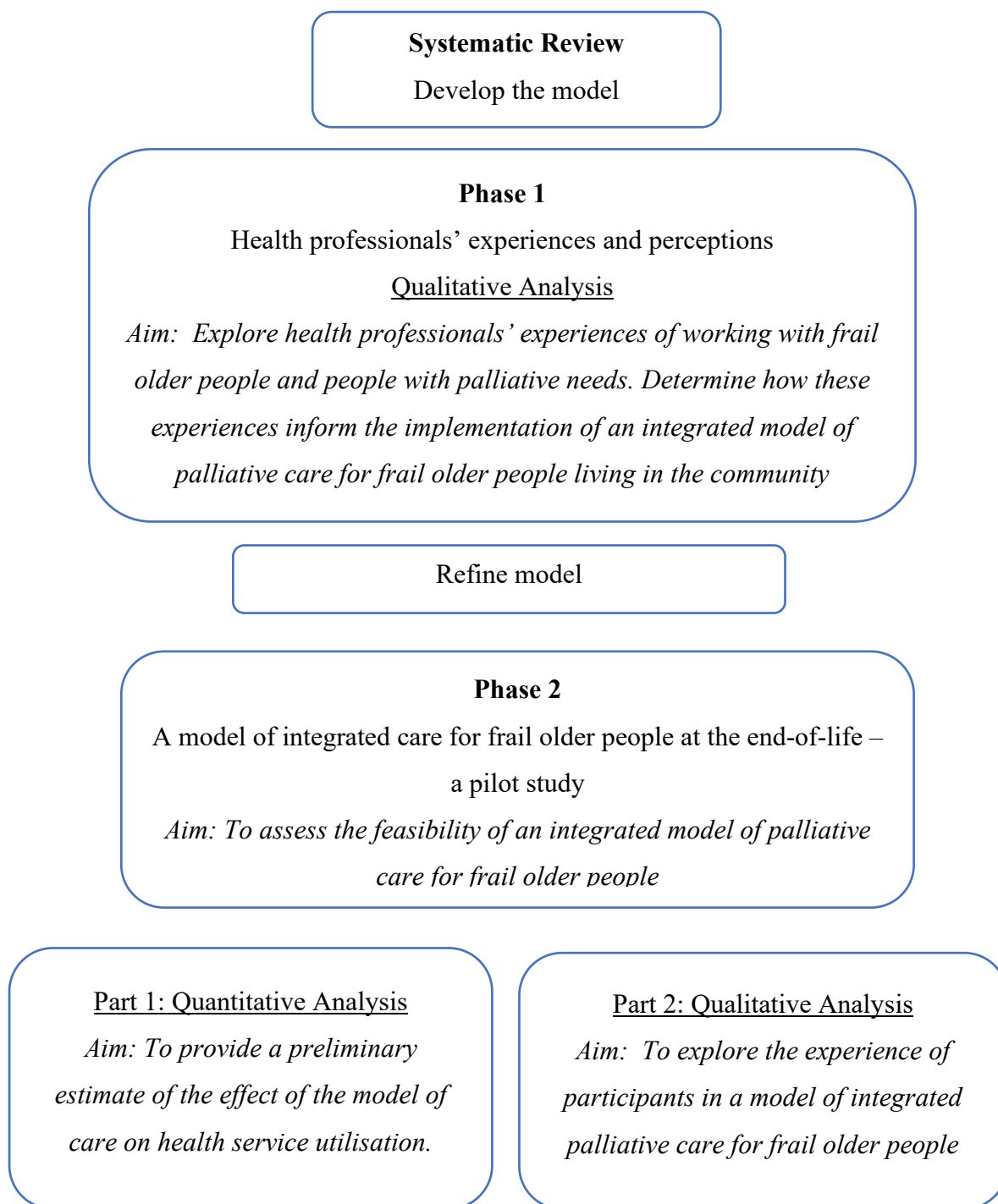


Figure 4.2: Study diagram

4.1.2.1 Study Setting

The setting for this study was the West Moreton Hospital and Health Service (WMHHS) district in Queensland, Australia. This health district encompasses a metropolitan area with a medium-sized public hospital supported by four rural facilities. Ipswich Hospital is the major public health care facility in the WMHHS district and serves a diverse population of both Ipswich city residents and

residents from small rural communities in the surrounding area. Ipswich is a city of 190,125 people with 9.6% over the age of 65 years.(153)

Health professionals for phase 1 of the study were recruited through GP offices in the WMHHS district and through the Ipswich Hospital. Patients for phase 2 of the study were recruited through the Older Person Evaluation, Review and Assessment (OPERA) unit in the Acute Care for the Elderly Ward at the Ipswich Hospital. This setting was chosen due to WMHHS district's diverse population across urban and rural communities and their strong focus on palliative care. The staff of the OPERA unit were interested in the research and were willing to be involved.

4.1.2.2 Ethical Clearance

Approval was granted for Phase 1 of the study by the Darling Downs Human Research Ethics Committee; Phase 2 of the study by the Royal Brisbane and Women's Hospital Human Research Ethics Committee and by The University of Queensland's Medical Research Ethics Committee for both phases of the study. Site Specific Governance Approval was granted by the West Moreton Hospital and Health Service Research Governance Office. A Research Collaboration Agreement was signed by West Moreton Hospital and Health Service (WMHHS) and The University of Queensland prior to the commencement of the project. Participants provided informed consent and were assured that their confidentiality would be protected. (See Appendix A for the Ethics approvals and Appendix C for Information Sheets and Consent Forms)

4.2 Phase 1: Health professionals' perceptions and experiences of integrated primary and secondary care for frail older people at the end-of-life

Phase 1 of the research was a qualitative study designed to elicit health professionals' experiences of working with frail older people and with patients with palliative and supportive needs and how these experiences could inform the design and implementation of an integrated model of palliative care for frail older people at the end-of-life in their local context.

4.2.1 Study Aim of Phase 1

Phase 1 of the research aimed to explore health professionals' experience caring for frail older people with palliative and supportive needs and their family carers, to inform the refinement and implementation of an integrated model of palliative care, engaging GPs and specialist secondary

services, for frail older people at the end-of-life. The outcome is the identification of key elements of an integrated model of care and its implementation. This is in accordance with the development phase of the MRC key elements of developing and testing complex interventions (Figure 4.1).

4.2.2 Study method of Phase 1

Focus groups were used to explore the health professionals' experiences of working with frail older people and people with palliative needs. The researcher inquired how these experiences could inform the design of an integrated model of palliative care for frail older people living in the community.

4.2.2.1 Sampling and Recruitment

A mix of purposive and snowball sampling was used to select the participants for the focus groups. Purposive sampling selects participants based on features, characteristics or criteria to enable understanding and exploration of the research question.(151) Snowball sampling contacts potential participants on the referral of other study participants.(151) A representative sample of health professionals from community and hospital settings involved in the provision of care for both frail older people and palliative patients were sought.

GPs, geriatricians, nursing and allied health staff from the Older Person Evaluation Review and Assessment (OPERA) unit at Ipswich Hospital were provided with information about the study and approached to participate. The staff geriatricians at the WMHHS OPERA unit were invited to participate and all other nursing and allied health staff at the unit were asked to participate. GPs from the WMHHS were identified through the health department and were initially contacted by email and followed up by phone by the researcher to inform them about the study and invite them to participate in a focus group. If more than one member of staff from a practice were willing to be involved, additional GPs at that practice and GPs from neighbouring practices would be invited to participate.

As there are relatively few palliative specialists in the WMHHS, palliative specialists from the adjoining health districts in the Queensland South-East corner were contacted, initially by email and then by phone and asked to participate. All palliative specialists within the South East Corner of Queensland were invited by email to participate in the focus group prior to the meeting.

Focus groups were conducted in 3 main groups (GP, hospital-based health professionals and palliative care specialists). The purpose of the focus group was to explore health professionals' experiences of providing care for frail older people with palliative care needs with a view to informing an integrated model of palliative care. Focus group discussions were used to explore roles and expectations within an integrated model of palliative care and the practical constraints to participation. The rationale for conducting discipline-specific or hospital-based groups was to encourage openness.(154) Separating the participants into groups also allowed the comparison of experiences of the perceived situational and power differentials between the primary and secondary health services from the perspective of their position in the system.(154) The different perspectives could then be analysed and integrated.

4.2.2.2 Characteristics of the Health Professional Participants

Participants included three groups of GPs, one group of specialist palliative care physicians, and two groups of hospital based-based staff, including geriatricians and allied health professionals with some experience of working with frail older people or experience of providing palliative care. The demographic characteristics of the health professionals are shown in Table 4.1 according to primary and secondary level services.

Table 4.1 Demographic characteristics of health professionals (N=36)

	Primary	Secondary	Total
Gender	N (%)	N (%)	N
Male	8 (61.5)	6 (26.1)	14
Female	5 (38.5)	17 (73.9)	22
Age			
18-25	1 (7.7)	1 (4.3)	2
26-35	3 (23.1)	6 (26.1)	9
36-45	3 (23.1)	9 (39.1)	12
46-55	2 (15.4)	4 (17.4)	6
56-65	2 (15.4)	2 (8.7)	4
66+	2 (15.4)	1 (4.3)	3
Discipline			
GP	12 (92.3)		12
Nursing	1 (7.7)	5 (21.7)	6
Geriatrician		4 (17.4)	4
Palliative		7 (30.4)	7
Allied Health		7 (30.4)	7
Duration in profession			
Mean	20.25	12.54	
Range	2.5 – 48 years	0.1 - 51 years	

Gender balance in the recruited general practice participants was in-line with the national statistics.(155) Similar statistics were unavailable for hospital staff. The participants from the secondary services were representative of the service available in the OPERA unit. There was a higher percentage of palliative specialists that participated than would be found in a single health service district, as they were sought specifically for their expertise. Most palliative specialists were from the greater Brisbane area, rather than restricted to the West Moreton health district.

4.2.2.3 *Data Collection: Phase 1 Focus Group*

Two strategies were used to stimulate focus group discussions and to ensure consistency of the topics explored. First, a question guide was developed (Appendix D). This guide used open-ended questions to explore key topics linked to the aim of the study. Topics explored in the focus groups included:

- Clinical and professional challenges of providing care to this population.
- The value health professionals attach to a model of integrated palliative care for frail older people.
- Perceived viability of a model of care and what are the barriers and facilitators in the local context.
- The key features of a model of integration in the local context.

Second, a generic patient example, ‘Jane’ with a typical list of symptoms and circumstances for a frail older patient nearing the end-of-life was used to stimulate and focus the discussions (Appendix G). This example was developed in consultation with a GP expert.

Demographic information, regarding gender, age, job title and length of time in profession, was also collected prior to the focus group commencing. Focus groups lasted approximately one hour and were all facilitated by the researcher with a co-facilitator. This ensured consistency across groups. Notes were taken to ensure points were covered or returned to and to monitor group dynamics, prompting inclusion of all participants. Each focus group was recorded, and a stenographer provided ‘real time’ transcription. All transcriptions were de-identified.

4.2.3 Data Analysis

A descriptive thematic analysis (156) was used to derive the main themes relating to key elements of the integrated model. Neergaard and colleagues(156) argue that although this can be criticised for being too simplistic and lacking rigour it is particularly relevant in mixed methods research and in projects aiming to gain firsthand knowledge of experience with a particular topic. Qualitative description is an appropriate choice in mixed methods health service research where the key purpose is to ascertain professional’s views,(156) such as on the key elements of a model of care. It is a flexible approach that allows for the analysis to stay close to the data.

The Framework method was used to identify themes in the data.(157) Transcripts were inductively coded. Initially, a transcript from the GP focus groups, a transcript from the hospital-based focus groups, and the transcript from the palliative specialists focus group were read and coded line by line. Links were identified between descriptive codes to develop a scaffold of codes, sub-categories and categories, with two assessors jointly agreeing on coding of the data (researcher and supervisor). The remaining transcripts were then coded. Meetings between the two assessors were regularly conducted to discuss and refine the coding. Any new codes arising or any divergence in

the application of the coding framework was discussed with the research team and resolved by consensus. The coding framework required no significant alteration. Links between the descriptive codes were identified, developing a scaffold of codes, sub-categories and categories. The framework was then discussed and reviewed with one advisor with expertise in qualitative research. NVivo 11 software (QSR International) was used to apply the framework and look for conceptual links between the categories to derive the themes. The views of the different groups of health professionals were compared, as major themes were developed. Extracts indicated both divergent and convergent views and were labelled to indicate the focus group by profession. Four key themes were derived that described the key elements required for an integrated model of care for frail older people at the end-of-life (Chapter 5). Themes were reviewed against findings in the literature.

4.2.4 Refining the model of care

A model of integrated palliative care, engaging GPs and specialist secondary services, was identified as part of the systematic literature review. Phase 1 of the study presented the model to key stakeholders. Findings from phase 1 were used to refine the delivery of the model of care at the local level. This was reviewed by the supervisory team and a final model was generated. The model of care and its implementation is described at the start of Chapter 6.

4.3 Phase 2: A model of integrated care – a pilot study

Phase 2 of the research aimed to assess the feasibility and acceptability of the model of integrated palliative care, engaging GPs and specialist secondary services, for frail older people living in the community. This is in accordance with the feasibility and piloting phase of the MRC key elements of developing and testing complex interventions (Figure 4.1).

4.3.1.1 Study Design and Rationale of phase 2

A mixed-methods design was used to provide a comprehensive analysis of the feasibility of the model. The first component of phase 2 was a quantitative analysis to provide a preliminary estimate of the effect of the model of care on health service utilisation, patient outcomes and carer outcomes. The second component was a qualitative study to explore the experience of stakeholders participating in the developed model of integrated palliative care for frail older people. The findings of both components were synthesised to enable a rigorous evaluation of the implementation of the intervention and to elicit the complexity of the model in clinical practice. For a model of care to be feasible it must have value, be workable and engage the relevant stakeholders.(158) A mixed methods design is the most appropriate methodology to assess these aspects.(159)

The pilot study was initially designed as a randomised controlled trial. Recruitment and retention challenges in the initial stages of the study required a redesign of the study due to the limited time frame available to the researcher. Recruitment was halted and the study reassessed. Based on previous research that used case conferences as a model of palliative care (107, 130) the decision was made that the model of care was worth pursuing. A pre-post design was used to determine the feasibility and acceptability of the model and to estimate the effects of the intervention on health service utilisation, and patient and carer health and social outcomes. A nonrandomised pre-post design was chosen due to the small available sample size and the ability of a pre-post design to use preintervention and post intervention measurements to demonstrate the causality between an intervention and an outcome.(160) All eligible patients were invited to participate in the intervention. Patients previously recruited to the control condition were offered an opportunity to participate in the intervention if they were readmitted to hospital. Due to PhD related time constraints recruitment occurred over 5 months. Individual qualitative interviews were conducted to explore the experiences of participants involved in the model. The researcher also kept detailed field notes to supplement the data in terms of organisation of the intervention. The qualitative and quantitative components were synthesised to determine the feasibility and acceptability of the study intervention.

4.4 Phase 2, Part 1: Quantitative component

4.4.1 Hypothesis

An integrated model of palliative care for frail older people at the end-of-life (6-12 months) between GPs (primary care) and hospital geriatricians and allied health teams (secondary care) will:

- decrease health service utilisation,
- improve health-related quality of life,
- reduce patient stress and anxiety, and
- improve functional status.

4.4.1.1 Primary Aim

The primary aim of the quantitative component of phase 2 is to provide a preliminary estimate of the effect of the model of care on hospital admissions.

4.4.1.2 Secondary Aims

The secondary aims of the study are to:

- estimate the effect of the model of care on older people’s health service utilisation, health-related quality of life, depression and anxiety levels, and functional status,
- estimate the effect of the model of care on completion of advance health directives, entry to residential aged care and place of death,
- estimate the effect of the model of care on health-related quality of life, carer strain, and depression and anxiety of the primary informal carer,
- determine the sample size required for a proposed randomised controlled trial, and
- estimate the salary cost of the intervention.

4.4.2 Study Participants

The study identified and recruited frail older patients approaching the end-of-life

4.4.2.1 *Eligibility*

To be eligible, patients had to meet the following criteria:

4.4.2.1.1 Inclusion criteria

Patients:

- Aged equal to or greater than 65 years.
- Patient of the Older Person Evaluation Review and Assessment (OPERA) unit at WMHHS.
- Identified by the Health Service as being at risk of dying in the next 12 months.
- Identified by the Health Service as being frail.
- Have a regular GP, whom they have consulted at least twice in the last 12 months.
- Informed consent of patient’s GP to participate in the study.

Please note: patients could still participate without participation of an informal carer.

Primary Carer:

- Identified by the patient as the primary carer.
- Resides with the patient or within 50km of the patient’s home.
- Able to provide informed consent.

Health Professionals:

- able to provide informed consent.

4.4.2.1.2 Exclusion criteria

Participants were excluded if they meet any of the following criteria:

- The patient was at risk of death within 3 months, according to the OPERA clinicians.
- Resides in permanent residential care.

4.4.2.2 Recruitment

4.4.2.2.1 Patients

The patient's geriatrician first screened the patient for cognitive impairment (CI), by checking to see if any reference to CI had been noted in the patient file, consulting the ward nurse responsible for the patient and speaking to the patient and making a professional judgement about their cognitive capacity.

Patient consent was obtained by the geriatrician. The geriatrician provided the patient with a brief comprehensive overview of the study with a particular focus on the following:

- the purpose of the research,
- what participation will involve for the patient,
- what will happen to patient information once collected,
- participation is voluntary, and
- that the patient's level of care will not be affected should they decide not to participate.

The patient was then provided with a copy of the Patient Information Sheet (Appendix C) and provided with the opportunity to read the sheet and to ask questions about the study. Patients were able to discuss participation with family before deciding whether they wished to participate.

If the patient was willing to participate, they were asked to read, complete and sign the Informed Consent Form. The geriatrician witnessed the patient's signature and completed the declaration section of the consent form.

When patients were not capable of providing consent (i.e. patient cognitively impaired), a substitute decision maker or legal guardian, as defined by the Queensland Guardianship and Administration Act 2000, was eligible to consent on their behalf. Using the Substitute Decision Maker Information Sheet and Substitute Decision Makers Consent Form, the geriatrician followed the same steps for the patient consent process.

The geriatrician provided the patient and the substitute decision maker with a brief but comprehensive overview of the study, as detailed above. If the patient and the substitute decision maker were willing to participate, then the substitute decision maker read and signed the Substitute Decision Maker Informed Consent Form (Appendix C).

4.4.2.2.2 Carers

The primary informal carer was identified by the patient. If the carer was eligible, the study was explained by the geriatrician and informed consent was sought. The patient could still participate if the carer did not wish to participate.

4.4.2.2.3 GPs

The GP was approached by research staff to participate. The GP was asked to participate and provide informed consent. The GP practice had to be willing to allow or assist research staff to conduct a chart review to gather evidence of the impact of the model of care. If the GP did not consent to participate the patient was informed and excluded from the study.

4.4.3 Outcome Measures of Phase 2

4.4.3.1 Primary Outcome

The primary outcome was the incidence of hospital admissions (defined as at least one overnight stay in a hospital ward) in the 12 months post-intervention.

4.4.3.2 Secondary Outcomes

Patient

The secondary outcomes for the patient were:

- health service utilisation (12 months pre and post intervention),
- functional status,
- health-related quality of life,
- anxiety and depression,
- advance health directive completed,
- place of death, and
- entry into permanent residential care.

Carer

The carer's outcome measures were:

- health-related quality of life,
- anxiety and depression, and
- carer strain.

Operationalisation of the model of care

The model of care contained actions that needed to be implemented by health professionals. Medical charts were used to assess whether these actions were implemented within the follow-up period.

4.4.4 Study Measures

The patient's geriatrician completed eligibility measures after the patient had consented to participate. Patients and carers were asked to complete questionnaires at three assessment points (baseline, one-month post-intervention and three-months post-intervention). If needed, patients received help from the researcher or their carers to complete these questionnaires, as preferred by the patient. Health service utilisation was measured at 12 months pre and 12 months post intervention.

4.4.4.1 Patient

Patient Demographics

The patient identified their gender and living arrangements which are relevant when considering the patient's mood, quality of life, and health service utilisation.

Frailty Phenotype

The frailty phenotype measure(4) assesses the absence or presence of weight loss, exhaustion, weakness, slow walking and inactivity. It does not include disabilities or cognitive function. The presence of at least 3 criteria indicates frailty. The frailty phenotype measure will be completed by the patient's geriatrician.

NECPAL

The NECPAL (161) is a case-finding tool that identifies patients within the general population who have chronic conditions and are in need of supportive care. The tool combines assessment of perception and objective indicators for severity, co-morbidity and service consumption. A positive identification, as specified by the tool, will be required for a patient to be eligible. The NECPAL is completed by the patient's geriatrician.

Functional Status

Australian Karnofsky Performance Scale (AKPS) (162) is a validated modification of the gold standard Karnofsky Performance Scale, altered to apply to both community and hospital patients. It has high test-retest reliability and has high predictability of survival time.

Health-Related Quality of Life

The SF-12v2 (163) is a valid and reliable measure of health-related quality of life. There are 12 items across the domains of physical functioning, general mental health, role limitations, vitality and general health perceptions. There are two summary scores calculated using weighted means of the domains, physical and mental health. Scores range from 0 – 100, with higher scores indicating better self-reported health.

Anxiety & Depression

The Hospital Anxiety and Depression Scale (HADS) (164) is a reliable and valid measure of presence and severity of anxiety and depression. It measures 14 items on a 4 point Likert scale. Scores range from 0 -21 indicating mild (8-10), moderate (11-14) or severe (15-21) anxiety and depression.

Health Service Utilisation

Health service utilisation was sourced from WMHHS, GP records, and self-reports. The following data were collected: hospitalisations, emergency department visits and length of stay in hospital in the 12 months previous to and 12 months post-intervention, or until death or study withdrawal. Self-report health service utilisation, including allied health, home help, meals on wheels, home modifications, medical equipment, and respite in residential care were collected at baseline, one-month and three-months post-intervention.

4.4.4.2 Carer

Carer demographics

Carers were asked about their gender, employment status and living arrangements. Each of which is relevant to carer strain, mood and quality of life.

Carer Stress and Anxiety

The Hospital Anxiety and Depression Scale (HADS) (164) as detailed above.

Carer Health-Related Quality of Life

SF-12v2 (163) as detailed above.

Carer strain

The Caregiver Strain Index (165) is a reliable and validated measure of strain related to the provision of care. It has 13 items with domains of employment, financial, physical, social, and time. Scores range from 0-13, with scores above 7 indicating a high level of strain.

4.4.4.3 Model of care

Any model of care proposed will involve a shared care plan. GP records were reviewed for evidence of adherence with the agreed care plan, as were Hospital records.

Proforma

A semi-structured schedule developed by Mitchell and colleagues, (142) based on the PEPSI COLA mnemonic used in the Gold Standards Framework(166) was used to assess adherence to the shared care plan. The PEPSI COLA is structured by domains:- Physical, Emotional, Personal, Social Support, Information/communication, Control, Out of hours/emergency, Late and Afterwards, with a list of issues to consider under each domain. The schedule references the World Health Organization's definition of palliative care.(22)

Salary Cost

The salary cost for the model of care was calculated. The time that each health professional contributed to the model of care was recorded and multiplied by the published professional salary scales.

4.4.5 Data Collection and Management

Patient and carer self-reported data were collected on paper forms and transferred to an electronic database within 48 hours of collection. This allowed for data to be checked and any data queries to be raised and answered. Eligibility forms were also completed on paper. All relevant paper copies of information were kept in patient files where the clinical care was provided. All other records were returned to the offices of the Discipline of General Practice, University of Queensland and kept in a locked filing cabinet on a secure floor (swipe card access only). Electronic files were kept in the secure, password-protected computer network of The University of Queensland. After

completion of the data collection phase of the study, data related to individuals were de-identified and coded in a potentially re-identifiable format. Storing the data in a re-identifiable format was necessary to enable further data collection at follow up time points to be completed.

4.4.6 Adverse Event Management

All adverse events (AEs) and serious adverse events (SAEs) were recorded from the time a participant consented to join the study until the last study visit. The Investigator asked about the occurrence of AEs/SAEs at every visit during the study. Open-ended and non-leading verbal questioning of the participant were used to enquire about AE/SAE occurrence. Participants were also asked if they were admitted to hospital or had any accidents. If there was any doubt as to whether a clinical observation was an AE, the event was recorded.

4.4.6.1 Definitions of AE & SAE

An AE is any untoward medical event affecting a participant. Each initial AE was considered for severity, causality, or expectedness and was reclassified as a serious event or reaction based on prevailing circumstances.

A SAE, is any AE, which

- resulted in death,
- was life-threatening (i.e. the subject was at risk of death at the time of the event, not an event which hypothetically might have caused death if it were more severe),
- required hospitalisation or prolongation of existing hospitalisation, and
- resulted in persistent or significant disability or incapacity.

Non-serious or expected AE were recorded and reported to the local HREC as part of annual reporting requirements, in accordance with the ICH GCP guidelines. As this study recruited participants where death is the expected outcome, death was reported as an expected adverse event where there was no question that the study contributed or hastened death and where the death was attributable to the underlying disease.

4.4.6.2 Assessment of Expectedness

The evaluation of expectedness was made based on the treating clinician's knowledge of the event and the patient's condition.

4.4.6.3 *Recording AEs and SAEs*

Depending on the severity, when an AE/SAE occurred, it was the responsibility of the Investigators to review all documentation (e.g. hospital notes, laboratory and diagnostic reports) related to the event. The Investigators recorded all relevant information in the case report forms and on the SAE form. Information collected included type of event, onset date, Investigator assessment of severity and causality, date of resolution as well as treatment required, investigations needed and outcome.

4.4.6.4 *Evaluation of AEs and SAEs*

The investigator evaluated the seriousness, causality, severity, and expectedness of the SAE/AE. The investigator assessed whether the AE/SAE was likely to be related to the intervention according to the following definitions:

Unrelated: when an event is not considered to be related to the study.

Possibly: when a relationship to the study cannot be completely ruled out, but the nature of the event, the underlying disease, concomitant medication or temporal relationship make other explanations possible.

Probably: when the temporal relationship and absence of a more likely explanation suggest the event could be related to the study.

Definitely: when the known effects of the study, suggest that study drug is the most likely cause.

4.4.7 **Data Analysis**

Pre-test post-test data, if normally distributed, would be analysed using a paired samples t-test, which determines whether the mean difference between two sets of observations is zero. In a paired samples t-test each participant observation is measured twice, resulting in pairs of observations.(167) A McNemar test, which is used for repeated measures instead of a chi-square test could also be used if the data were normally distributed.(167) . However, as the study had a small sample size a normal distribution could not be assumed so the Wilcoxon Rank-sum test for non-normally distributed data was utilised. The Wilcoxon Rank sum test compares repeated measurements to assess whether population mean ranks differ.(167) Significance level was set at $p \leq 0.05$.

4.5 Phase 2, Part 2: Qualitative component

4.5.1 Study Aim

The aim of the qualitative study in Phase 2 was to explore the experience of participants of the model of integrated palliative care, engaging GPs and specialist secondary services, for frail older people living in the community. Specifically, the study aimed to:

- explore the experience of frail older people and their carers with the model of care, and
- explore the experience of health professionals in the use of the model of care for frail older people in the last 6-12 months of life.

4.5.2 Study method

Semi-structured interviews were used to explore the experiences of participants in a model of integrated palliative care for frail older people.

4.5.3 Sampling and Recruitment

All consented participants were interviewed and were reminded before the interview began that they were able to withdraw from the study at any stage.

4.5.3.1 Patients and carers

Patients and carers were invited to participate in a semi-structured interview 12 -14 weeks after the intervention to investigate their experiences with the model of care, and their overall appraisal of the model, and to ensure they understood what was expected of them. Nine patients enrolled in the project and each patient and carer were invited to participate in the interview. Two patients that did not have carers participated. Five carers participated without the patient completing an interview. Two patients participate in joint interviews with their carer. This was done at the patient's request in both instances. Interviews were conducted in the participants' homes and lasted approximately 20 minutes. Interviews were recorded and transcribed. See Table 5.2 for demographics.

4.5.3.2 Health Professionals

Health professionals consented to participate in the study, as detailed in Part 1 of Phase 2, prior to the intervention occurring. Health professionals involved in the intervention were asked to participate in semi-structured interviews to explore their experience of the model of care. This occurred at 14-16 weeks after the health professional had completed their final intervention. Several professionals completed more than one intervention for the study. Each health professional was free to withdraw from the study prior to the interview, as detailed in the information and consent forms.

Table 4.2 Demographic characteristics of participants (Interviews n=25)

	Male	Female
Health Professionals		
General Practitioners	5	1
Geriatricians	-	3
Registered Nurses	1	1
Hospital-Based Allied Health	1	3
Community-Based Allied Health	-	1
Patient and Carer		
Patient only	1	1
Carer only	-	5
Patient Carer interviewed together	2 (Patients) 1 (Carer)	1 (Carer)

4.5.4 Data collection

A question guide was developed to ensure consistency across interviews (Appendix E). This guide used open-ended questions to explore key topics linked to the study aim. Topics explored in the interviews included:

- the process of the model of care;
- the benefit or value, if any, of the model of care; and
- how this model would work in the local context.

Patients and carers were interviewed at home by the researcher, and each interview lasted on average 20 minutes. When interviewing carers at home patients were often present with the carer's consent, even when not participating in the interview. The carer may have been reluctant to fully express issues when the patient was there. Where possible, this was mitigated by the researcher by further exploring those issues in a sensitive manner and moving on when the carer indicated. There were two instances when the patient and carer were interviewed together. This was managed by giving each participant an opportunity to answer each question and explore any agreement or disagreement with major points raised.

General practitioners were interviewed by the researcher in their clinic setting. Health professionals based at the hospital were interviewed in a private room at the hospital. Health professionals were occasionally interrupted by pagers or phone calls during an interview. This was necessary in a busy environment, with patient needs prioritised and this was accommodated by the researcher. The community allied health participant was interviewed at a quiet local café chosen by the participant. Each interview was recorded and then transcribed by the researcher. All transcriptions were de-identified.

4.5.5 Data Analysis

Interviews were transcribed and a deductive then an inductive thematic analysis was conducted, informed by the Framework method(151). The Framework method is ideally suited to applied research with specific objectives and a practice dimension.(151) The analysis approach is initially conducted deductively, according to interview questions. The next step was to develop themes inductively based around the key areas aligned with the literature, with a view to developing analytical codes, categories and relationships in the data. Therefore, the thematic analysis builds on the descriptive analysis where data are initially categorized according to the topics of interest (interview guide) and the analytical approach stays close to the actual text. Further interrogation of the data sought to identify repetition and linkages across the data. The data was explored from the different perspectives of the participant groups, GPs, hospital-based health professionals, patients and carers. Where patients and carers were interviewed together the person who provided the information was considered the source, however, during analysis care was taken to consider any influence from the other participant. The primary interest was to elicit the essential patterns and contrasts in the data, across, within and between the different groups involved in the focus groups. The thematic analysis also provided theoretical flexibility(156) and consequently, there was application to key theoretical concepts as part of the analysis to derive an interpretative dimension of the professionals' and patients' experiences and views in the data.

4.5.5.1 Case examples

A series of case exemplars were developed to show how the intervention was experienced. A case was based on an individual patient who participated in a case conference, and included.(154, 159) Each patient who participated in the case conference had detailed case notes prepared by the researcher, collating the quantitative and qualitative data that detailed how the intervention was experienced and the outcome of the intervention for that patient. Written case examples were structured according to demographic information, primary disease and comorbidities, participants in

the case conference, an analysis, identifying convergence and divergence of patient, carer and health professional experiences of the case conference, and quantitative data including the self-report measures and the health service utilisation. Based on the qualitative data, in the first instance cases were selected carefully to enable comparison and then refined further based on differences in quantitative outcome data. Three cases were chosen based on this individual analysis. Case A was where the reported experiences of the case conference were mainly positive in nature and the quantitative results indicated an improvement on self-reported measures between baseline and follow-up. Case B was chosen as participants indicated both positive and negative experiences of the case conference and the self-reported outcomes showed improvement in some outcome measures and decline in others. Case C was chosen as the participants in the case conference indicated the case conference was not useful and did not meet their needs.

4.6 Summary

This chapter has described the methodology used to develop a model of integrated palliative care from frail older people and to assess the feasibility and acceptability of the model. Using the Medical Research Council's process for developing and testing complex interventions the study used a mixed-methods design, consisting of two-phase sequential design with two components in the second phase of the study. Phase 1 of the study was a qualitative work and explored health professionals' experiences of care for frail older people, palliative care provision and the perception of integrated primary and secondary palliative care for frail older people. This chapter described the focus groups, purposive sampling, and the descriptive thematic analysis used. Phase 2 of the study was a mixed-methods design, employing both qualitative and quantitative data collection to determine the feasibility of the model of integrated palliative care for frail older people, designed from phase 1. The quantitative aspect of the methodology was described first, detailing the recruitment, intervention and data collection and analysis followed by the qualitative methodology, describing the semi-structured interviews with the participants and the data analysis.

As a mixed methods design, data from both the quantitative and qualitative provide a more comprehensive understanding of the phenomena under examination. The following chapters describe the effect of integrated palliative care for frail older people and the experience of the participants in the model of care.

Chapter 5 Phase 1. Health professionals' experiences and perceptions

5.1 Introduction

This chapter reports the findings of the focus groups with health professionals' which explore the experiences of working with frail older people and patients with palliative needs. Specifically, the objective of the focus groups was to use the experiences of health professionals to refine the development of multidisciplinary case conferences for frail older people at the end-of-life and to inform implementation of a model of integrated palliative care. Moreover, the intention was to expand from the systematic review in chapter three, which showed that integrated models of care that engage the GP and specialist secondary services in palliative care provide improved patient outcomes and improved outcomes for the health system. Specifically, the systematic review identified multidisciplinary case conferences as a model to provide integrated palliative care, engaging the GPs with specialist secondary services. In this case, analysis of focus groups was intended to elicit the key elements of the case conference model specifically for frail older people in the community and its successful implementation in the local context.

Four themes were derived from the analysis and these indicate the complexity of working with frail older people and the challenges of identifying and discussing issues related to palliative care. The themes identified were: 1) complex trajectory of frail older people; 2) constructing the appropriate frame; 3) inclusivity and; 4) constraining boundaries. Themes are discussed with extracts that represent the central theme and sub-themes. Extracts are labelled to show the inclusion of a range of views:-

P# - the participant number of the individual in the focus group.

G, H or S identifies whether the focus group was G (GPs), H (hospital) or S (Palliative Medicine specialist).

FG1 – FG6 is the focus group number.

For example, an extract from participant number 2 in the GP focus group, identified as FG3 would appear as:

“quote” (P2:G:FG3).

5.2 Findings

The major themes and sub-themes are shown in Table 5.2. Two of the major themes: complex trajectory and constructing the appropriate frame were mainly about the health professionals' experiences with frail older people and with providing palliative care. The first theme indicated the complex trajectory of frail older people that confronts health professionals. Specifically, how the extent and perhaps urgency of need might be missed due to a combination of factors such as the patient's stoical presentation and the lack of a clear tipping point that assists in identifying the onset of the palliative stage. The second theme: constructing an appropriate frame, captured the perceived sensitivities of discussing palliative care issues with patients and in some cases hesitancy to use this language because of how it might be interpreted and understood by patients.

The final two themes, inclusivity and constraining boundaries, were specific to case conferences as a model of integrated palliative care: The third theme, inclusivity, revealed the various perceptions and opinions about the roles of patients, carers and health professionals in an integrated model of care. The final theme, constraining boundaries, identified potential problems in the local context for implementing an integrated model of palliative care, including, communication, time and funding as. The findings of these themes will shape the model of integrated palliative care for frail older people.

Table 5.1: Participants in focus groups

Discipline	Primary (N= 13)	Secondary (N=23)
GP	12	
Palliative Specialist		7
Geriatrician		4
Nursing	1	5
Allied Health		7

Six focus groups were conducted with 36 health professionals (Table 5.1). Three focus groups involving 12 GP participants were conducted. One of the GP focus groups also included a nurse practitioner. Two focus groups were conducted with hospital-based health professionals working on a geriatric ward, including a mix of nursing staff (n=6), allied health staff (n=7), geriatricians (n=4) and a palliative specialist. One focus group was conducted with six palliative specialists. All focus group participants had some experience of working with frail older people or experience of

providing palliative care. Two strategies were used to stimulate discussion and provide consistency. First, a question guide used open-ended questions to ensure consistency of the topics explored. Second, a generic patient example, ‘Jane’, with a familiar list of symptoms and circumstances for a typical frail older patient nearing the end-of-life, was developed in consultation with a GP expert

Table 5.2 Themes from analysis of focus groups

Major theme	Sub-theme
Complex trajectory of frail older people	Complexity hidden
	Complexity overlooked
	No clear tipping point
Constructing the appropriate frame	Uncomfortable communication
	Passive language for public consumption
Inclusivity	Paternalism
	Professional expertise
Constraining boundaries	Communication
	Time
	Funding

5.2.1 Complex trajectory of frail older people

The theme of complex trajectory of frail older people was a dominant theme, particularly for the GP focus group discussions. This encapsulated difficulties of managing the complex needs and identifying when in their frailty trajectory they require palliative care. Although the trajectory of decline in frailty is fairly predictable, the rate and permanency of decline is not.(168) Discussion of this theme comprises three main sub-themes (Table 5.2).

The complexity of older people’s trajectories for many of the GP focus group participants was often complicated by the way individual patients’ presented to the doctor. This was a reference to the tendency for some frail older patients to present themselves in a positive situation despite having multiple comorbidities. As one GP participant noted, patients

“put on their best face for the doctor.” (P2:G:FG2)

Many GP participants agreed that such presentations could make it difficult to get a true picture of the patient's situation. GP participants highlighted problems of identifying those patients who may require palliative care. The lack of an explicit indicator was problematic for GP participants.

“The point I made earlier: I have nothing that makes it explicit in my thinking that says this is now terminal care or this is now palliative care. It is such a gradual progression and then somewhere you get to a place where you go, oh, we should be talking about this but there is never something that clear-cut that lets us make that decision.” (P4:G:FG2)

“It is just a continuum for us. I guess we don't always make that distinction so it is sort of challenging, tough, to find the way that you treat those people differently necessarily than the ordinary patient.” (P3:G:FG1)

Both extracts highlight how GPs experience the progressive nature of managing complex needs and the absence of a disease marker to show if or when a patient is palliative. This was complicated by the time constraints of the general practice setting. A typical scenario put forward by one GP participant was that

“Sometimes we actually see patients here for five or ten minutes. We get a bit of a false idea because they have actually made their way here and they have got all their supports here. They actually look better here than they do [at home].” (P5:G:FG2)

Comments from hospital-based participants reinforced that the complexity of frail older patients in the hospital system is missed when patients present at the emergency department. Patients arrive with an acute problem and are processed rapidly in the hospital system, identified in the extract below. In discussing the hypothetical patient Jane and the list of familiar symptoms from frail older people at the end-of-life, a hospital focus group participant identified that while the acute medical issues would be treated, the patient would not likely be identified as palliative. The objective of moving people through the system quickly could mean that the more complex needs are overlooked in favour of addressing the acute medical problem.

“Someone coming into emergency with this presentation, that probably wouldn't trigger anyone to question, to make that judgment, I wouldn't have thought, certainly not in the

current climate where people are getting people through the hospital very quickly and focused on an acute medical problem.” (P6:H:FG6)

For the hospital focus group participants, an emergency department presentation or hospital admission was usually the trigger to start thinking about patients that may require palliative care. However, explicit indicators often coincided with the patient’s final hospital admission.

“I think, in this environment, it takes an event before we start thinking about that. Sometimes, when we have people who have had an event that may signal the end of their life but they haven’t, they don’t pass away during this admission, we then refer them on to say an advance care planner.” (P7:H:FG4)

Both GP and hospital-based participants favoured the use of an independent measure of frailty and an independent measure of impending end-of-life to assist with identifying people who would benefit from supportive care. An independent measure for end-of-life would also provide a tool to approach the end-of-life conversation.

“Yes, specific questions, like the SPICT tool - just asks you. You are not having to think outside the box. That is what puts people off, isn’t it, having these difficult conversations, these difficult discussions.” (P6:H:FG6)

While there was lack of consensus about which measures to use, there was agreement in the hospital focus groups that the process should be efficient, with a measure easy to complete. Participants identified time as a challenge for measuring frailty.

“A frailty index would be the thing. It is quite time consuming to do. I guess you would choose which one.” (P9:H:FG4)

“A lot of it is based on data that we already collect. It is just about working it out and creating the score but we struggle to get our FIMs¹ done.” (P1:H:FG4)

¹ Functional Independence Measure.

This theme shows that frail older people have a complex trajectory that makes identification of palliative care needs challenging. The GPs in the focus groups reported difficulties in identifying palliative frail older patients due to the patient presenting better than they are and the hospital-based health professionals identified that a focus on acute medical issues in the health system meant complexity could be overlooked. Even given the high number of frail patients(66), they can be difficult to identify, as there is no agreed definition of frailty, with definitions dependent on screening tools used.(4, 43, 54, 169) A systematic way of identifying frail older patients at both the primary (GP) and secondary (hospital) level of service provision is required.

5.2.2 Constructing the appropriate frame

The theme of constructing the appropriate frame explores the language of palliative care in response to the sensitivities and challenges of this type of communication, so health professionals must construct a frame in which to engage the patients in conversation. Discussion of this theme addresses two sub-themes: uncomfortable communication and passive language for public consumption (Table 5.2).

Participants in each focus group expressed concern about discussing palliative care because of how it is viewed by the community. A GP put this succinctly by saying:

“The public thinks ‘palliative care’ means you are dying.” (P1:G:FG1)

Most focus group participants, GPs, hospital-based health professionals and the palliative specialists, agreed that the language of palliative care could be interpreted by the patients to be indicative of an immediate decline, quickly followed by death.

“The person themselves might - if they hear the word ‘palliative’ - they will go ‘I am going to die’.” (P5:H:FG4)

Consequently, there was a concern that patients would object to the term palliative care and refuse to participate any further in their care. As one of the hospital focus group participants identified,

“As far as challenges go, unfortunately the word ‘palliative care’ is an emotive word or phrase. The patient themselves may object to being labelled with that and being told you have got 12 months to live so you now are into the palliative-phase care of your life so you

may get some very strong objections from people who do not want to be part of it at all”.
(P7:H:FG6)

Participants in the GP and hospital focus groups agreed that when providing palliative care alongside acute medical treatment the term palliative was problematic. In addition to the concern that patients could disengage, there was a sense it created expectations of a timeline, which was largely unpredictable. The extract below shows the perceived implications of using the term palliative.

“Also the expectation of family and carers: Once you say this person has only got 12 months to live and the family arranges their life, expecting in 12 months’ time they are going to have their life back, not being a carer, 18 months back down the track, they think, ‘Wow’. It is enormously inconvenient now.” (P4:G:FG2)

Palliative specialists also discussed the language of palliative care between professionals, not just between professional and patient, as noted above. Some participants described their frustration about the hesitancy of using appropriate language with other health professionals after attending a recent conference for health professionals on palliative care.

“If palliative care people can’t talk about dying and having to talk about passing away, what hope is there for any of us?” (P1)

“We had a whole week about it. Let’s talk about death, and everyone is ‘passing away’.”
(P1:S:FG5)

As part of the focus group discussions, the alternative language of supportive care was explored with participants. This term is used in cancer care to encompass palliative care and symptom management. Where palliative specialists prefer a direct language, there was consensus among GP and hospital focus group participants that using the language of supportive care could avoid preconceived ideas and uncomfortable and alienating conversations for patients.

This was articulated clearly by one participant of a hospital focus group.

“That is the phrase I would choose, when I know that a patient is a little bit uncertain about being introduced to palliative care, and approach it as a supportive care specialty”
(P7:H:FG6)

This theme indicates how the language of palliative care can evoke interpretations and expectations, which participants perceive can create distress and alienate patients and families. Supportive care on the other hand was perceived as potentially a more positive way of conversing with patients and families. Researchers have shown that there are contradictory understandings of palliative care (170) and that this could be a deterrent to earlier referral to palliative care.(171, 172) Fadul and colleagues(173) also found that the term created a barrier to referral, caused distress in patients and families and decreased hope compared to the term supportive care. Creating an appropriate frame is not unique to discussions about palliative care. In general practice, with diabetic patients it was found that to engage patients it was better to frame the benefits of changes rather than the risks of not changing behaviour.(174) While this theme highlights the language of palliative care it also implies the inclusion of patients in the process of palliative care.

5.2.3 Inclusivity of the case conference process

The theme of inclusivity of the case conference process addressed the perceptions and opinions about the roles of patients, carers and health professionals in a case conference. Discussions focused on the inclusion or exclusion of patients and carers, as well as professionals according to their area of expertise.

Regarding involvement of patients and carers, there were mixed opinions in each focus group and no clear consensus across groups. The dominant view of all groups, GP, hospital-based and palliative specialists, was that at the very least patients and families should be provided choice about their involvement, including being in attendance.

“I think they have to be involved. Otherwise they feel sidelined and they will feel that it is not about them, all of those paternalistic things that doctors get accused of being”
(P4:G:FG2)

As this participant indicated, support for the inclusion of patients was also a way of avoiding being paternalistic. In contrast, there were a small number of participants in the GP and the hospital focus groups, who preferred separate discussions with patients/carers and the team. This was based on

the notion of a case conference being a professional meeting. For these participants, a separate family meeting was appropriate prior to the case conference to understand the patient and/or family preferences.

“Personally, I think you should have a case conference with the family first, then find out what they want, their expectations, then go and have your multidisciplinary case conference. A lot of stuff we talk about, they won’t understand, they won’t know about.” (P5:G:FG2)

The extract above also indicates the perception of information asymmetry being both a barrier to patients’ and families’ full participation in a case conference and a rationale for holding separate meetings. In response to this, a small number of participants from both the GP and hospital focus groups thought that it was up to the health professional, based on their knowledge of the patients and carers, to determine whether and how they would be involved, as explained below by one of the GPs.

“I think you probably have to pick your patient and your family and your carer. Some of them would work quite well in at the beginning. Some of them, you might prefer to have [case conferences] without them there and then do the family conference with them, one or two of them“ (P2:G:FG2)

A common ground for all focus group participants was the right of patients and carers to be involved if they expressed a desire. Specific reference was made about families and their involvement as a way of communicating to them the importance of their engagement.

“You can ask people if they want to be involved. I just think, if you have got somebody - and I am specifically thinking about a family who are carers - I think it is quite hard to sideline them and say, ‘Now all of these other people are important and they are all communicating with each other but you are actually not important’.” (P4:G:FG2)

A further area of common ground among focus group participants concerned ensuring that patients and carers were aware of the case conference even if not attending and provided with information following the conference. In these cases, participants also supported a discussion prior to the case conference so the patients’ needs, concerns and expectations are represented.

“Look, we have been throwing together some ideas. Here is what we are thinking as some ideas, what do you think of that?’, and putting it to them as a draft set of ideas.”

(P2:G:FG2)

Independent of whether the patient and family were involved, participants agreed that the patient’s GP and a specialist service medical officer would be required to participate in the case conference. Attendance of other health professionals would depend on the needs of the patient and the agenda.

“You have got to have a medical officer.” (P7)

“Then I think it’s dependent on - each patient often has a primary allied health specialty that is involved. I think you need to pull the one out that is appropriate for that patient.”

(P1:H:FG4)

Palliative specialists were not seen as essential to the case conference by any of the health professionals involved, GP, hospital-based or palliative specialist participants, as illustrated by the extract below.

“Like we said, there are so many similar patients to Jane (hypothetical patient) that there just wouldn’t be the capacity for a specialist to attend each and every one of those conferences. Whether specific patients could be flagged for care input, maybe that would be the way to go. Would it be that the need for a palliative care specialist would arise out of having this actually meeting and then, once that is identified that could be brought on board, rather than being here when they might not necessarily be so.” (P7:H:FG6)

Somewhat consistent with this, palliative specialists also saw themselves in an advisory capacity, when required, rather than as a routine participant, seen in the extract below, when the palliative specialists were asked if they saw themselves attending each case conference.

“That’s right. It should be very much a consult.”(P3:S:FG5)

This theme highlights the views and rationales of participants about who to include in a case conference and in what manner they should be involved. It also uncovered notions about paternalism in care processes. Previous research has highlighted paternalism as a health professional making decisions on behalf of a patient, based on clinical expertise without considering

the patient's preferences.(175) In this theme, the health professionals have identified they should involve patients in shared decision making , with patients making informed choices about their participation in consultation with their health professionals.(176) The theme identifies that by their nature, case conferences are human resource intensive, so it is necessary to consider the context.

5.2.4 Constraining Boundaries

The theme of constraining boundaries represents the specific barriers perceived by the health professionals in implementing integrated palliative care, based on multidisciplinary case conferences engaging GPs and specialist secondary services, for frail older people in the local context. Communication, time and funding were the main sub-themes.

From GP focus groups, poor communication about the patient between the GP and hospital was a constraint. According to one GP participant, the families of the patient, rather than from the health professionals at the hospital, were likely to inform them about their patients who might have recently had an event or admission.

“Yes. Usually you get the phone call from the daughter or son saying ‘Dad has been home for two weeks now but he is not getting better’. ‘Home from where?’ ‘Oh, hospital.’ ‘Oh, what’s happened?’ ‘Oh, he had a heart attack’. ‘Oh, okay.’” (P2:G:FG2)

Participants in the hospital focus groups agreed that often the quality of communication with the GPs is dependent on which area of the hospital the patient has accessed.

“I think different areas of the hospital are better at linking patients in with GPs and services.” (P2:H:FG4)

As discussed in the first theme, complex trajectory, the difficulty in hospital staff identifying the complexity of the patient may also impact on the quality of the communication between the hospital and the GP.

Poor communication and a lack of professional regard was a dominant experience reported across all GP focus groups. Overall, GPs related this to an inequitable exchange of information and a concern that specialist services tended to dictate rather than negotiate care plans:

“It is always about other services telling me what they are going to do but there is no actual GP input, so it is always about other services telling me what they are going to do but there is no actually predetermined action plan of what is going to happen when things go wrong in the community.” (P4:G:FG2)

Case conferences on the other hand were perceived as a potential way of facilitating communication and creating a common care plan.

“I guess the one thing that could be helpful is that it actually synchronises the plan between everyone because sometimes my plan might be different to what the hospital's plan is or our vision of the care for this particular patient might be slightly different.” (P3:G:FG1)

Both GP and hospital-based participants anticipated that successful case conferences would rely on clear roles and responsibilities for the participants and a plan for what to do when things go wrong. Further, as one GP expressed, participants would need to accept responsibility.

“There has to be an acceptance of responsibility by everyone and everyone clear on their roles and sign off on that, this is what we are going to do, and then there has always to be an escalation plan.” (P4:G:FG2)

Most participants agreed that one person should be responsible for coordination of communication. This role would be responsible for managing the patient and coordinating the care and communication regarding the patient.

“You could almost argue - this is just a thought of mine - there is a role to be created for case managers, someone to be managing these patients in conjunction with - one person coordinating all of this care.” (P6:H:FG6)

There was agreement that good preparation through sharing information and efficiency of time and content during the process were key elements of a successful case conference process. There was little consensus across GP and hospital-based focus groups with suggested times ranging from 15 minutes up to half an hour, however a few participants across the different groups suggested 30 minutes as realistic, as identified by this hospital-based participant. Although 30 minutes was considered a realistic amount of time, there was still a concern that this was too long.

“Half an hour a week would be realistic, I think. Everyone’s time - half an hour a week is still quite a lot of time.” (P6:H:FG6)

It was universally agreed, however, that if patients and families were included, as suggested in the previous theme, the time required would increase and complicate the process, reducing efficiency. The extracts below were from separate focus groups each discussing patient and family involvement in a case conference.

“It is going to be harder; it will take longer.” (P4:S:FG5)

“It makes it really complicated and the case conferences three times longer.” (P1:G:FG2)

Participants in the GP focus groups also indicated that the timing of case conferences would be important to increase efficiency for all involved. The routines of general practice meant scheduling at the start of sessions (e.g. after lunch at the start of the afternoon session) was important to ensure case conference meetings happened on time.

“For this practice anyway, the beginning of a session, either morning or afternoon, is a much more workable time for us. In the middle of a session, it is really very difficult.”

(P3:G:FG2)

With time a critical aspect of efficient case conferences, there was a general wariness of protracted conversations with little accomplishment. In this case, some participants cited past experiences of unacceptably long conferences with little perceived benefit.

“The last one I did, the last formal case conference, was only two weeks ago with an outpatient and her family. It lasted an hour and a half and then the director of nursing did another three hours. Those sort of runout times are just not practical. At the end of the day, it is a complete waste of time. Nothing at all changed. You get one experience like that, we are disinclined to go and perhaps do the next three or four, which could be more useful and productive. Once we get our fingers burned once or twice, we tend to shy away and retreat.” (P1:G:FG3)

“I guess if you had like – I suppose the case conference can sometimes be a gabfest. P1 and I do a bit of case conferencing up at the hospice basically and sometimes there are relevant things and sometimes there is pretty irrelevant stuff that is talked about.” (P3:G:FG1)

Communicating information prior to a case conference was considered necessary to improving time efficiency. Exchange of relevant information prior to conferences not only prepared everyone for the process, it also was perceived to be a way of accounting for everyone’s contributions.

“I would like some paperwork beforehand. I would like the contributions to the care plan, like to be able to have a look at those, and I am sure other people would like to have a look at mine but contributions to the care plan beforehand so that we were not actually discussing at the case conference what everyone’s contribution was going to be; it was really just a matter of, ‘Okay, this is what’s happening, how do we take it along?’” (P4:G:FG2)

Most participants agreed videoconferencing or teleconferencing would be suitable to improve efficiency.

“Having a video conference is handy” (P4:G:FG1)

Some participants preferred teleconferencing given the need to manage constraints on time, as indicated by this GP.

“If someone is going to telephone conference me at lunchtime, I will be eating at the same time.” (P4:G:FG2)

Time, flexibility and efficiency were key elements of implementation according to participants. However, lack of funding was noted as a potential deterrent to health professionals providing case conferences for frail older people at the end-of-life. Within the GP focus groups there was a general opinion that existing funding options did not extend adequately to case conferences, compensation was not adequate for the time involved. One participant also noted that not everyone would be willing to allocate resources to a case conference.

“Time and money - you could use the words - they are - indistinguishable, isn't it, time and money? When someone says, they don't have time, what they are really saying is they don't have - they are not prepared to spend the money on it.” (P1:G:FG3)

“As I said initially, it is ideal to have the case conference. I suppose it is the time, and I hate to bring money into it, but obviously that is going to play a part if you are having to have a four-hour case conference. There is no remuneration for that.” (P2:G:FG3)

Funding was also a concern for hospital-based participants from two perspectives. Firstly, the hospital focus groups identified that providing clinician time was a cost. While the perception that potential benefits would balance out costs to the system, the view was that the financial benefits would not be experienced at the ward level where the cost was incurred.

“Case conferences were quite beneficial both to the patient, the GP, decreased readmission rate. I think the difficulty for the system is that the money doesn't come back. If you are in an in-patient hospital like this and you do case conferences and organise it all and don't have readmissions, you don't get any extra money for it.” (P4:S:FG5)

This suggests that direct funding of activities at both the general practice and hospital settings would be required for implementation of an integrated model of palliative care.

Secondly, there was some concern that identifying patients for palliative care could create a demand for service that could not be met within current resources.

“We have got so many people coming through that we wouldn't be able to provide that for everyone.” (P5:H:FG4)

In relation to this concern, hospital focus group participants raised the question about whether case conferences should be targeted toward the more complex cases, those at higher risk.

“As soon as it starts happening for too high a percentage of the patients, it's going to all become too difficult. The really at-risk patients” (P2:H:FG4)

To mitigate the barriers of poor communication and time, a structured agenda was suggested by the researchers to direct communication during the case conference, focussing on a care plan and responsibilities. Most focus group participants would support using a structured agenda during the case conference to direct discussion, as illustrated in the below extract. This would also act as a prompt to remind participants to discuss topics not always covered in discussions with other health professionals, such as advance care planning or spirituality and religion. The extract below identifies that an agenda covering various topics would be a useful tool in case conferences.

“I can see it working with this agenda. That would certainly keep us focused on various topics. That is quite a reasonable expectation.” (P1:G:FG3)

There was discrepancy among participants regarding the relevance of all prompts for each patient and this was related to the contexts of care and focus of care. In this extract taken from a hospital focus group it was evident that the focus on discharge could minimise the likelihood of some prompts being used.

“There is a lot of stuff here that we don’t really cover. It is all about getting people out of hospital here so we are not really troubled by the spiritual or religious needs.” (P1:H:FG4)

This theme highlights the perceived barriers and enablers to case conferences from a contextual level. Time constraints, funding and no clear path for sharing of information were identified as barriers with exchange of relevant information prior to the case conference and a clear agenda identified as enablers. Implementation science studies the methods used to embed evidence based practice from research into routine practice.(177) Researchers identified that Normalisation Process Theory provided a framework to identify the factors that promote or inhibit change in healthcare.(178, 179) Kennedy and colleagues found that to embed and sustain change in routine practice, one piece of the puzzle is that the change must be relevant to the staff and fit the existing ethos of the organisation. Organisational change may be required so that staff see the change as a professional priority and facilities, policies and procedures are adequate to support the change.(179)

5.3 Discussion

The qualitative focus groups explored the experiences of health professionals working with frail older people and people with palliative needs and how these experiences inform the design and implementation of case conferences as an integrated model of palliative care for frail older patients

at the end-of-life. The analysis elicited some of the key elements of an integrated model of care and how it could be implemented successfully in the local context.

The findings revealed the challenges of managing patients with complex needs within the professional relationship. Patients can present in a positive way, hiding their multiple comorbidities when visiting their GPs. Within the hospital system, patients present for an acute medical condition and their frailty or their need for palliative care is likely to be overlooked in favour of the immediate medical problem. It was also identified that there is no clear point at which a patient is considered frail or palliative. Frailty is a complex syndrome of functional decline with no clear definition.(43, 44, 47) Although frailty is predictive of mortality(4, 53), not all frail patients are palliative. It is also difficult to identify a patient with palliative care needs.(180) A screening process for both frailty and for palliative needs would be required to identify patients for an integrated model of palliative care for frail older people.

The clear message from the GP and hospital-based participants about care of frail older people at the end-of-life is that language matters, particularly for maintaining their engagement in care and retaining a therapeutic relationship. Terminology used for end-of-life care, such as terminal care, palliative care, hospice care, supportive care and transition care are often used interchangeably(181-183), which can lead to confusion. The findings indicate some reluctance among GPs and hospital-based health professionals to use the term palliative care with their patients for fear of damaging the patient-doctor relationship. Medical providers have indicated in prior research(173) that the term palliative care causes distress to patient/families. Specifically, this study found there was a concern that some patients might be unwilling or not ready to accept their palliative status and that sensitivity is required to negotiate those conversations. Palliative specialists, however, were frustrated by euphemisms, such as 'passing on', rather than using terms such as palliative and dying. The difference in language preference between the GP and hospital-based health professionals and the palliative specialists may indicate their involvement at different points of a patient's end-of-life trajectory. Patients are referred to the palliative specialists on average one to two months prior to death.(184) Past research using discourse analysis of palliative care decisions has shown that there are several repertoires used to encourage patient participation in decision making to covertly navigate decisions about dying.(185) In this example, medical practitioners indicated that decisions about dying are discussed with their patients, without using the term palliative.(185) For those GPs and health professionals concerned with damaging the patient-doctor

relationship, it would be possible for doctors to navigate a model of palliative care with a patient, engaging the patient and retaining the patient-doctor relationship by using the term supportive care.

Previous research based on discourse analysis shows that the language of dying is complex and contradictory.(186, 187) There is an argument in the literature for patients to accept their death and participate in the process.(188, 189) There is an acknowledgement that a repertoire has been developed to encourage patients to participate in decisions around end-of-life(185), without identifying that the conversation is about palliative care. To facilitate an integrated model of palliative care for frail older people in the community it is important to understand the discourse of dying and to use terminology that allows the doctor and patient to navigate the decisions and care required without damaging the patient-doctor relationship.

The hesitation among GPs and hospital-based health professionals to discuss death directly also has an impact on how patients and families are best involved in a model of palliative care. The doctor-patient relationship is about respecting patient rights, involving patients in their care and is based on mutual respect.(141, 190) Patient-centred care is an approach to care that elevates the patient from passive recipient to active participant in managing their care.(191) The findings indicate that a small number of GPs and hospital-based health professionals would prefer to conduct the case conference without the patient and carer, discussing the case conference with them beforehand so their views are represented. However, there was overall agreement that patients and families should be offered the option to fully participate in the model of care proposed. There was also an acknowledgement that by including patients in the process it would take longer and the language used by health professionals would be modified so that patients and families could follow and be included in the conversation. Previous models of case conferences, as a model of integrated care, excluded the patient from the case conference(109), with others providing a choice to patients to be involved.(130, 192) Mitchell and colleagues(130) found that when the patient was present, obvious problems, such as symptom control and isolation, were discussed. Sensitive topics about the patient themselves (eg alcohol dependence or anxiety) or the family (eg anxiety, depression or abuse) were not discussed. There was recognition that a patient-centred approach to care would be required, including patients and families in decisions about their desired level of participation. A model of integrated palliative care for frail older people in the community requires the flexibility of patient and carer participation.

The findings show that there are impediments to conducting case conferences as an integrated model of palliative care, and in particular, some concern about where the burden of effort will be placed. Time pressures, funding pressures and specified roles within the health system are perceived by the participants in this research as barriers to implementing a new model of care. There have been similar findings of time pressure in the implementation of integrated care for palliative patients.(135, 137, 140) Health sector intra-professional boundaries are also entrenched.(193, 194) By involving health professionals in the design of a model of care and working with them to identify benefits of the model to encourage its use, it may be possible to overcome some of the barriers, even if they cannot be eliminated. Additionally, rather than reconfiguring intra-professional boundaries from the top down, the ability to negotiate roles within the proposed model of care may enable more collaborative partnerships. By providing processes through which professionals invest in the model and provide structures and processes to assist in the implementation of a model, is there potential for that model to become embedded in practice and sustainable?

There is some understanding of what an integrated model of palliative care for frail older people in the community may look like locally. The purpose of integrated palliative care is well understood and supported. This is not unexpected, with other models of integrated palliative care(135, 141) showing health professionals understand the uses and utility of integrated palliative care. Each of the themes has provided information that informs the design and implementation of case conferences as an integrated model of palliative care for frail older people. The key elements to be included are: a screening tool for frailty and palliative needs, a change in language from palliative care to supportive needs, an invitation to patients and their carers to be involved in the case conference and flexibility in the delivery of the model of care with support provided to negotiate roles and build collaborative relationships.

Chapters 6 and 7 present the results of a pilot study of multidisciplinary case conferences as an integrated model of palliative care for frail older people in the community. Chapter 6 provides a preliminary estimate of the effect of the model of care on hospital admissions, health service utilisation, health related quality of life, functional status and provides illustrative case examples to explore experiences of the model of care. In chapter 7, the feasibility and acceptability of the model of care is explored through the experiences of the participants.

Chapter 6 Phase 2 Results, Part 1. Insights into the effect of integrated specialist-GP care.

The findings from *Phase 1* identified key elements of the case conference model specifically for frail older people in the community and for its successful implementation in the local context. The developed model is described in later in this chapter. *Phase 2* of the research consisted of a pilot study of the integrated model of palliative care. The pilot study followed the MRC's process for developing and testing complex interventions and was designed: 1) to estimate the effect of case conferences on health service utilisation, patient outcomes, and carer outcomes; and 2) to determine the feasibility and acceptability of multidisciplinary case conferences for frail older people approaching the end-of-life, presented in chapters 6 and 7 respectively.

Chapter 6 provides recruitment and demographic information for the participants in the case conferences. The quantitative data for patient outcomes, carer outcomes and health service utilisation are presented, providing preliminary estimates of the effect of the case conferences. As the sample size was small, illustrative case examples of different patient and carer trajectories are used to indicate the different types of impact the intervention had on individuals and their carers. These examples use individual patient and carer quantitative data, including health service utilisation, and qualitative data from one-on-one interviews with patients and/or carers and health professionals at three-months post-intervention. Chapter 6 provides a preliminary estimate of the effect of the model of care for study participants and determines the sample size to conduct a randomised controlled trial of the model of care.

The aims of Chapter 6 were to:

- provide a preliminary estimate of the effect of the model of care on hospital admissions,
- provide a preliminary estimate of the effect of the model of care on older people's health service utilisation, health-related quality of life, depression, anxiety, and functional status,
- provide a preliminary estimate of the effect of the model of care on completion of advanced health directives, entry to residential aged care and place of death,
- provide a preliminary estimate of the effect of the model of care on health-related quality of life, carer strain, and depression and anxiety of the primary informal carer,
- determine the sample size required for a proposed randomised controlled trial, and

- estimate the salary cost of the intervention.

Chapter 7 explores the experience of participants in the integrated specialist-GP case conferences to answer the primary objective of the pilot study, to determine the feasibility and acceptability of a model of integrated care for frail older people at the end-of-life.

6.1 Recruitment of participants

6.1.1 Recruitment of patients and carers

Recruitment occurred over 5 months and at the end of the recruitment period, fifty potentially eligible patients from OPERA at Ipswich Hospital had been screened. Twenty-one (42%) of those screened did not consent to participate. Of these, 15 patients and/or carer declined to participate, and an additional six did not return consent forms despite repeated attempts at follow-up. Forty percent of patients screened were ineligible to participate. Four patients did not meet the frailty criteria, eight patients were placed in a residential aged care facility (RACF), and eight patients did not have agreement from their GP. Nine patients and seven carers were enrolled in the study (Figure 6.1).

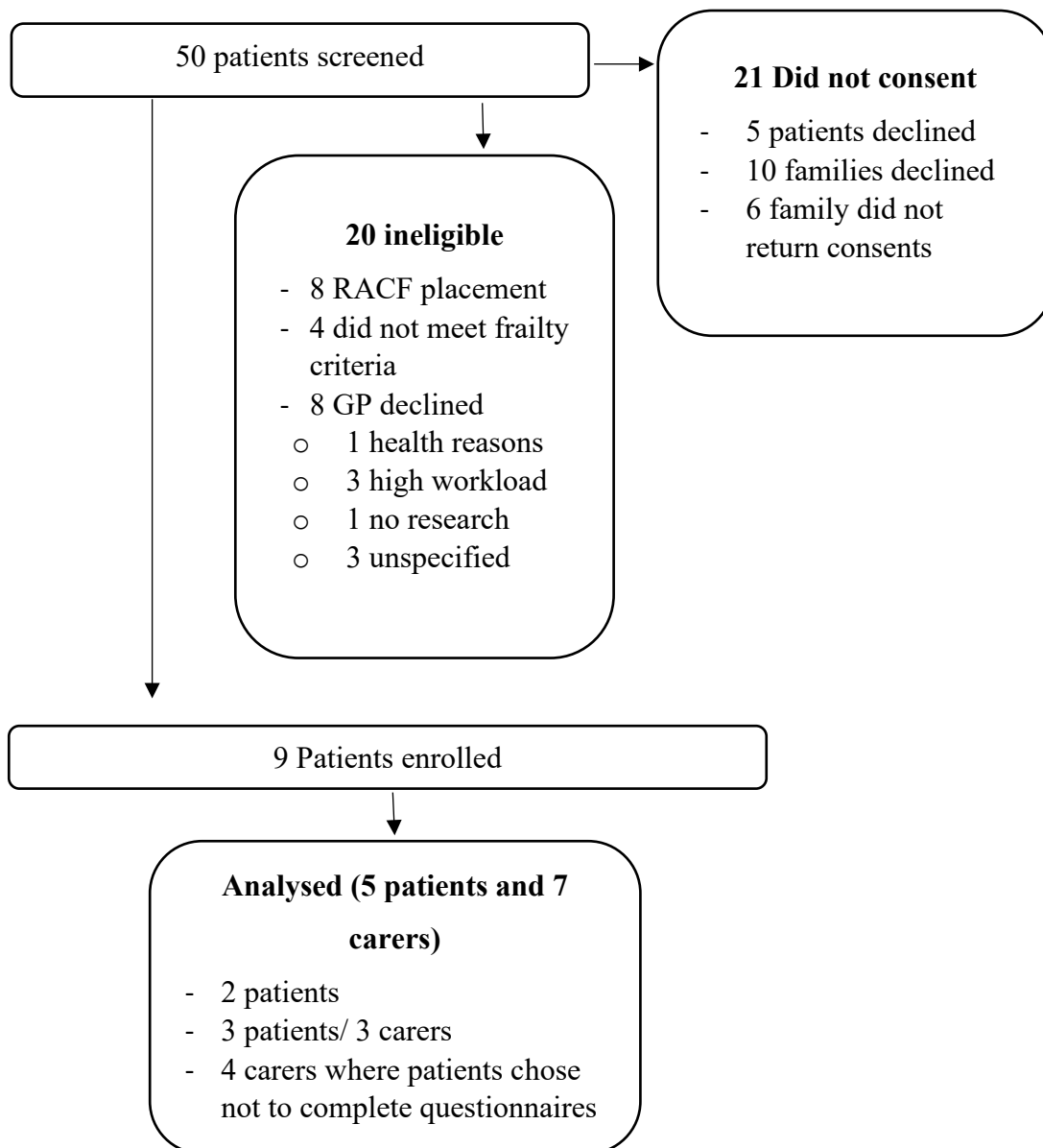


Figure 6.1: Flowchart for patient recruitment and enrolment

Patients participated with their informal primary caregiver where possible (n=3). Patients were also able to participate without an informal primary caregiver (n=2). Patients were able to enrol to participate and choose not to complete the questionnaires if their caregiver consented to participate and complete the paperwork for themselves (n=4). Although 9 patients were enrolled in the study and followed for the duration of the study, only 5 patients completed questionnaires.

6.1.2 Recruitment of Health Professionals

Patients were only enrolled in the study if their GP agreed to participate. Six GPs (43%) participated in the study. Of those GPs who participated, one GP had three patients enrolled, one GP had two enrolled patients, four GPs had one patient each. Of the eight GPs who declined to participate, one GP declined on personal health grounds, three GPs refused due to recent increases in workload and one did not participate in research. Three geriatricians, six allied health/nurses from the OPERA unit, and one community based allied health professional also participated in the case conferences. There were no refusals among hospital staff.

6.2 Participants

6.2.1 Patients and Carers

The age range of patients was 65 to 93 years at baseline (Table 6.1). The mean age was 83.9 years (males = 81.0 years, females = 86.2 years). Patients were balanced in gender; whereas, primary informal carers were predominantly female. Primary caregivers' ages were not recorded. Their relationships with the patients were mixed, including spouse (n=1), adult child(n=5), granddaughter (n=1) daughter-in-law (n=1), and sibling (n=1). Patients lived predominantly with their carer (n=5), however, two lived alone, one lived with his spouse who was not his carer (n=1), and one lived with his father who was not his carer (n=1).

Table 6.1: Demographics of patients (n=9) and carers (n=7).

	Patients	Carers
Gender		
Male	4	1
Female	5	6
Age		
65-69	1	n/a*
70-79	0	
80-84	4	n/a
85-89	1	n/a
90+	3	n/a
Living arrangements		
Lives alone	2	n/a
Lives with carer	5	n/a
Lives with family who are not carer	2	n/a

*Carers were not asked their age or their living arrangements.

6.2.2 Health Professionals

The gender and disciplines of each of the health professionals who participated in the study are shown in Table 6.2. There were more male GPs (71%) than female, while there were slightly more females (56%) who participated from the OPERA unit at Ipswich Hospital. Reflective of the discipline mix of the OPERA unit, there was likewise a mix of disciplines represented in the participants from the hospital (Table 6.2).

Table 6.2: Demographics of health professionals that participated in the intervention

	Primary Care	OPERA
	n (%)	n (%)
Gender		
Male	5 (71%)	4 (44%)
Female	2 (29%)	5 (56%)
Discipline		
GP	6	0
Geriatrician	0	3
Registered Nurses	0	2
Allied Health	0	4
Community-based Allied Health	1	0

6.3 Case conference process

As a result of the findings from the qualitative study the intervention was designed in the following way: in addition to usual care, patients received a model of supportive care in the community, promoting multidisciplinary collaboration and integration across the primary and secondary/tertiary interfaces. This used a palliative approach, as described in the introduction.

The model was a multidisciplinary case conference between specialist based geriatric services and the patient's GP (and the GPs primary care team if required), to inform the development and implementation of a comprehensive care plan. The case conferences were conducted between 3 or 4 health professionals: (1) the patient's GP, (2) a geriatrician from the hospital-based service, (3) allied health services from the hospital-based specialist service as required, and (4) community-based health professionals as identified by the patients and/or carer. A palliative specialist was also consulted if required. If the patient and/or carer chose not to be involved, a member of the team discussed the case conference with them and ensured their concerns were represented at the case conference.

The case conferences occurred via video conference facilities where possible, or by teleconference. The patient and/or carer were asked to attend the GP office or the hospital to participate in the case conference. To schedule the meeting, a time convenient for all participants was chosen and an

appointment was made within the GP's schedule. This occurred between two and three weeks after the baseline assessment. The researcher coordinated this process.

Prior to the case conference, the GP and the geriatrician were provided with the structured proforma which contained nine different sections for discussion: Physical, Emotional, Personal, Social Support, Information/Communication, Control, Out of Hours/Emergency, Late (future terminal care) and Afterwards (PEPSI-COLA). Preparation was required by the health professionals prior to the case conference to review recent medical records and provide notes to be shared with the other participants relevant to the sections of the proforma. The researcher acted as coordinator, organising an appropriate time and prompting participants for information to share prior to the case conference.

The case conference was a semi-structured comprehensive case review following the PEPSI-COLA assessment structure. Critical to this process was that the tasks generated by the conferences were clearly delegated to relevant clinicians, introducing an accountability and timeliness to the process.

A written comprehensive care plan from the case conference, based on the notes of the participants was circulated to the health professionals involved. A member of the team was tasked with providing the plan to the patient. If the patient was not involved in the case conference, the plan was discussed with the patient (by one of the health professionals in attendance), to inform the patient of the content of the ongoing care plan, to ensure the patient was comfortable with the plan and to identify any changes or additional support requested by the patient. These changes were integrated into the plan and changes sent to the health professionals.

The researcher was involved in the organisation of the case conference and provided technical support if required. The researcher did not attend the case conferences, as per the ethics requirement, but received notes from the case conference to transcribe the care plan. Thorough notes regarding the conduct of each case conference were also kept, including detailed information regarding organisation of the case conference appointment, the attendees, the information requested and circulated prior to the case conference, the start and finish time of each case conference, and any information technology or other issues that affected the case conferences process.

6.3.1 Outcomes

The researcher maintained detailed notes regarding the case conference process, including detailed information regarding the number and type of calls required to confirm a case conference appointment with all attendees, the nominated attendees and the attendees that participated, the information requested and circulated prior to the case conference, the start and finish time of each case conference, and any information technology issues that affected the case conferences. The completed case conference structured proforma also provided additional detail to assess the fidelity of the case conference process.

6.3.1.1 Preparation

Before each case conference, the GP, geriatrician, relevant allied health professionals and, if known, community-based health professionals working with the patient and family, were given the proforma for the case conference (Appendix E). They were asked to share any relevant information prior to the case conference, by providing this information to the coordinator to be shared with other attendees. GPs and geriatricians were followed up prior to each case conference by the researcher to request any information to be shared with other attendees. Out of nine teleconferences held for nine patients, one GP provided notes to share prior to one case conference, the geriatrician also provided notes in this same case. Although the study protocol required allied health participants to be identified in advance, so they could contribute to sharing information prior to the case conference, this did not occur.

6.3.1.2 Use of case conference structured proforma

Each GP and geriatrician were supplied with the structured proforma prior to the case conference. The proforma contained 9 different sections (Table 7.3), each to be considered as determined by the participants. Each section of the proforma was completed by the participants and the information was collated into the comprehensive care plan. Subsequently, the care plan was circulated to the health professional participants and shared with the patient and family by the GP. Table 6.3 shows the sections of the proforma and how many case conferences completed each section.

Table 6.3: Use of structure proforma by section.

Case Conference Proforma Sections		Number of case conferences that completed each section	Percentage of case conferences*
P	Physical	9	100%
E	Emotional	8	89%
P	Personal	7	78%
S	Social Support	9	100%
I	Information/Communication	7	78%
C	Control	7	78%
O	Out of Hours/Emergency	9	100%
L	Late (future Terminal care)	2	22%
A	Afterwards	1	11%

* Rounded to nearest whole percent.

Sections of the proforma regarding the person's health and management of health issues were routinely completed, at least 78% of the time, as were sections pertaining to the patients social and personal support. However, the final two sections regarding end-of-life were not completed at most of the case conferences. It cannot be determined if these sections were discussed, however the proforma was not completed to indicate that they had been discussed.

6.3.1.3 *Care plans created and followed*

When the case conference was completed, the notes from each health professional participant were returned to the coordinator, who combined the notes into the care plan, on request of the geriatrician. The plan was then provided to the geriatrician to approve and then the care plan was circulated to the other participants. Every health professional that participated returned notes to the coordinator. Table 6.4 identifies the number of action items created through the completion of the proforma.

The number of action items completed was determined during a chart audit of the GP and hospital records.

Table 6.4: Care plan action items created and completed (n=9 patients).

Case Conference Proforma Sections		Number of action items	Items completed (%)*
P	Physical	22	11 (50%)
E	Emotional	2	2 (100%)
P	Personal	3	2 (67%)
S	Social Support	9	7 (78%)
I	Information/Communication	1	0 (0%)
C	Control	4	1 (25%)
O	Out of Hours/Emergency	5	1 (20%)
L	Late (future Terminal care)	0	0 (0%)
A	Afterwards	0	0 (0%)

*Rounded to whole percent.

Of the items related to the emotional, personal and social situations of the patient, 23 out of 36 items were completed. Only half of the physical items were completed, however some of these items may not have been actioned because an anticipated event had not taken place or a change in patient condition or circumstances. Recommendations made in the control and out of hours sections were wishes of the patients and families and were to be actioned by them when appropriate. Therefore, the researcher was unable to use patients' medical records at the hospital or the GPs' office to verify completion of the task.

Each case conference resulted in a comprehensive care plan which recommended further actions and identified a person responsible for each action. The geriatricians depended on the researcher, in a coordinator role, to collate the information from the proforma into a care plan that was submitted for their approval prior to circulation. The structured proforma was used consistently, however it is not possible to identify if each section was discussed as not all sections were completed. There was evidence in the medical records that over half of all action items generated were followed up.

6.4 Patient Outcomes

Due to the small numbers of participants and the design of the study, very limited effectiveness testing was possible and results cannot be generalisable to the larger population of frail older people at the end of life. The Wilcoxon signed-rank test was used as the small population cannot be assumed to be normally distributed. The Wilcoxon signed-rank tests were carried out between baseline and one-month post case conference (Table 6.5), and baseline and three months post case conference for each measure (Table 6.6). Functional status was measured by the Australia-modified Karnofsky Performance Status Scale (AKPS).(162) A higher score indicates better functional status. Physical health and mental health were measured using the physical component score and the mental component score of the SF12v2(163). A higher score indicates better physical or mental health respectively. Depression and anxiety were measured by the HADS (the Hospital Anxiety and Depression Scale).(164) Scores range from 0-21, where 8-10 indicates mild, 11-14 moderate, and 15-21 severe anxiety or depression.

Table 6.5: Results of Wilcoxon signed-rank tests for patient outcome measures at one month from baseline.

Outcome	Baseline		One Month		n	z	p
	Median	IQR*	Median	IQR*			
Functional Status	50	60, 45	50	60, 40	5	0.156	0.876
Physical Health	37.3	42.5, 25.4	30.3	39.8, 26.9	5	0.674	0.500
Mental Health	41.0	52.6, 33.2	56.8	4.5, 43.3	5	-1.753	0.080
Depression	9	12, 2	7	10.5, 3.5	5	0.406	0.685
Anxiety	9	11, 1.5	9	12, 0.5	5	0.000	1.000

*IQR – Inter-quartile range.

Table 6.6: Results of Wilcoxon signed-rank tests for patient outcome measures at three months from baseline.

Outcome	Baseline		Three Months		n	Z	P
	Median	IQR*	Median	IQR*			
Functional Status	50	60, 45	50	60, 40	5	0.156	0.876
Physical Health	37.3	42.5, 25.4	32.5	34.5, 22.7	5	0.674	0.500
Mental Health	41	52.6, 33.2	50	56.5, 45	5	-2.023	0.043
Depression	9	12, 2	4	13.5, 3.5	5	-0.544	0.586
Anxiety	9	11, 1.5	7	11.5, 1.5	5	0.272	0.786

*IQR – Inter-quartile range.

There was a trend towards significance for mental health from baseline to one month, and a significant improvement from baseline to three months for patients. This will be explored further below. These results are based on a very small sample and were skewed by one or two patients' results. Each measure has also been graphed (Figures 6.4 – 6.6) to illustrate the impact of outliers if present. Regression analyses were conducted to provide a line of best fit for each outcome measure. Regression analyses did not provide any significant results. The sections below describe the patient results over time in detail.

6.4.1 Patient Physical Health

Figure 6.2 shows the functional status as measured by the AKPS at each time point for the five patients that completed measures in the study. Over three months, three patients remained stable, one patient improved slightly, and one patient deteriorated. The Wilcoxon signed-rank tests (Tables 6.5 & 6.6) showed no significant difference between baseline and one month, and baseline and three-month assessments. In this population, it would be expected that each patient's functional status deteriorates over time with declining health.

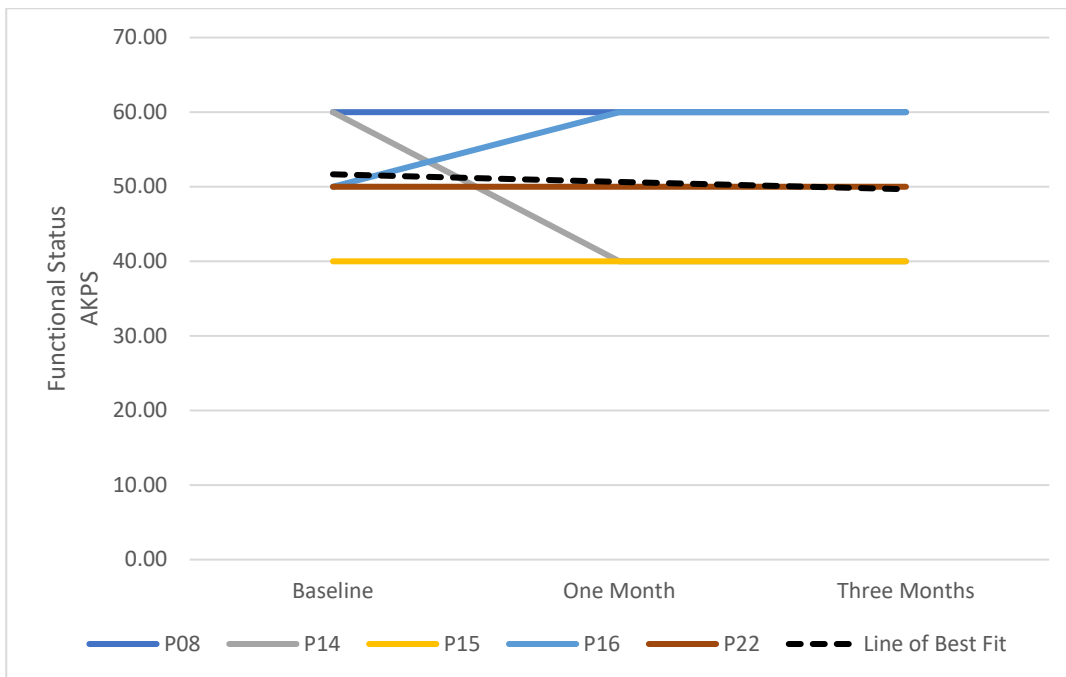


Figure 6.2: Functional status of patients as measured by the AKPS.

Although the AKPS was relatively stable over three months (Figure 6.2), there was a noted decline in physical health, measured by the physical component score (PCS) of the SF12 for three of the five patients who completed the three time periods (Figure 6.3). A 2003 South Australian survey has shown the mean PCS score for an adult with three to five chronic health conditions is 35.2(195). The patients in this study, on average, show a similar PCS score.

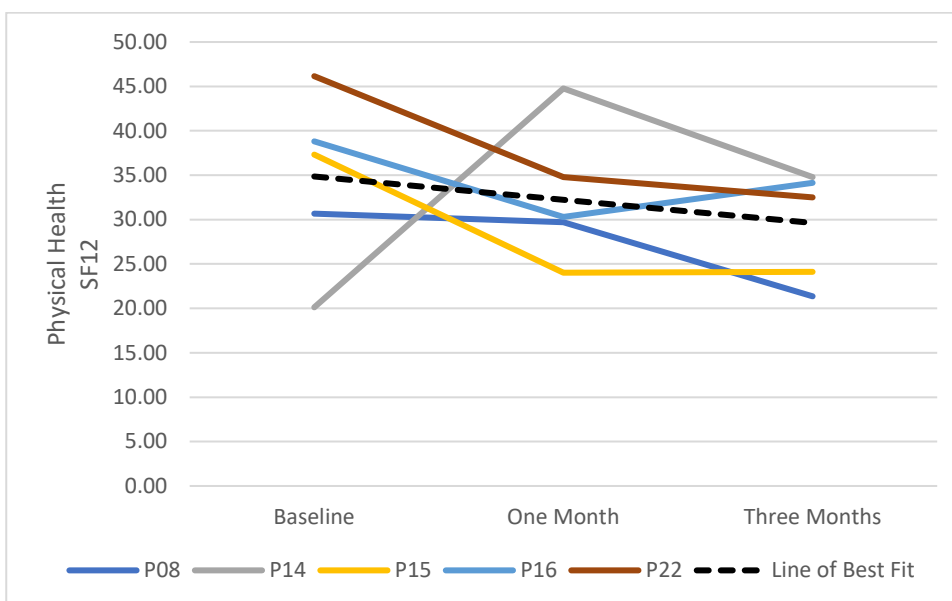


Figure 6.3: Patient physical health as measured by the SF12.

6.4.2 Patient Mental Health

Overall findings indicate that mental health improved over time. There was a significant improvement ($z=-2.023$, $p=0.043$) in patients' mental component score (MCS) as measured by the SF12 health survey between baseline (Median=41, IQR=52.6, 33.2) and the three-month follow-up (Median =50.1, IQR=56.5, 45), after approaching statistical significance at the one-month follow-up (Table 6.5). This was not reflected in the HADS outcome measure for either depression or anxiety (Figure 6.5).

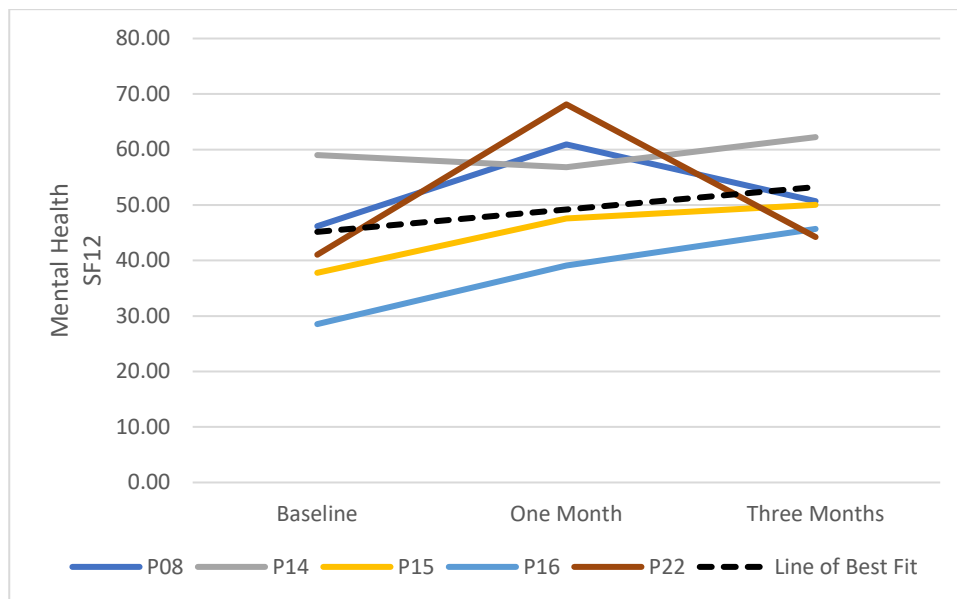


Figure 6.4: Patient mental health as measured by the SF12.

Figure 6.4 shows the mental health scores from the SF12 for each patient. There is an upward trend which indicates an improvement in mental health for each of the patients. A 2003 South Australian survey measured the mean MCS score for an adult with three to five chronic conditions is 49.4 (195). This sample showed four patients had scores below this South Australian average at baseline, however by three months post case conference only two of the five patients had scores below 49.4. This improvement was not replicated by the HADS depression (Figure 6.5) and anxiety scores (Figure 6.6).

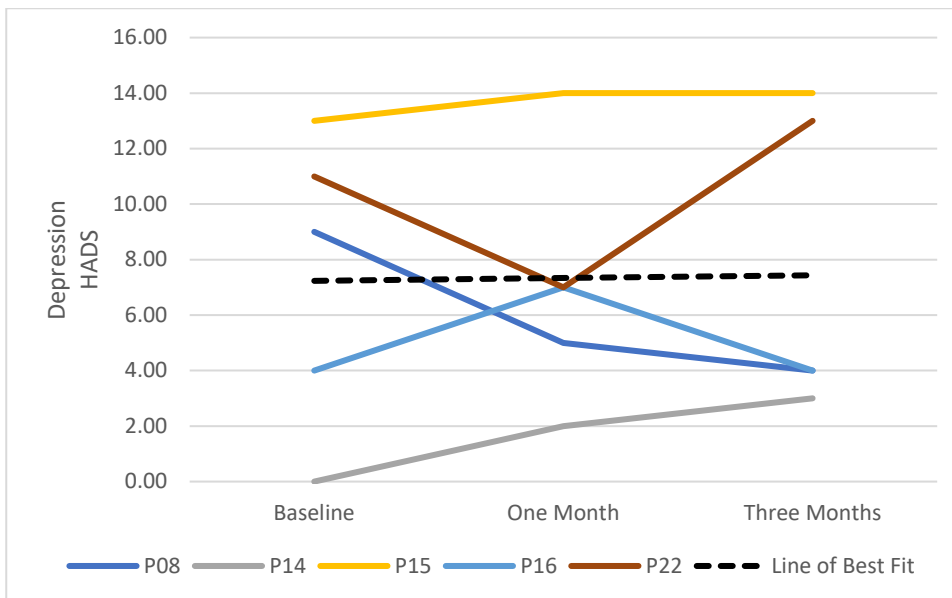


Figure 6.5: Patient depression measured by HADS.

The depression scores for the patients are quite varied (Figure 6.5), with two patients demonstrating no clinical depression (0-7), one patient moving from mild depression (8-10) to no depression, one patient moving from moderate (11-14) to no depression back to moderate depression and one patient continuing to show moderate depression. A minimally important difference in HADS is 1.5 (196), which is the magnitude of change for four out of five patients. Although this does not show a clinical change with only one patient moving from one clinical range (mild) to another (no depression). Of those patients with clinical depression, one patient improved, one deteriorated and one stayed stable.

The anxiety scores were stable (Figure 6.6). Two patients had no anxiety (0-7), two patients had mild anxiety (8-10), one of which indicated no anxiety by three months. One patient's anxiety increased from moderate (11-14) to severe (15-21) over three months. Three patients reported a minimally important difference (a change of 1.5), with two patients showing a change in the clinical range. Overall, two patients with anxiety at baseline showed improvement in anxiety scores and only one patient with anxiety showed an increase in anxiety.

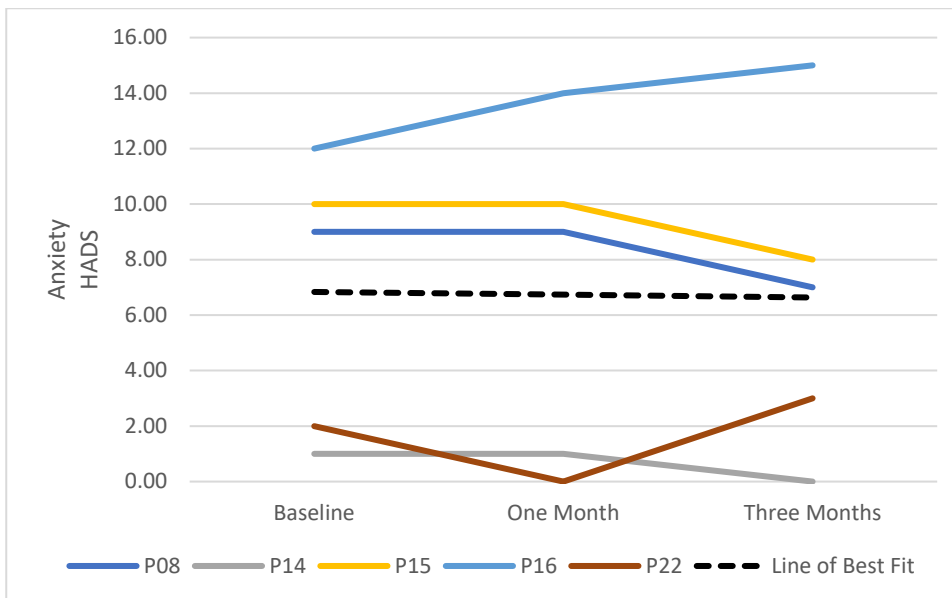


Figure 6.6: Patient anxiety measure by HADS.

6.5 Primary Informal Carer Outcomes

Five carers (4 female and 1 male) completed the questionnaires. One carer did not complete the one-month post case conference measures. One carer only completed the baseline questionnaires and therefore was not included in analyses. Another carer did not complete the measures. Both participated in the case conference and interview. Wilcoxon signed-rank tests were carried out between baseline and one month, and baseline and three months for each measure. Caregiver Strain was measured using the Caregiver Strain Index (165) with a score of seven or more indicating a high level of strain. Physical health and mental health were measured by the SF12v2 (163) with a higher score indicating better physical or mental health. Depression and anxiety were measured using the HADS(164), with a higher score indicating higher levels of depression or anxiety.

Table 6.7: Results of Wilcoxon signed-rank tests for carer outcome measures at one month from baseline.

Outcome	Baseline		One Month		n	z	p
	Median	IQR*	Median	IQR*			
Caregiver Strain	6	7.5, 5	7.00	8.5, 5.5	4	-0.749	0.454
Physical Health	36.6	51.2, 29.7	46.6	53.9, 36.8	4	-0.730	0.465
Mental Health	41.2	58.3, 26.7	47.1	57.3, 39.6	4	-0.730	0.465
Depression	6	9.5, 3	6.5	9, 2.5	4	0.187	0.851
Anxiety	9.5	14, 7.5	9	12.5, 5	4	1.289	0.198

*IQR – Inter-quartile range.

Table 6.8: Results of Wilcoxon signed-rank tests for carer outcome measures at three months from baseline.

Outcome	Baseline		Three Months		n	z	p
	Median	IQR*	Median	IQR*			
Caregiver Strain	6	7.5, 5	8.5	9.5, 7.5	4	-1.841	0.066
Physical Health	40.2	55.4, 29.7	42.6	53.8, 33.1	5	-0.135	0.893
Mental Health	30.67	58.3, 22.7	45.6	51.2, 40.2	5	-0.944	0.345
Depression	7	13.5, 3	8	9.5, 2	5	1.361	0.174
Anxiety	11	16.5, 7.5	12	15, 5.5	5	0.813	0.416

*IQR – Inter-quartile range.

There was an increase in caregiver strain approaching significance ($z=-1.841$, $p=0.066$) between baseline (Median =6, IQR=7.5, 5) and three months (Median =8.5, IQR=9.5, 7.5) (Table 6.8), but not at the one month follow-up (Table 6.7). At both one month (Median =7) and at three months (Median =8.5), the score indicates that there is a high level of stress. However, participant numbers are very low and consequently, there is a lack of power in the statistical analysis. The findings have also been graphed (Figures 6.7 – 6.11) to show the changes for each of the caregivers.

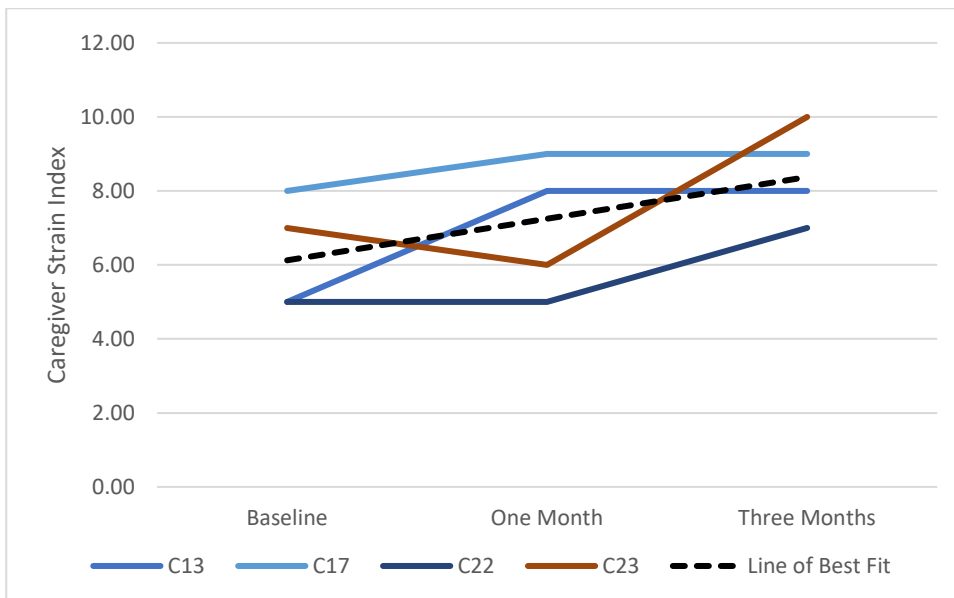
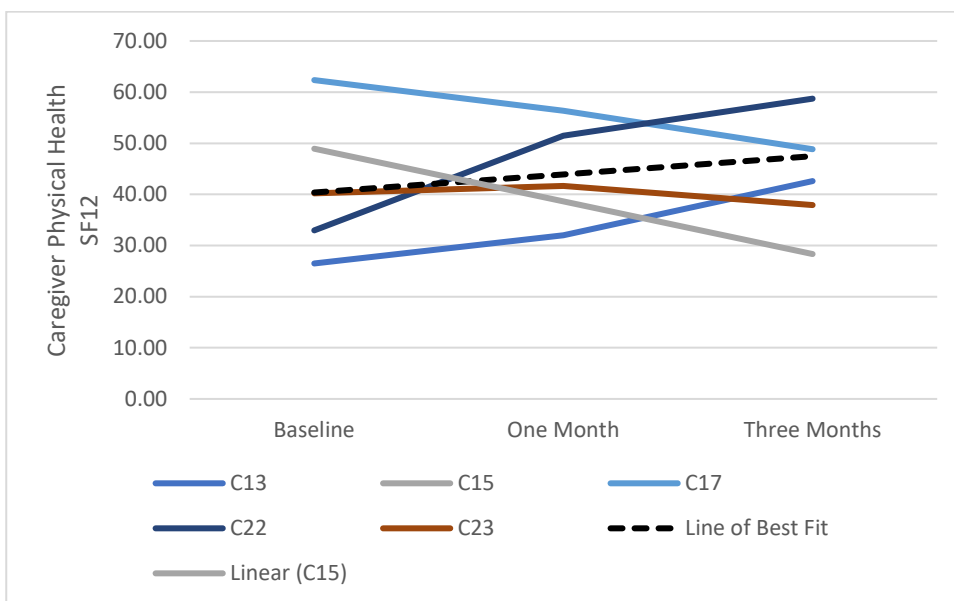


Figure 6.7: Caregiver strain index across time.

The findings in Table 6.8 support the findings shown in Figure 6.7 in that the caregivers experienced increased caregiver strain ($z=-1.841$, $p=0.066$) from baseline to the three-month follow-up. Each of the participants indicated higher caregiver strain at the three-month follow-up than at pre-intervention. The increase in the caregiver strain score could reflect the patients' health deteriorating over time, as seen in Figure 6.3.

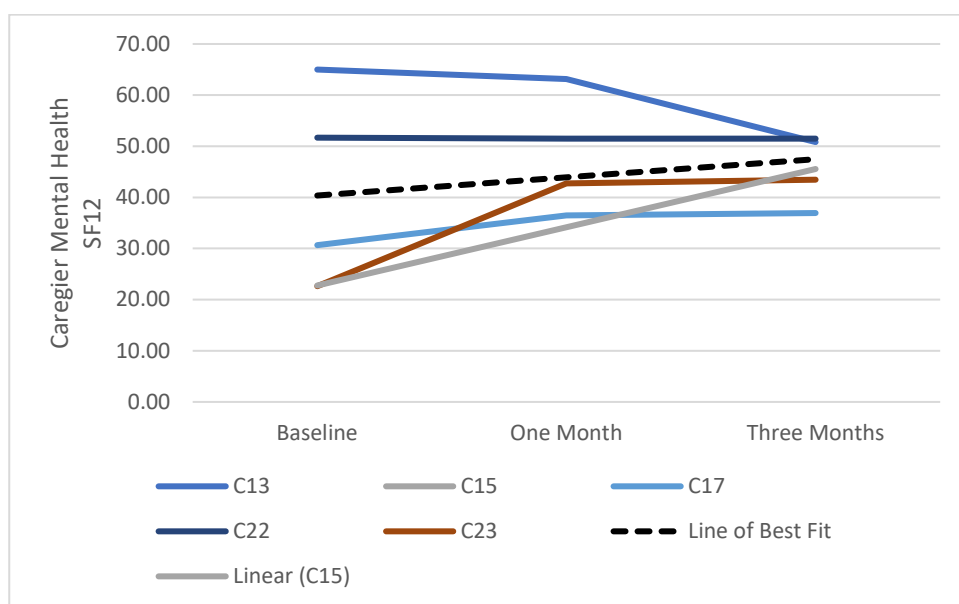


NB: Caregiver ID 15 did not complete one-month measures so a trendline has been inserted between baseline and three-month follow-up.

Figure 6.8: Caregiver physical health as measured by the SF12 over time.

There were slight improvements in the caregivers' physical health over time (Figure 6.8). Although there were improvements for two of the caregivers and deterioration in other caregivers. Given the limitations of the small dataset, it is not possible to examine possible correlations between the demographic characteristics of the caregivers and changes in physical health.

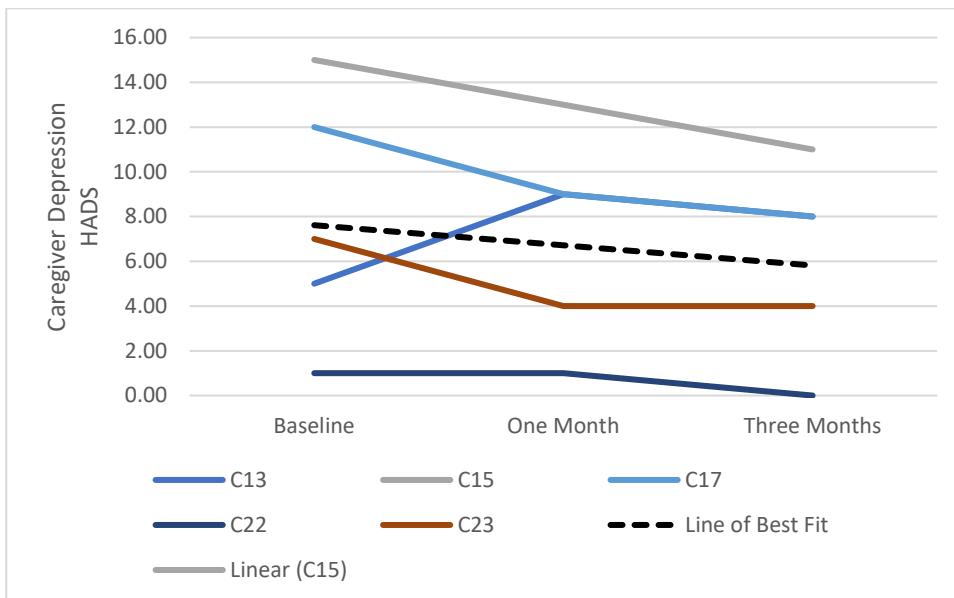
Caregivers were not asked and did not reflect on their own health at all during qualitative interviews about the case conferences. Several of the caregivers did provide information regarding their own personal health issues (including terminal cancer, depression and back pain) that were being managed in addition to the needs of the patient.



NB: Caregiver ID 15 did not complete one-month measures so a trendline has been inserted between baseline and three-month follow-up.

Figure 6.9: Caregiver mental health as measured by the SF12 over time.

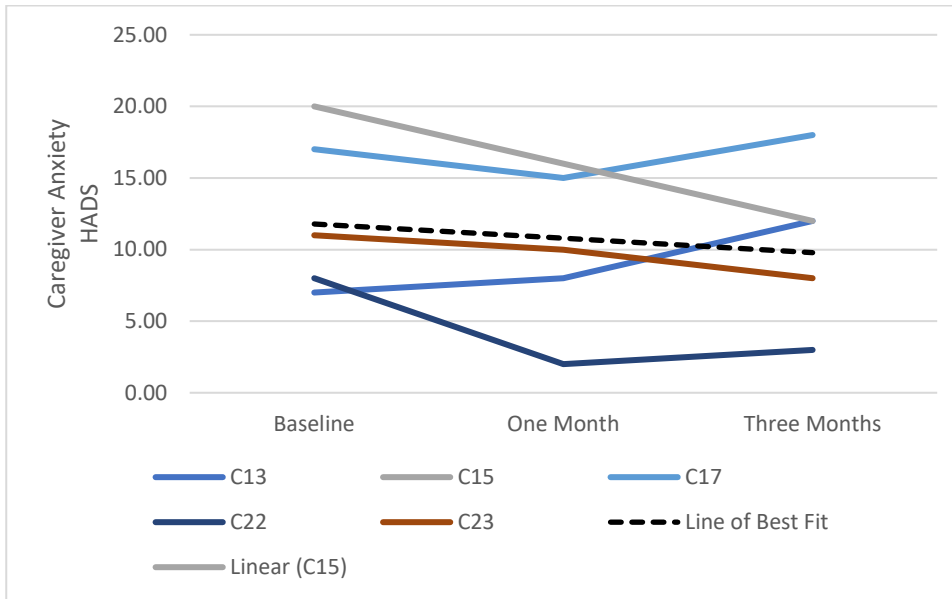
Carer's mental health was measured by the SF12 and showed a small improvement (Figure 6.9). One caregiver showed a deterioration and one remained stable, while three caregivers indicated an improvement in mental health. These results are replicated for the HADS measures of depression (Figure 6.10) and anxiety (Figure 6.11).



NB: Caregiver ID 15 did not complete one-month measures so a trendline has been inserted between baseline and three-month follow-up.

Figure 6.10: Caregiver depression as measured by HADS over time

Carer depression scores showed improvement for two participants, one moving from severe (15-21) to moderate (11-14), and another from moderate to mild (8-10). One carer experienced deteriorated mental health developing mild depression. Two carers indicated no clinical depression at any time. Four out of five caregivers showed a minimally important difference of at least 1.5. Anxiety scores also showed a slight improvement overall, although two carers showed increased anxiety, one moving from no anxiety to moderate anxiety and the other staying in the clinically severe threshold. Three of the carers showed improved anxiety, moving from severe to moderate, moderate to mild, and mild to no anxiety.



NB: Caregiver ID 15 did not complete one-month measures so a trendline has been inserted between baseline and three-month follow-up.

Figure 6.11: Caregiver anxiety as measure by HADS over time.

In summary, the results indicate that the case conferences did not improve or adversely affect the carers' physical or mental health to any significant degree. There was a significant increase in caregiver strain, with most carers experiencing a high degree of strain by three months after the case conference. However, there was a slight, although not significant, improvement in physical and mental health. This may indicate that the case conference had an effect on improving or maintaining carers' physical and mental health, even though the patients' physical health was deteriorating.

6.6 Health System Outcomes

6.6.1 Health service utilisation

Hospital records were accessed to determine the utilisation of the hospital 12 months pre-case conference and 12 months post-case conference (Table 6.9). There were no statistically significant differences for the number of emergency department (ED) visits, number of ED visits leading to hospital admission, number of hospital admissions, total days in hospital, or the average number of days per admission. Due to the small sample size, there is a lack of power to determine statistical significance reliably.

Table 6.9: Results of Wilcoxon signed-rank tests for emergency department visits and hospital admissions for the year prior and post case conference.

Outcome	Prior		Post		n	z	p
	Median	IQR	Median	IQR			
ED Visits	4	9, 2	4	5, 1	7	1.474	0.141
ED visits leading to hospital admission	3	8, 1	2	4, 1	7	1.296	0.195
Hospital admission	3	10, 1	4	8, 2	7	0.340	0.734
Total days in hospital	15	54, 7	9	28.5, 3	9	0.949	0.342
Average days in hospital for each admission	5	11.1, 3.7	3	5, 1.6	9	1.718	0.086

NB: ED visit was a recorded presentation at the emergency department; hospital admission was admission to a hospital ward other than the emergency department.

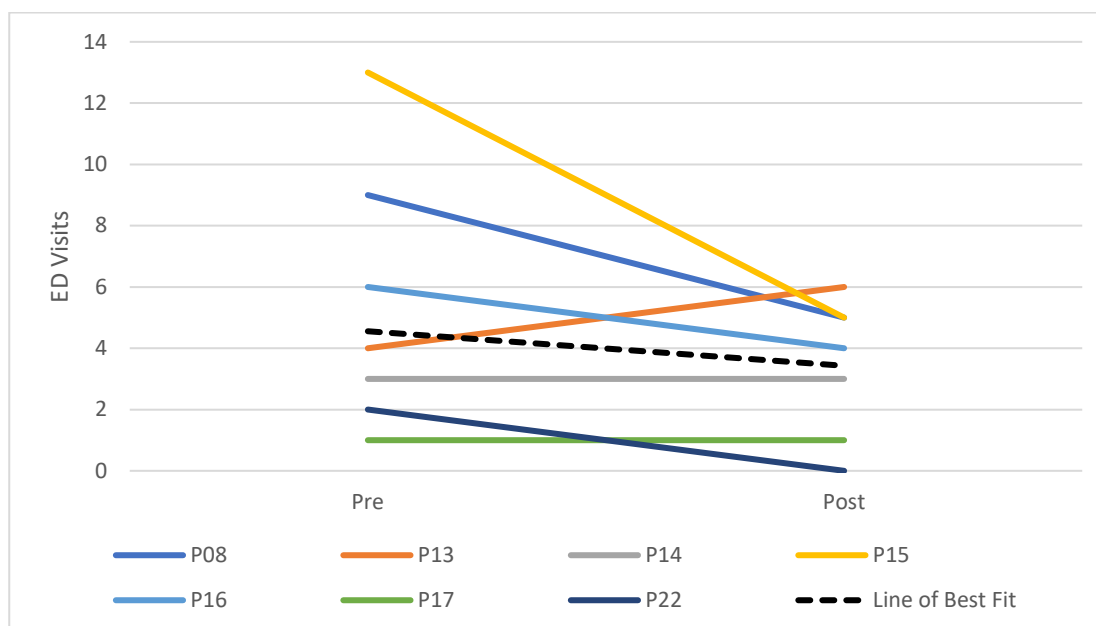


Figure 6.12: Number of ED visits for 12 months pre-case conference and 12 months post-case conference

On average there was a 37% drop in the number of ED visits in the 12 months after the case conference (Figure 6.12). Most patients made fewer ED visits, however two remained stable and one increased the number of visits made.

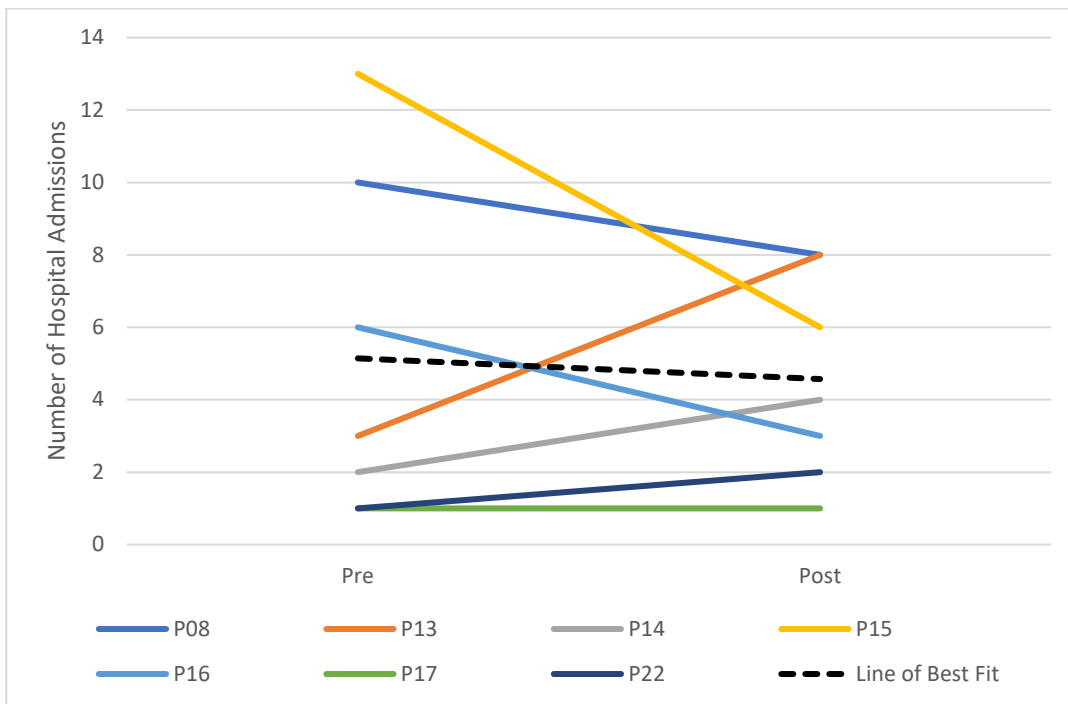


Figure 6.13: Number of hospital admissions for 12 months pre-case conference and 12 months post-case conference.

The number of hospital admissions in the 12 months post case conference decreased by 11% compared to the 12 months pre-case conference (Figure 6.13). These results were quite mixed with some patients doubling the number of hospital admissions, while others halved their admission rate.

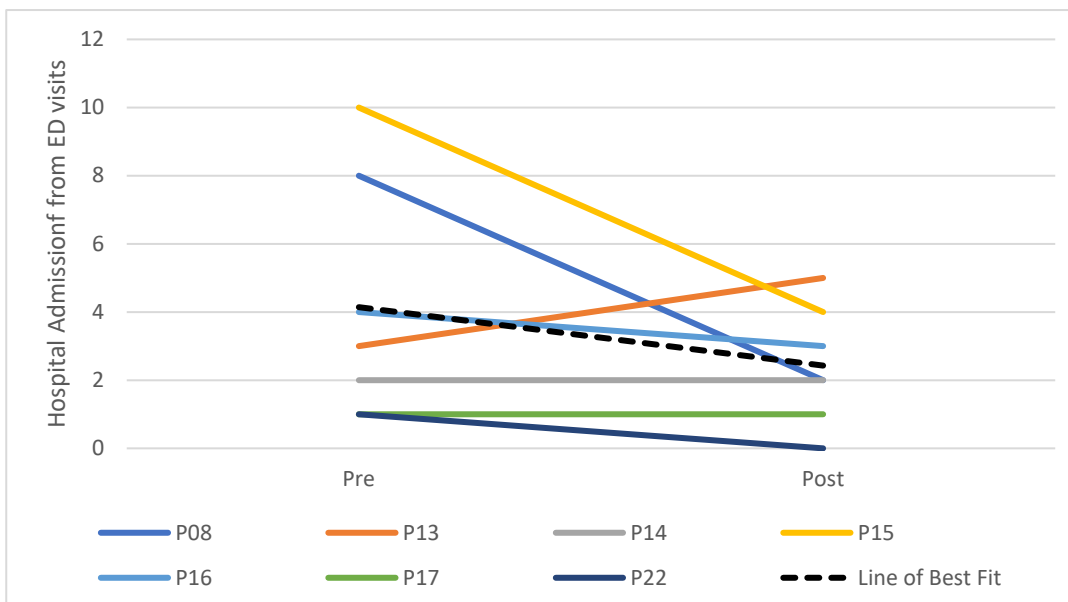


Figure 6.14: Number of ED visits that led to hospital admissions for 12 months pre-case conference and 12 months post-case conference.

Figure 6.14 shows that along with a declining number of visits to ED (Figure 7.12), there was also a decline in hospital admission after attending the ED. There was a 42% decline in the number of hospital admissions from an ED visit. This suggests that post case conference, patients were less unwell when presenting at ED or that ED staff were more confident in discharging the patient due to adequate home support (Figure 6.13).

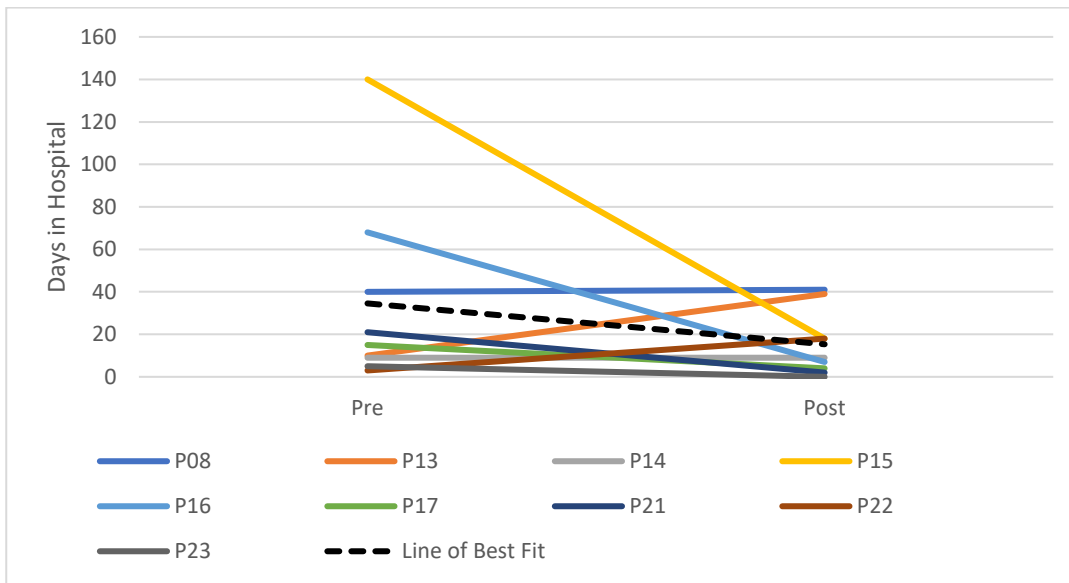


Figure 6.15: Total days in hospital for 12 months pre-case conference and 12 months post-case conference

The total days in hospital 12 months post case conference was 56% lower than pre-case conference. As Figure 6.15 shows, this was largely due to only two patients having quite numerous days in hospital in the 12 months before the case conference.

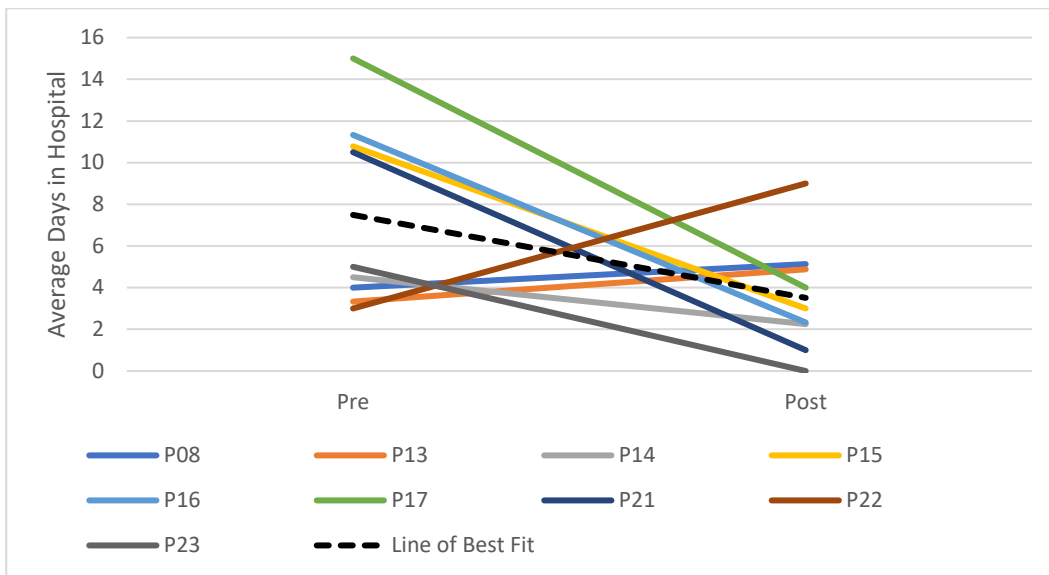


Figure 6.16: Average days in hospital per admission 12 months pre and 12 months post-case conference.

There was a 47% reduction in average days in hospital for each admission, which approached statistical significance ($z=1.718$, $p=0.086$; Table 6.9). Only three patients experienced an increase in their average days in hospital, while six patients experienced a decrease.

There was also no substantial uptake of hospice or respite care, with only one patient accessing respite care, in the 12 months post-case conference. Hospice care was not accessed by any patient. Patients did not report an increase in utilisation of services (meals on wheels, domestic help, volunteer help) at three months after the case conference compared to prior to the case conference. However, carers did report more service use by the patients at the three-month follow-up. Three patients used meals on wheels every week compared to one at baseline. Two patients had volunteer help every week compared to no volunteer help at baseline.

Carers reported the type and number of times the patient accessed health professionals, including GPs, specialists, community nurses, specialist nurses, pharmacists, physiotherapists, occupational therapists, social workers, psychologists and dieticians. There was no difference in the number or type of health professionals accessed by the patient at baseline, compared to three months after the case conference. Patients did not access alternative therapies (e.g. naturopathy, hypnosis, acupuncturist) at all, before or after the case conference.

Overall, there is a non-significant reduction in health service utilisation over the three-month period, despite the patients' physical health declining (Figure 6.3). This could indicate that the patients were being better managed in the community, arriving at hospital less unwell, which was reflected in reduced admissions to hospital after attending ED and a reduction in the number of days in hospital, both identified in the data.

6.6.2 Salary cost

A cost estimate for each case conference in terms of salary was established. However, this estimate does not account for additional time involved on part of health service workers, who arranged for patient files to be available or followed up after the case conference with the family or with additional services. This extra staff support was not arranged for the pilot and therefore not included in this summary. The time used by a GP, specialist or allied health professional to prepare for a case conference was included in the calculations. All calculations were based on the Queensland Health Pay Scales from 2016 and the Medicare rebate for case conference participation for GPs and community nurses (Table 6.10).

Table 6.10: Salary cost of case conference.

Case conference	Time (in minutes)	Health service personnel	Cost per case conference for staff time (AUD \$)	Case conference total cost of staff time (AUD\$)
1	65	Geriatrician* Allied Health# GP^ GP (prep time 30 minutes)^^	100.95 45.74 190.80 71.70	409.19
2	60	Geriatrician* Allied Health# GP^	93.18 42.22 190.80	326.20
3	45	Geriatrician* Clinical Nurse** GP^	69.89 41.64 190.80	302.33
4	60	Geriatrician* Clinical Nurse** GP^	93.18 55.52 190.80	339.50
5	45	Geriatrician* Allied Health# GP^	69.89 31.66 190.8	292.35
6	30	Geriatrician* GP	46.59 146.40	192.99
7	30	Geriatrician* Allied Health# GP^	46.59 21.11 146.4	214.10
8	70	Geriatrician* Community Nurse*^ GP^	108.71 27.07 190.80	326.58
9	20	Geriatrician* Allied Health # GP	31.06 14.07 146.4	191.53

*Based on Staff specialist salary of \$193, 833per annum and a 40 hour week (L24 Medical Officers scale).

#Based on Health Professional salary of \$87, 817 per annum and a 40 hour week (HP3 Level 6).

^Based on the rebate available for Medicare item numbers for case conference participation for GPs and community nurses.

^^Based on income forgone – the Medicare rebate if seeing patient for 30 minutes (business cost to GP in this instance, not health service).

** Based on Salary scale of \$115, 482 per annum and a 40 hour week (Nurse grade 7.3).

*^Based on registered nurse level 1 award wage of \$45,838.

The cost of additional support for each case conference should also be included. Estimated at 4 hours per case conference, this included providing all information in relation to the case conference, liaising with participants to schedule an appropriate time, organising IT facilities, providing information about the proforma to each participant, and finally collecting and collating notes into a care plan and circulating. Based on the Queensland Health Pay Scale Nurse Grade 7.3 of

\$69.89/hour, this is an additional cost of \$279.56 per case conference. The most expensive case conference cost \$688.75 in direct salary costs (\bar{x} = \$567.86, range \$472.55 - \$688.75). Previous research has shown that the cost of hospitalisation for palliative patients with either heart failure or lung disease was \$1386 per day.(16) The case conference reduced the average number of days in hospital by two (Table 6.9). Therefore, based on the salary costs incurred for the study sample, the case conference was cost saving.

Indirect costs to the patient or caregiver, costs such as transport or time away from were not collected for this pilot study. The calculation also did not account for additional staff resources that may have been required at the hospital, to cover staff time away from the ward to attend case conferences.

6.7 Individual Patient Examples

Three patient examples are described in this section. Examples were chosen based on the experiences of the patient and/or carer of the case conference and self-report outcomes, one case conference with positive feedback, one with neutral feedback and one with negative feedback. Examples were rated on the patient and carer self-report outcomes and health service utilisation data, as well as qualitative data interviews conducted three months post case conference with each case conference participant. The most positive example on all measures was chosen as Case A, a more centrally rated example was chosen as Case B, due to the different experiences of the participants, and the one case conference with the carer indicating a negative or disappointing experience was chosen as Case C. The background of each patient is presented first, with the experience as related by the participants, followed by the patient and carer outcomes, health service utilisation data and a case summary.

6.7.1 Example 1: Case A

P15 Male 65 years old Parkinson's disease - Dysphagia (difficulty swallowing) - Dysarthria (difficulty speaking) - Recurrent Falls Living Independently /moved to respite 2 ½ months after the case conference	Case conference attendees: - GP - Geriatrician - Clinical nurse - Patient - Carer (brother)
---	--

Patient

Patient P15 is a 65 year old male who was diagnosed with Parkinson's disease and was experiencing dysphagia (difficulty swallowing) and dysarthria (difficulty speaking). The patient was living independently at home and did not have a carer living with him. The patient's brother was nominated as his primary carer, with each of his siblings taking some responsibility for visiting him at home to care for him. The patient was moved into respite care two weeks and one day prior to the three month follow up. During this two weeks of respite, the decision had been made by the patient and the residential aged care facility for this to become a permanent arrangement.

Experience

The case conference was a positive experience for the participants. The patient's carer stated after the case conference:-

"I was reasonably happy when we left. Like I knew where it was going and they had [patient]'s best interest at heart." (Carer 15)

The carer spoke about the relationship built with the hospital, particularly the case worker.

"The caseworker was really good, wasn't she? They tried really hard to help him out and he was in hospital more times than he was out. They did a pretty good job for him in hospital." (Carer 15)

The caregiver highlighted during the qualitative interview that he was anxious about his efforts to help.

“Yeah. I try me best but I don’t know if that’s good enough. I don’t know if it’s helping [patient] or hindering him. I like to think I’m helping.” (Carer 15)

The patient’s GP also found the case conference worked well in building relationships with other health professionals involved in this patient’s care.

“The other thing that happened was, because I had a connection to the specialist and those clinics and things like that, I was emailing them saying ‘What’s happened to this? Have you been able to, or we haven’t had any feedback about this!’ and then I was getting some feedback from that.” (GP 3)

The allied health professional involved in the case conference at the OPERA unit found that the case conference was good for this patient.

“Yes, definitely. Having the GP, [geriatrician name] and [patient name] and his brother involved I think is really really good. Um, yeah, I really think it helped.” (Allied Health Professional, 06)

The geriatrician also found the case conference resulted in a better outcome for this patient.

“For instance, people like [patient name] a lot of those things were actioned and then taken up further. By using our social worker, our community social worker, she wasn’t in the case conferences but she works closely with us, she was able to action some of those things and actually get them an outcome which was initially not what [patient name] wanted, clearly identified himself, actually, I think realised later it was a better outcome for him was actually to find a new home in aged care, which has actually been a good outcome for him. But that was a process, but I think that came out of the relationship we built and the work that was done as a consequence of the case conference.” (Geriatrician 3)

The allied health professional, as the geriatrician described above, built working relationships with the patient and family, allowing more complex problems to be worked through. The allied health

professional involved with this patient also discussed the difficulty in enacting the patient's decisions and providing a safe environment for the patient.

“There was quite a bit of follow up that [was] needed because the main problem or issue that needed to be addressed was that [patient name] wasn't safe to be at home. He wasn't safe in the environment that he was in and he was really, really scared of a nursing home. So, we needed to advocate on [patient name]'s behalf not to force him to do something he didn't want to do. And advocate that he had a voice because it was very difficult for him to talk. People were pushing him towards a nursing home. I believed he would be safer and better in a nursing home, but I wasn't going to push him that way. So, the “after” stuff was quite complex.” (Allied Health Professional, 06)

The carer identified that admission to respite has been a positive outcome.

“The best thing that's happened for him is the respite and him being here for a while, you know.” (Carer 15)

The case conference resulted in ten recommendations being made. Five recommendations for physical symptoms were made, with two followed up and one no longer required, as detailed in the GP and hospital patient files. Two recommendations were not followed up, with no detail as to whether these were still applicable to the patient after admission to respite and permanent placement in residential aged care. Three recommendations were made in the area of social support and each of these was followed up. One recommendation was made to facilitate a reassessment for residential permanent placement and one to liaise with a community nursing agency, these were completed.

Self-report outcome measures

The patient completed each of the surveys with the researcher and although experiencing dysarthria, was able to clearly communicate his responses to the survey. The patient retained a low but stable functional status, as measured on the AKPS. There was deterioration on the physical component score of the SF12 (163) from baseline to one month of over 13 points (37.32-24.02), and then the score remained stable between one month and three months. The patient was in permanent care at this time point, which likely contributed to the stability. The average for an Australian population with multiple chronic conditions was 35.2(195), two points lower than the baseline for this patient.

At follow-up the patient was 10 points below this average at both time points. A lower score indicates worse function.

The patient's mental component score on the SF12 improved over time by over 10 points (37.78-50.03). Although at three months post case conference the patient's score was still below the average for an adult with multiple chronic conditions.(195) This was consistent with the patient's HADS scores which indicated persistent severe depression and mild anxiety over time.

The caregiver did not complete the survey questions at one-month post-case conference. The caregiver did not complete the CSI at the three-month follow-up but did complete the other measures at three months. The caregiver's physical component score on the SF12 deteriorated over time, from 49 to 29, lower than the general male population average of 47 for age 55-64 (195). Although the caregiver's physical health deteriorated his mental health improved. The caregiver's mental component score of the SF12 improved by over 20 points between baseline (22) and 3 months follow up.(45) This is still below the male average for the 55-64 age group of 53.7.(195) The improvement was reflected in the caregiver's depression score moving from severe to moderate, and his anxiety score also improving from severe to moderate. Again, this may be reflective of the patient going into permanent care, thereby lessening the burden.

Health service utilisation

The patient's health service utilisation declined post case conference. P15 experienced repeated falls while living at home and was regularly admitted to hospital as a result. After the case conference, the patient made fewer trips to the ED, was hospitalised less often, and when hospitalised, spent fewer days in hospital. As noted previously, the patient was admitted to respite care two weeks prior to the three-month follow-up and this became a permanent placement. After placement in the care facility, there was only one further hospital visit.

Summary

Each of the participants in the case conference for this patient found the experience positive and believed the case conference helped the patient. There was a reduction in health service utilisation, as defined by the study, however given the patient was admitted to permanent placement in an aged residential care facility, there is an argument to be made that health service utilisation has increased in this instance. Although acute hospital service utilisation has decreased. The patient outcome measures were mixed. Physical health for the carer continued to deteriorate, whilst carer mental

health improved. In this patient's situation, the quantitative outcome measures were not reflective of the result of the case conference identified by the participants.

6.7.2 Example 2: Case B

P14	
Male	Case conference attendees:
93 years old	- GP
	- Geriatrician
Mild cognitive impairment	- Occupational Therapist
	- Patient
- Macular degeneration	- Carer (daughter)
- Hearing loss	
- Postural hypotension	
- Falls	
Living with wife (carer for wife)	

Patient

Patient 14 is a 93 years old male with mild cognitive impairment, macular degeneration, hearing loss, postural hypotension, weight loss and increased number of falls. The patient was living at home independently and was carer for his wife. His daughter was his informal primary carer, visiting each day and helping to organise services such as meals on wheels, daily showering and weekly help with shopping. The patient completed the surveys with the researcher. His carer did not complete the surveys but did attend the case conference and participate in the qualitative interview. The patient was present during the interview but although encouraged, did not contribute, instead deferring to his daughter.

Experience

This example is considered neutral as the carer did not remember much about the case conference and although generally positive, did not identify any positive outcomes from the process.

“I can't remember all that was discussed. I know they were trying to look after Dad's wellbeing I think. [geriatrician name] mentioned the men's shed, but I don't think that's um something that Dad might enjoy. He's been in the garden all his life and he's been doing some gardening. So I just said 'Anything along that line', but um I don't know what's

around. It's trying to get some social contact for dad that would be good. I can't remember the other things we discussed.”(Carer 14)

The carer had the impression that the case conference was to look after the patient's wellbeing and that generally, it was a positive experience. However, the carer did not remember the detail of the case conference.

“Yeah and once again I just can't remember everything that was said, but um, it was all good feedback that was happening.” (Carer 14)

The GP indicated that the case conference worked well and improved the patient's outcomes, involving the family in the patient's care and increasing access to services.

For some of them, I think, for [patient] in particular it made a good difference I think because we organised some other services for home care, like meals on wheels. The family got involved a bit better, so they had a better understanding of his condition. [Patient] I think he was kind of a more classic case, he is still living in his place with his wife and the family is around as well. So there was potentially some services that he wasn't utilising, so he is now receiving more services. I think in his case it was a better outcome.” (GP 2)

The GP was able to identify some increased use of services, of which the carer was unsure. There were eight recommendations made during the case conference. Three recommendations regarding physical symptoms were made, with only one recommendation enacted. Funding was unavailable for the other two recommendations (dietician and OT). This highlights a limitation of the case conference, that expectations cannot always be met. One recommendation for social support was made and followed up by the patient's GP. Recommendations for the family to complete an advance health directive and to increase GP visits were not followed.

Self-report outcome measures

This patient showed a decline in functional status (as measured by the AKPS). However, he reported a large improvement in the SF12 physical health component between the baseline (20), while still in hospital, and the one month follow up.(45) This dropped again at the three-month follow up.(35) The three-month score is close to the average for a person with multiple chronic conditions.(195)

The SF12 mental health component score (MCS) was quite stable, starting at 59, dropping slightly then improving again to 62. At each time point, it was above the average score for someone with multiple chronic health conditions.(195) The patient did not have clinical anxiety or depression as measured on the HADS at any time point, although the depression score did increase by 3 points over time, indicating a small deterioration.

Health service utilisation

Health service utilisation remained stable with the same number of ED visits and hospital admissions. There was a small decrease in the average number of days the patient spent in hospital per admission. The patient reported no change in accessing services post case conference, having accessed meals on wheels and domestic help prior to the case conference.

Summary

The carer and the GP had quite different experiences of the case conference. Although both the carer and GP were positive about the experience, the carer could not remember any detail and did not follow the recommendations. The GP indicated that the case conference resulted in additional services recommended for the patient, however the patient reported no change in access to services. The GP also indicated that the family was now involved and understood the patient's circumstances. The carer reported that she was more likely to attend GP appointments after the case conference with the patient but was unsure of the services accessed. The patient's functional status declined, but his mental health and health service utilisation remained unchanged (in contrast to the GPs recommendations). Although a positive experience for the participants, the carer and the GP had different recollections regarding the recommendations from the case conference and whether they were carried out.

6.7.3 Example 3: Case C

P 23 Female 85 years old Vascular dementia - Hypotension - Depression / anxiety - Aortic valve regurgitation - Falls Living with carers (daughter and granddaughter)	Case conference attendees: - GP - Geriatrician - Occupational therapist - Patient - Carers (daughter and granddaughter)
---	--

Patient

Patient 23 was female, 85 years old with vascular dementia, hypotension, depression, anxiety, aortic valve regurgitation, a pressure injury and an increased risk of falls. The patient was living at home with her daughter and granddaughter, with both acting as her caregivers.

Experience

The granddaughter of the patient did not find the case conference useful.

“We didn’t really get that much out of it.” (Carer 23.1)

The patient’s daughter agreed. Their personal expectations of the case conference were not met.

“Well we didn’t get any information about alternative therapies that we could do at home, or anything like that. It was just all information that we already knew. So, we didn’t get anything out of it.” (Carer 23.2)

The granddaughter highlighted that the family wanted information from the health professionals during the case conference that they did not receive.

“It could have been across the board because that way we would have got more because the hospital deal with these people, like she has vascular dementia, so they have more ideas of

what we can incorporate in our daily dealings with her to what we can and can't do. Just give us an idea, yeah.” (Carer 23.1)

The granddaughter identified that the case conference focused on the issues important to the health professionals and did not take into account the experience of the carers.

“It was more about the professionals than the people totally hands on with the person that's the main function, our main function is to make sure she is comfortable.” (Carer 23.1)

The GP confirmed that although his experience of the case conference was efficient, they discussed those issues that had been solved previously.

“It was a very simple and straight forward sort of a case conference. I'm sure if it had been a much more complicated problem there might have been a few teething problems, but it did flow very well because in [patient name]'s case most of the services are already in place, most of the hard work has already been done. We were really just fine tuning and confirming everything was working well.” (GP 6)

The allied health professional at the hospital also identified that this case conference was a process to confirm no further action was required.

“There was nothing raised as outstanding for OT so I didn't need to do anything further. I just kind of closed off everything, wrote some notes and put my stats in and that was it.” (Allied Health Professional, 23)

The case conference resulted in one recommendation, to acquire a wheelie walker to reduce the risk of falls. This recommendation was followed by the family. It was noted during the case conference that the family did not require additional assistance due to the daughter's experience of working in the aged care sector. However, from the family perspective, they wanted further information about how to best care for the patient although they reported that this was not received. Notes were also made to highlight that an advance health directive was available for the hospital and GP, and that end-of-life decisions had already been made by the patient and family.

Self-report outcome measures

Patient measures were not completed due to impaired cognition. The granddaughter completed the carer measures as she was noted as the primary caregiver. The carer's physical health, as measured by the SF12 remained stable. Caregiver strain increased from 7 at baseline to 10 at three-months post case conference. Although there was an increase in caregiver strain, there was a decrease in anxiety from moderate at baseline to mild at three-months post case conference. Depression remained non clinical, although there was a 3 point rise, with 1.5 considered a minimally important difference.(196)

Health service utilisation

Health service utilisation decreased to no admissions or ED visits post case conference. The patient had only been admitted twice in the 12 months prior to the case conference. The patient died at home 4 months after the case conference, researcher notified by family, without providing the date of death.

Summary

The daughter and granddaughter's experience of the case conference were negative. Both felt that the case conference centred on the health professionals, which is likely a factor in why they did not receive the desired information about how to best care for the patient. The family's expectations of the case conference were either not communicated to the health professionals, or not understood by the health professionals. The family's view that the case conference did not provide anything new for the patient or the carers was supported by the health professionals involved. The health professionals identified that the services were already in place and very little additional support was required. However, a wheeled walker was provided to reduce falls, with no additional hospitalisations for falls recorded. The advance health directive was discussed and the patient's wishes at end-of-life were followed by the family. This is a positive outcome of the case conference.

6.7.4 Summary of individual patient examples

Although each of the participants in the three case examples were quite different, there are similarities across the experiences of those participating in the case conferences. Each patient described had an informal primary carer, although only the patient who was deteriorating had a carer living with them. The carers were each involved with the case conference and participated in the qualitative interview.

The GPs involved all indicated that either the patient, the carer/family or both benefited from the case conference. Even in cases where there was no improvement in patient or carer outcomes the GPs identified the case conference as beneficial for the patient. Positive outcomes included, providing additional community services that were previously not utilised.

Improved communication was identified as a benefit of the case conference in the positive and neutral patient examples. Health professionals involved with Patient 15 identified that the communication established by the case conference was beneficial in discussing the complex and emotional issue of respite and permanent care. The GPs identified the improved communication with specialists and with the family. Carers in two of the examples also identified improved communication and improved relationships as a benefit of the case conference. However, one family identified unsatisfactory communication with health professionals. They were expecting further information on what to do, whereas the health professionals thought that the case conference finalised the care that was being offered. This did not meet the family's expectations and in this instance, communication failed.

6.8 Sample Size

In this pilot study, the aim was to approach every potentially eligible patient to participate in the study for a three-month period. However, the number of potentially eligible patients admitted on the ward was considerably lower than estimated due to hospital policy changes. Only the most advanced cases were admitted as inpatients, leading to increased numbers of patients being discharged to residential care facilities (an exclusion criterion) rather than to the community. As per the protocol, these people were not eligible for the research. This increased the recruitment time required to achieve the small sample ultimately achieved for the pilot study. Further, the eligibility criteria for the case conference service excluded many older people who were less frail than the frailty definition used in the study.

As one aim of the trial was to reduce health service utilisation, the sample size calculation for the full trial was to be based on the average days in hospital (7.42) and the standard deviation (4.84) found in the current pilot study. A meaningful reduction in hospital utilisation would be 26% based on literature.⁽¹⁹²⁾ A multi-site trial, with patients randomised to intervention (case conferences) and control groups would require a sample size of 268 to provide a power of 90% with a two-sided α of 0.05 to detect a 26% reduction in hospital utilisation (days in hospital) over 12 months. A two

tailed test with an alpha of 0.05 was chosen to account for the possibility of either an increase or decrease in hospital utilisation. The refusal rate (initiated at least 2:1 by the carers) of 42% was much higher than expected.(192) Additionally, 40% of those screened were ineligible. Taking this into account, 1489 potentially eligible older people would have to be screened in a full trial.

6.9 Discussion

The study aimed to test the effectiveness of case conferences with patients, primary informal caregivers, GPs and hospital specialists to reduce hospital admissions, and improve patient and carer outcomes. Of fifty patients identified, 21 (42%) did not proceed to assessment, and 20 (40%) were ineligible, leaving only nine patients who completed the study. The high rate of ineligible patients (40%) was due to changes in discharge destination of patients from home to residential aged care facilities, overly strict definitions of frailty, and GPs declining to participate. Although changes in discharge destination were expected, previous research in palliative care indicated a much higher rate of GP participation than this project was able to achieve.(142) Sample size calculations were based on this higher rate of refusal.

There were also eight patients (15%) whose discharge destination changed. Frail patients may deteriorate quickly in hospital or may not improve as expected after admission. This may lead hospital staff and families having to negotiate placement for patients, rather than have patients return to their pre-admission living situations. These patients were ineligible for the pilot.

Recruitment was further compromised by the stringent measure of frailty, given that 8% of patients whom geriatricians identified as potentially frail, did not qualify as frail on the chosen measure. In particular, the physical measure of grip strength led those patients that staff considered frail to fail to meet the frailty requirement for the study. It was suggested by staff that although the patients were functionally dependent, grip strength may be preserved due to their background, often as farmers or labourers.

There was a significant improvement in mental health from baseline to three months post-case conference for patients. This was not replicated in the measurements of anxiety or depression. This may have been due to improved communication with the patient's care providers and knowing a plan had been developed to care for the patient. There was no statistically significant decline in the SF12 physical health subscale, although there was a trend toward reduced physical health. This

decline in physical health is expected in a frail population with frailty predictive of increasingly poor outcomes.(4, 5, 61)

There was an increase in carers' strain from baseline to three months with carers experiencing a high level of strain throughout the duration of the study. There was also a small improvement in physical health for carers and a small improvement in mental health, supported by small decreases in anxiety and depression. Whilst these changes were not statistically significant, they do reflect the experience of the participants in this small sample. Additionally, the small improvements were seen while carer strain increased, and the patients' physical health declined, indicating that the case conference intervention may have had a positive effect for the participants in the study as a group.

There was no statistically significant decrease in health service utilisation for study participants. However, on average there were large drops in ED visits (37%), total days in hospital (56%) and the average days per admission (47%) in the 12 months after the case conference. Previous research in end-of-life cancer and heart and lung failure populations showed that a case conference decreased health service utilisation.(142, 192) A meaningful reduction in this study was considered to be 26%, in line with that achieved by Abernethy et al in palliative care service patients (90% cancer).(192) In spite of the patients in this sample experiencing declining physical health, patients attended hospital less frequently and stayed for shorter periods post case conference. There was also no significant difference in the uptake of hospice or respite care, and no increase in the uptake of community-based health service utilisation for study participants.

Due to the small sample size and lack of power, it is not possible to draw any conclusions as to the efficacy of the case conferences in improving patient and carer outcomes and reducing health service utilisation. However, trends in this sample of patients provide preliminary evidence that further research into the effectiveness of case conferences for frail older people at the end-of-life may be warranted. This study's findings are consistent with published research in testing case conferences for people with other diseases.(107, 142)

Recruitment and retention of patient and health professionals proved difficult with this type of patient and provides a challenge for further research. Of the eight GPs who declined, four chose not to participate due to ill health or high workload. This reflects the reality of the general practice landscape in regional and rural areas. All GPs who did participate found the case conferences useful, with one GP organising further case conferences for his patients. The challenge is to get GPs

to undertake the first case conference to experience the benefit. Rogers(197) identified that to implement a new intervention communication channels and time were important factors, that adoption starts slowly, with innovators and early adopters. Communication with these early adopters will provide the knowledge and persuasive knowledge needed for wider adoption. To increase participation in case conferences it would be necessary for GPs to see value in integrating care through case conferences.

Case conferences provide a platform to coordinate care and potentially to keep the patient at home where appropriate. Improved communication encourages coordination with allied health to provide services and with community services to provide equipment to minimise the risk of falls and to provide support services. The case conference is an opportunity for GPs and specialists to work together to provide a patient centred outcome, but strategies are required to improve GP participation There may be a role for practice nurses to coordinate follow up for the patient. There may be value in targeting GPs who have less experience, either because they are just starting, or because they trained in countries where infectious diseases are more prevalent than chronic disease and multimorbidity. This would provide learning opportunities for the GPs in the areas of frailty and palliative care and may improve GP participation.

This chapter provided a preliminary estimate of the effect of case conferences on health service utilisation, patient outcomes, carer outcomes and the fidelity of the case conference process. Due to a small sample size it was not possible to draw any conclusions about the effectiveness of case conferences for frail older people at the end-of-life. However, trends in the sample of patients suggested a reduction in health service utilisation and improved physical and mental health for carers even while carer strain increased. At the same time, patients' physical health declined. Three patient examples illustrated the different impacts the intervention had on individual patients and their carers. Chapter 7 will explore the experience of participants in an integrated specialist-GP case conferences to determine the feasibility and acceptability of case conferences.

Chapter 7 Phase 2 Results, Part 2. Experience of participation in a case conference as a model of integrated palliative care for frail older people in the community.

The aim of this chapter is to explore feasibility and acceptability of multidisciplinary case conferences for frail older people at the end-of-life, through the experiences of participants; patients, carers, GPs, geriatricians and allied health professionals. The findings are based on qualitative semi-structured interviews with participants (see chapter 4 for details of the method).

Twenty-three individual interviews were completed, involving patients (n=2), carers (n=5), GPs (n=6), geriatricians (n=3), hospital-based health professionals (n=6) and a community nurse(n=1). An additional two interviews were completed with both the patient and carer together, when this was requested by the participants due to health issues.

The intention of the analysis was to understand the feasibility and acceptability of case conferences as an integrated model of care. What constitutes feasibility is not clearly defined in guidelines on evaluating complex interventions.(198, 199) Bowen and colleagues(200) proposed eight areas of feasibility encompassing; acceptability, demand, implementation, practicality, adaption, integration, expansion and efficacy. Acceptability is the extent to which an intervention is suitable, satisfying or attractive to those providing and receiving the intervention. Demand is how likely the intervention is to be used, how much demand is there likely to be. Implementation is whether the intervention is delivered as intended. Practicality is whether the intervention can be used within the current system without outside intervention. Adaption considers whether the intervention performs as expected when changes are made to the format or population of a program previously tested successfully in other palliative populations. Integration determines if the intervention is perceived as sustainable and fits within the infrastructure. Expansion considers whether the intervention can be expanded to provide a new service or program. Efficacy tests the effects of the intervention on key variables and provides an effect size estimation.

For the purposes of this research the focus on feasibility included implementation, demand, practicality and acceptability.(200) As the intervention in this study is patient-specific, rather than service specific and is implemented over a short period of time, integration, concerned with sustainability and embedding the intervention into practice is not considered in the analysis. As the

intervention is part of a pilot study, expansion relating to the provision of an additional service or program; and adaption, what is expected when changes are introduced to a previously tested program were not considered in the analysis.

A deductive analysis was conducted using the four aspects of feasibility, implementation, demand, practicality and acceptability, as the initial sensitising concepts for the categorisation of the data. Then an inductive thematic analysis(151) was undertaken to develop the themes. Table 7.1 shows the key sub-themes that relate to each of the four topics of interest. Each is described and discussed in the following section, with extracts included to indicate the central ideas. Extracts are labelled according to the type of participant (GP = General Practitioner; AHP = Allied Health Professional; Geriatrician; Patient; Carer) and a participant number).

Table 7.1 Topics for analysis of semi-structured interviews

Topic	Sub-topic
Implementation	Preparation
	Use of proforma
	Care plans created and used
	Participants
Practicality	Information Technology
	Time
Demand	Funding
	Choice of participants
Acceptability (health professionals)	
Acceptability (patients and carers)	

7.1 Implementation

Implementation considers how the proposed intervention was conducted in the local context based on the experiences of health professionals. The current section explores the implementation from the perspective of the experiences of the participants. The health professionals were asked to: prepare for the case conference by sharing information relevant to the case conference structured proforma (Appendix B); use the structured proforma during the case conference to guide discussion; complete the proforma during the case conference with action items and identify a

person responsible for each item; return information to the person who completes the care plan and to then follow-up items the care plans identified. In designing the case conference, the hospital-based geriatrician, an allied health professional from the hospital and the patient's GP were all identified as necessary to the process. In addition to these core participants, the patient, the patient's carer (with the patient's permission) and any relevant community-based health providers were invited to participate. This topic explores the health professional perceptions of their implementation of the case conference, focussing on the preparation, the use of the structured proforma and the creation and use of the patients' care plan.

7.1.1 Preparation

As identified in Chapter 6, health professionals rarely prepared information to share prior to the case conference. In one case only the GP and the geriatrician prepared information and shared information prior to the case conference. In this case, preparation may have been motivated by an unknown patient, as the patient was new to the practice.

“I think I did find that I had to spend a bit of extra time, say in my lunch break, reading up on [patient name]'s notes which um I guess in an ideal world wouldn't be so good. But that was also because of the fact that [patient name] has transferred from another medical centre and some of the notes were from that centre as well and so you know.”(GP1)

This GP also indicated that the time required for preparation had to be found, which was not easily achieved in a regular working day. The issue of time for preparation was also noted by the geriatrician in this case conference, indicating that they had spare time to complete the preparation for this case conference.

*“The preparation was good because I had met [patient name] before and I had a bit of time to go through the proforma as to what was required for the day, so that was good”
(Geriatrician 2)*

The geriatrician noted that this preparation was, in part, familiarising themselves with the case conference materials. The geriatrician also indicated that the preparation was not required as they were familiar with the patient. This was a recurring idea, with all the GPs, except the one above, identifying that because they were familiar with their patient, they felt the preparation was not really required.

“Those patients, I actually I think I pretty much know everything about them, so I was like quite involved with them, so I didn’t really need to do much preparation.”(GP 2)

Hospital staff also had a general perception that the GPs had long term, established relationships with the patient and for this reason were better prepared for the case conferences.

“Yes, the general practitioners were generally much better prepared than any of us, any of the hospital staff and that’s likely a reflection of the longitudinal relationship with their patients and that they clearly knew them very well. That was clearly apparent.”(Geriatrician 3)

Although GPs felt they were prepared for the case conference, as they were familiar with the patient and their needs, the lack of sharing of information with other health professionals prior to the case conference left other health professionals feeling less prepared, as evidenced above.

Generally, however, preparation was not completed by the hospital-based health professionals. The geriatrician below identified that delays between patient discharge and the case conference occurring, created difficulties with familiarity of the patient and their details, often leaving the hospital-based staff feeling underprepared.

“I think I was probably a little bit under prepared. Because, I think the case I did, the patient may have been discharged, there may have been a bit of a delay between the case I think and then not having the patient chart and then the rest of my work spilling over into the time allotted, I think made it a bit tricky.” (Geriatrician 1)

Interestingly, although GPs and hospital-based staff identified that preparation was not completed due to familiarity with a patient, a lack of familiarity was not a motivating factor for preparation, as identified above. The geriatrician also identified systemic issues faced by the hospital-based health professionals, with workload impacting available time and difficulties in obtaining patient information in time for the case conference. These difficulties were routinely identified by hospital-based health professionals.

In addition to heavy workloads for the hospital-based staff, roster changes also meant allied health professionals were not given sufficient notice of an impending of the case. This created a situation where the allied health team member would be familiarising themselves with the patient as the case conference progressed.

“I was pulled into the case conference and I hadn’t really had any preparation time. So I think that that perhaps took away from the experience that I had, certainly. I walked into it and I was trying to remember patient details as we were going through the case conference where if I had of got[sic] that preparation time and been able to read through the chart, twigged who the patient was and got all those cues, certainly I think would have been a better situation.” (AHP 02)

Although most of the allied health professionals expressed a wish to have prior notice to allow preparation time, as previous hospital-based staff noted, preparation was rarely completed. The allied health professional below suggested ways to improve preparation, but identified that workload limits the time available.

“I guess maybe having a little bit more notice, so we could get the chart out and you know have a really good look through. Maybe looking at older charts that might have had some more information from previous admissions, things like that. Um, maybe talking to some of the other allied health that might have been involved with the person. Yes, I guess having a little bit more time, but I realise it’s difficult.” (AHP 03)

Preparation prior to the case conference is a part of the implementation of the integrated model of palliative care. Although preparation and completion of paperwork were requested before each case conference, it was only completed for one patient. The GPs involved in the case conferences have identified that they are prepared for the case conference as they knew their patients well. The hospital-based health professionals agreed that the GPs are prepared for the case conferences for the same reason. By contrast, they felt unprepared for the case conference and have identified some systemic issues creating barriers to completing preparation, including changing rosters of allied health staff, a lack of time to prepare, and a delay between diagnosis and case conference. The GPs and the hospital-based health professionals did not provide information to other participants as part of the preparation process, indicating they did not fully appreciate that the preparation was for the benefit of everyone attending the case conference, not just preparing themselves for participating,

irrespective of how familiar they were with the patient. The method of preparation used in this pilot is not feasible, with participants identifying that they do not complete the preparation. Recent research has indicated that palliative care multidisciplinary case conferences are feasible without preparation and sharing of information before the case conference(201, 202), however the case conference is more effective when held within 14 days of hospital discharge.(201)

7.1.2 Use of case conference structured proforma

A structured proforma was provided to each health professional participant in the case conference. The expectation was the proforma would guide discussion and each section of the proforma, as required, would be completed by the health professionals. This ensured that the full range of issues likely to be of concern in a palliative approach were considered as part of developing a comprehensive palliative care plan. Subsequently, the proforma would be returned to the researcher to create a care plan for circulation and action.

The proforma was used successfully to focus the case conference discussion on the areas prescribed by the proforma as identified by the allied health professional below.

“I think the proforma was basically used to jot down what the concerns were and then what the outcome was once we had the discussion as to which way it was going to go. So it was a way of keeping [records] in a streamlined way, I think, what was, what the concern was, what we did and who was going to do it, so I suppose it did.” (AHP06)

Most of the health professionals identified that the proforma was a good way to keep the discussion on topic and that this was a positive outcome. Alternatively, one GP did highlight that by using the proforma the conversation became artificial and too structured (see below). Although there was a concession that keeping the conversation on topic was good, there was a concern expressed that by stiling the conversation, issues were not explored as fully as a normal conversation might allow.

“Not too bad. It felt a bit structured um. You know, sometimes when you are having a clinical discussion you’ll head off on a tangent and like other conversations you wonder how you ended up at a certain point, because you head off on a number of tangents but eventually get there. Here it was a bit more, well it was a lot more structured and so you would finish one subject and then [Geriatrician’s name] would say “well now we would like to talk about x” and you move onto the next subject. So that kept it on track which was good.

It was a little bit artificial I guess because it's not how a normal conversation takes place.”
(GP 5)

Most of the GPs and hospital-based professionals found the proforma useful. They identified that using the proforma was a reminder to discuss patient needs that may be overlooked, as detailed by the GP below. There was a minor concern over how to complete sections that were not relevant for a patient, however all health professionals agreed that this was easily overcome.

“I always find those useful because it helps to prompt me, remind me about stuff that I may have forgotten to put in there. And I occasionally run into a section that requires an answer that you don't really have a good answer for, it doesn't, may not be appropriate to that particular patient but you can usually just write something along those lines in those spaces. So yeah, I'm happy with proformas. They work well.” (GP6)

A few reported that some sections were not useful. One geriatrician commented on the lack of clarity and unnecessary inclusion of some sections. This geriatrician identified that the six case conferences they were involved in avoided the sections of the proforma regarding end-of-life. They thought the patient was not interested in discussing these issues yet. The geriatrician indicated that the patient preferred discussing what they were going to do in life, rather than how they were going to die.

“It was good. I found a lot of the questions were redundant and I felt a bit, I wasn't sure if I should be filling them out and I felt like I didn't complete it well, adequately. And that may just be that, not that, yet to become that familiar with it. With the end-of-life things most patients didn't want to talk about, that issue wasn't an issue for them, quite yet. So even though they were in their last year of life they were more engaged in what they wanted to do with their remaining time rather than, didn't want to waste time talking about end-of-life process and you know. I think there was one question about afterward at the end-of-life, where they actually die and what happens afterwards. We didn't really even touch on that very much because patients were more actively wanting to plan their next months of life.”
(Geriatrician 3)

This geriatrician also identified that they were unfamiliar with the proforma and that with improved familiarity their confidence in working with the proforma would improve. The unfamiliarity with

the proforma was identified by a small number of participants, including GPs and allied health participants.

The proforma was completed by each of the health professionals in every case conference. The health professionals, in most cases identified that the proforma was easily understood and familiarity with the proforma would improve their competence in completing it. Some sections of the proforma were not used. Concern was expressed over the end-of-life sections with health care professionals indicating a preference for patients to avoid these discussions. Researchers have noted that there is concern that end-of-life discussions cause distress in patients and their families.(173) The proforma was generally well used and is a feasible tool for a structured case conference. However, not all sections were considered necessary and the tool could be refined for future use.

7.1.3 Care plans created and followed

A formal care plan was developed from the notes received from the health professionals for each case conference. The care plan included action items and identified a person responsible for following-up each action item. Health professionals received a copy of this plan and the GP discussed the plan with the patient and carer. In this section, the analysis addresses how care plans were perceived by participants.

All the GPs, hospital-based health professionals and the community-based health professional identified that the care plan was received and was an accurate summary of the case conference. This is expressed by the GP below.

“I think it was just a good recap of their condition and the services they needed.” (GP2)

Most of the health professionals identified an improvement in circumstances for the patient and where applicable, the carer in direct response to the case conference. The case conference was able to identify any services lacking and facilitate the implementation of any changes required to access these services.

“I guess I am just more aware of some of the issues that I need to focus on, so um [geriatrician], I remember was emphasising the fact on how a lot of his hospital presentations stemmed from his issues with constipation, so I’ve just been more reminded to emphasise that each time I see him and um I think we have subsequently got a home

medicines review and had a pharmacist out to um to see him and I've sent a few letters to blue care and um just to make sure we are all on the same page.” (GP8)

However, there was a small number of hospital-based health professionals who expressed concern about whether care plans were followed. The hospital-based health professionals are not routinely informed if the items to be completed by the GP, the patient, or their family had been actioned. The extract below also highlights that although this geriatrician was unsure of the patient's preferences, there was concern that items were not actioned as they should have been and that the patient's preferences were not followed.

“I think she, I was on holiday, but I think she came in and passed away, in hospital briefly. I'm not sure that was quite, whether things we suggested were actioned before that happened or whether she actually wanted to come into hospital at the end. I'm not entirely sure with that one. So sometimes you just felt like I don't know if they quite got there with her. So I think that's variable.” (Geriatrician 3)

The geriatrician also expressed a concern that there was more that could have been done for this patient and that the case conference process does not provide the same solution for every patient.

The patients and carers identified that the care plan resulting from the case conference resulted in additional services being provided in the community. The extract below shows the breadth of services provided after the case conferences. This provided an incentive for carers to organise further services. However, this was not supported by the quantitative findings in chapter 7.

“Yes, she has had occupational therapists come out, um she's had exercise physiologists come out. The occupational therapist changed the toilet seating arrangement at the house and a couple of other things. We had arranged to have a podiatrist come. We had arranged for extra care in that sort of sense, so there were extra facilities provided after the conference, through that conference.” (Carer 22)

The case conferences were not just a passive experience for the patients and the carers with most patients and carers indicating that they were also involved in organising additional services and planning for future needs.

“It got me thinking ‘well I do have to organise this respite stuff’. Even though I may not be using it, it’s got to be put in place.” (Carer17)

A care plan was created for each patient after the case conference. Overall, health professionals reported an improvement for their patients with extra services being received in the community. There were some concerns expressed that it was not possible to know if action items had been completed by other participants of the case conference and that not every case conference provided the expected results. The patients and carers indicated that the case conference was successful in providing additional services and involving the carers in organising further services. However, this was not the case for every carer with one expressing disappointment with the case conference and the outcomes.

7.1.4 Participants

In Phase 1, health professionals with experience in providing care for frail older people and people at the end-of-life, considered the mix of participants required for a case conference. Participants of the pilot of the model of integrated palliative care for frail older people in the community, identified similar thoughts about the other participants included in the case conference process. The geriatricians each identified that it would be preferable to have a short conversation with the health professionals without the patient or family involved, to allow for a frank conversation of any potential additional issues that impact on the care provided. As the extract below illustrates, there is a concern that a frank conversation between participants is unlikely when those participating are concerned about expressing themselves fully in front of the patient or the patient’s family.

“Cause sometimes you have to sort of separate the patient and GP or family to get a really true picture of what is going on, because sometimes the family or the GP might find it really hard to fully express themselves, in their concerns or frustrations in front of the patient. So I don’t know whether with other cases you allow for a little bit of separation of the clients for a few minutes or yeah” (Geriatrician 2)

The GPs agreed that the opportunity to speak with the hospital staff independent of the carer and family would be useful. One GP also identified that although they had held concerns prior to the case conference about the carer being involved, it was a valuable experience.

“I was a little wary of having a relative there but I, it was very valuable.” (GP5)

One of the carers was also in agreement with the health professionals, that the conversation would have been limited if the patient had attended the case conference. The carer indicated that they would have been unable to have the same frank conversation with the patient in attendance.

“I thought that was very well coordinated and I thought it was very very well structured um and the fact that there was that openness. The only thing that I would say would have been that the candidness that was at that particular conference would not have been able as my part of a carer had [patient name] been at that interview. So I think that for future case references or conferences, um if the carer and the client are there at the same time it makes it extremely hard, I believe, for the carer to be candid.” (Carer 22)

A small number of GPs also noted that although the patients attended with their carers, some of the patients weren't involved in the discussion.

“They all were able to come at the same time and they were all able to contribute to it. That was good. Oh, [patient name] didn't contribute much at all, she tends to sit there and absorb.” (GP6)

This finding was also reflected in a small number of carer interviews, with carers identifying that the patient was not involved- indeed having the patient involved was a distraction for a small number of carers.

“It, it did work well, except having mum there was a distraction because mum could not understand everything that was going on. When she heard the word care home and all that she just thought she was going to be put straight into one. Yeah, mum was a distraction, that's all.” (Carer 17)

Overall, most participants identified that the opportunity to have everyone involved was helpful.

“The GP, (patient name) and his brother, plus (geriatrician name) and myself, we all had time to raise our concerns. Um, discuss what we thought might be helpful. Ask (patient name) and his brother what they would like as well.” (AHP 06)

Overall there was agreement that the mix of participants was generally suitable for the case conference. One carer identified that for case conferences to be successful additional support would be required. This participant identified that a case manager would be preferable, providing one point of contact for not only the community-based health service and the GPs but also for the patients and their families.

“I would believe that in an ideal situation where you have this case conference and you have 4 parties- that there be an actual fifth party and be they an administrative type person, and whether it’s in the [community nursing service] or whether it’s in the hospital or wherever , they’d actually, is the ‘go to’ person. And I know that means another department as such, but ideally if there was someone they all had to report back to with regard to their care and it goes into her one file. It would to me mean that, or there be a computer program that they could all have access to, remotely, whatever, and even the carer could have access to. They could put in that they are concerned about so and so and that they’ve spoken with [name], or whoever, from [community nursing service] and then [name] could put in there that she’s addressed that. As in that form that we had and we got sent out about the report, the conference report. I believe if there was something like that you could access and type into and then when they go to visit her they add to that report.” (Carer 22)

This topic has shown that implementation of a case conference as an integrated specialist-GP model of palliative care for frail older people is difficult in a busy functioning health service. Preparation is required, but workload and time restraints are a barrier to effective preparation.(178, 179) A structured proforma is a useful tool and most health professionals are confident of making choices as to the relevance of each section based on their patient’s need, given time to familiarise with the structured. However, as other researchers have found, discussion of palliative needs can be overlooked. This may reflect paternalism from the health practitioner(185), discomfort with the topic, or the patient may not wish to have these discussions.(203) Even with limited preparation, this theme indicates the care plan facilitates an overall increase in access to community-based services for the patients and carers. The case conferences, as designed, were feasible, however additional changes in design may facilitate the use of case conferences in practice.

7.2 Practicality

This topic considers some of practicalities of making changes to practice within the current health system. Specifically, as the interviews highlighted, the main practical issues related to information

technology requirements and timing of the case conferences given the structured but varied routines of health professionals across diverse practice contexts.

7.2.1 Information Technology

The case conference was dependent on the availability of appropriate IT facilities. The discussion of information technology was a minor part of the discussion and very little data about it was gathered. The hospital at which the case conferences were conducted had appropriate facilities to conduct video conferencing. As indicated by the geriatrician below, the initial connection process at the hospital was quite easy.

“That worked quite smoothly.” (Geriatrician 1)

However, there were quite a few technical issues with video conferencing that were experienced by the GPs, hospital-based health professionals, and the patients.

“Um but I think the biggest problem actually was the just the technical glitches that we had. Um it seemed like because [patient name] was hard of hearing and he wears hearing aids he had a lot of trouble with hearing the um just hearing um the sound from the laptop and then we had some issues with the visuals cutting in and out um and so I had to um relay a lot of information that I was hearing through either the laptop and we eventually um actually ended up using the phone um but I had to relay it. So it didn't work as efficiently as it would have been face to face, um but we got there in the end.” (GP1)

Overall, even with the technical issues, most of the GPs and hospital-based health professionals indicated that the video conferencing went well.

“It went pretty smooth. It was nice. Apart from a couple of, I think internet connections and things, it went very well.” (GP2)

There was an expectation that technology issues were expected when conducting video conferences, as expressed by one of the GP participants.

“We had a crash, you know, with the connections, but that's to be expected, I guess.” (GP15)

The hospital-based staff did not indicate any concern about the equipment used for the case conferences, but each GP office indicated that they did not have the correct equipment to conduct case conferences.

“I don’t think we, yeah we should be able but I don’t think we have the right equipment. I don’t think we, we probably need a laptop or maybe a webcam or something. We don’t have a webcam here. We have a laptop in the other room but it’s pretty old, so I’m not sure if it...” (GP2)

In Australia, there is no government incentive to have videoconferencing capabilities unless the GP is in a rural area, nursing home or in an Aboriginal health centre. The lack of available technology at the primary care level, apart from these areas, is an impediment to the feasibility of the intervention.

7.3 Timing of case conferences

There were some concerns about the timing of the case conferences due to the differing schedules of health professionals and also demands on time. Case conferences in this study were scheduled early in the morning prior to opening hours for GPs.

“We had to reschedule to make sure it was done first thing in the morning or otherwise it gets too difficult to schedule it in the course of our working day, so we always kept it to the beginning of the day” (GP3)

However, this early morning timing of conferences did not align well with the routines and needs of hospital-based health professionals, who typically had staff meetings for change of shift. During the study some accommodations were made, although experiences of those involved suggest this could be a challenging aspect of the model longer-term. Case conferences scheduled before the GP started seeing other patients meant these started on time. Three case conferences were held during GP lunch breaks to accommodate different routines and in each instance, it was difficult for the GP to connect on time. Consequently, so other participants were kept waiting. Where GPs and geriatricians were involved in scheduling the case conference there tended to be a better fit with routines:

“The timing was fine.”(Geriatrician 1)

One participant suggested having a scheduled time each week, for case conferences. This would also provide some certainty to timing and allow adjustments to be made locally.

“So I think if it’s something that is going to be initiated and expanded it would be setting aside a time, sort of like a clinic time, or a telehealth clinic where GPs can refer and if they are linked in with community services or allied health services here then they can be present and family can be present and then it’s you know you can assess the patient in that way. The teleconference time itself with the patient might be lengthy but as with this particular case that allied health were present, the GP was present, information was pre-populated, then it means the specialists time is well utilised. So I think that’s how I can see it working.”

(Geriatrician 2)

This extract provided the preference for hospital-based health professionals. However, this may be more difficult for GPs to keep set times if other patient appointments are running late. This extract also highlighted that although teleconferences are time intensive it is time well utilised and if preparation was completed prior to the case conference, this would optimise the time further. The following extract further explores the preparation needed prior to the case conference to optimise the time spent on the case conference.

“Maybe if there was a way to, in advance have them share what their thoughts, in advance, with each other and then at the meeting we could just explore those a bit more rather than just spending some time identifying them. I think that maybe I wasted time identifying with the GP whether they thought they were the same issues. Maybe if we did that in advance of the meeting, on paper or email, then talked about it we might have optimised the interview time a little bit, but that was my only thought there.” (Geriatrician 3)

These preparations would also require time, but the geriatrician highlights that the time spent on preparation would be preferable, so the case conference would be more focussed.

This sub-topic has identified that preparation would improve the time efficiency of the case conference. Preparation was a sub-topic of implementation and the findings suggested that although preparation was required for the case conference, it was often not completed, unless the GP was

unfamiliar with the patient. Participants have again identified that preparation is a key component to improving time efficiency of the case conference.

This topic of practicality found that the intervention is dependent on the technical capability of the participants and time constraints. The health department provided the facilities at the hospitals; however, it is up to the GP practices to upgrade equipment to make an intervention like this viable. Access to information technology is known to be a barrier to telehealth use.(204) Time constraints were also discussed, with time optimisation an important component to improving feasibility. Preparation was considered the most likely avenue to optimise time, however as noted in section 7.1, preparation requires impetus from the health professionals.

7.4 Demand

The topic of demand is concerned with the adoption of the integrated model of palliative care for frail older people at the end-of-life. The sub-topics are: the level of funding required to support the uptake of the intervention, and choice of participants, which is concerned with moderating likely uptake.

7.4.1 Funding

The financial cost of the time, rather than the time itself was a further issue of feasibility raised by health professionals. The GPs focussed on the limited time in their day. Outside of the study, a GP tried to schedule a case conference with the hospital, however without the framework of the study found that setting aside a time when there were competing interests was difficult.

“I requested several times from [geriatrician name] and the social workers in the hospital to have a case conference but I couldn’t make it because of time limitations. Our nurse’s [time limitations] actually. The other ones, because there was a good one or two weeks before hand, I was aware it was going to happen, so. It wasn’t too bad.” (GP2)

There were concerns about opportunity cost by the hospital-based health professionals. The concern that by being involved in case conferences removed the health professional from seeing a patient on the ward.

“So, you know, if you go and put in case conferencing all the time you don’t get that patient contact and you don’t get that information as well.” (AHP06)

If the patient has been discharged and is no longer a hospital patient, the staff perceive this time as being spent away from their inpatients on the ward. However, a small number of allied health professionals indicated that the case conferences were similar in length to the time they would spend with a patient on the ward.

“Yeah, well it was um in so far as the time taken for me to attend was no more than me seeing a patient on the ward.” (AHP04)

Concern that the time spent in case conferences is not financially compensated was a further issue raised. Although the patient may benefit from the case conference this allied health professional expressed a concern that the process requires external funding to recompense the hospital for time staff contribute to a process involving GPs and community-based service providers.

“So there’s going to have to be, I know that on that end there’s a payment attached. There would certainly have to be some sort of payment attached to the hospital side of things to justify why we were spending time doing this. You know, aside from the obvious patient benefits which we can all see but going up the line there also has to be a dollar value attached to that as well. You have to recompensate (sic) the hospital for the time that their health professionals are spending talking to external providers.” (AHP02)

The extract above reflects how the various hospital departments are funded. If a ward spends the time, and therefore the money, conducting case conferences and the result is a reduction in emergency department visits, the emergency department has the financial benefit, but the ward has the financial cost. In order to become a more routine part of the health care system the health professionals identified the importance of revising the current funding model to take account of case conferences.

7.4.2 Choice of participants

Due to funding pressures, hospital-based health professionals identified that it would not be practical to provide a case conference for every frail older person that attended the hospital. It would be preferable to identify those patients that would derive the most benefit from participation. Patients that return frequently to hospital for acute medical issues and are released prior to their

more complex needs being assessed would benefit. A case conference would provide an opportunity for all those involved in the patient's care to be participate.

“I think it would be good fitting (it) in if it's tailored towards the patients with the greatest need. So the complex patients, the patients who are frequently presenting with similar issues that often on short one off admissions don't get solved, or don't get looked at. They need a sort of more involved approach from all the parties, which doesn't always happen.”
(AHP04)

There was also recognition that not all patients require the level of intervention provided by a case conference and for those patients who would benefit from a higher level of intervention, this could be identified early, and a case conference could be scheduled at discharge.

“I mean you wouldn't do it for everybody. Some people would be more of a simple discharge, you know, where we feel fairly confident that that's going to go well. Where its more complex it could be identified say on, even through the admission paperwork, through the assessment from a discharge planner or from the OPERA team, as being a priority, or you know, something that could be flagged for discharge that, and then it could be scheduled.” (AHP01)

A concern was also raised in the extract below by hospital staff that even if the case conference was restricted to complex cases the demand would still be too high to allow time to consult with patients on the ward. This reflects the concerns from hospital-based staff around time and funding as discussed in the section above.

“I think it's the volume because the amount of patients we have and even if a case conference only goes for say 15 – 20 minutes and you are using it daily and hospital wide you could easily have 10 complex patients a day and it's just.... we still need that face to face contact as well.” (AHP06)

Hospital-based health professionals agreed that the more complex patients should be identified and would benefit from this intervention. Hospital-based staff also expressed concern about the ability to meet demand if case conferences were widely implemented. GP participants in the case conferences did not express the same concerns.

This topic found that there are concerns from the health professionals about implementing case conferences as an integrated model of palliative care for frail older people. The findings indicate a concern from the health professionals that uptake of case conferences would be too high, and it would be necessary to target the case conferences at the more complex patients. Even with a restricted offering there is a concern that uptake would be too high to service. The intervention is not feasible if additional funding is not provided to free up staff time to prioritise case conferences as part of patient care.

7.5 Acceptability

In seeking to understand the acceptability of the case conference intervention the focus was on how participants reacted, in terms of satisfaction with the case conference model, perceived positive effects, perceived appropriateness and the intent to continue to use the intervention.(200) Further, in reporting acceptability, it was of interest to identify these matters according to various perspectives. Consequently, the analysis is presented separately for health professionals, and patients and carers.

7.5.1 Health Professionals

The health professionals perceived the benefits of case conferences as: improved knowledge and understanding of the patient; improved access to services; and improved communication with other health providers and with the patient and carer. Overall, the reports of health professionals indicated the general acceptability of the case conference intervention.

The geriatricians noted that there were perceived benefits for the patients, with the treating team's knowledge of the patient improving as a result of the case conference. The extract below highlights how an increased understanding of the patient's community situation improved the ability of the geriatrician to care for the patient when readmitted. The case conference also improved the geriatrician's understanding of the patient's wishes, allowing the team to focus on what the patient wanted in terms of care.

“Well I think it just so happened that I had to see [patient name] again even though she wasn't one of my regular patients. But um it was good having that background, like when I saw her the second time [it was] very easy to then set goals and discuss expectations and just have a good understanding of what it was she wanted. And make it easy for us as the treating team to accept what her wishes were, because we knew that, you know, this is consistent with

what we knew about her before she became unwell. That's often the difficult thing when you [see] somebody, who you don't know before and you don't know, you're not privy to all this that we discussed in the case conference. Are they saying this just because they are unwell or is this consistent with their wishes? So, I think it helped in that way, yeah." (Geriatrician 2)

The hospital-based allied health professionals identified an improved knowledge of the patients' situation in the community as a result of the case conference and the benefit to the patient of this additional knowledge. The communication between the GPs and the geriatrician informed the allied health providers' care by providing information on what was occurring in the home for that patient.

"I think the other thing that was good was when we did have patients come back into hospital, having the geriatricians having contact with the GPs they had a bit of an understanding of what had been happening in the community. Which helped in an acute setting being able to treat them a little bit better, and having an understanding of what has been going on and what has and hasn't been working." (AHP01)

The geriatricians identified an improved channel of communication with the patient and with the patient's other health professionals. Improved communication was seen to foster relationships between the primary and secondary care services that are not normally there, indicating a perceived benefit of the case conference.

"I think that was one of the most valuable things, building that trust and relationship, that we were all trying to work together for the person. I wasn't sure how much in the way of concrete plans we would definitely solidify during that meeting because I think it's a process but um I think it was good for building the rapport and the connection because otherwise it is so disconnected, what goes on in hospital and what goes on in the community, general practice, so." (Geriatrician 3)

The allied health professionals also identified that improved communication resulted in a more cohesive treatment plan which may prevent readmissions to hospital.

"So I think the case conference obviously is going to be beneficial to these patients, the complex patient, to um to try and get their medical management more cohesive between the acute service and GPs and community and prevent readmissions etc." (AHP04)

While there was a perceived improvement in the communication between the GP and the geriatrician, the allied health professionals did not identify an improved communication with the GP themselves. This message was repeated by all but one of the allied health professionals.

“I don’t think from me, but I think between the GP and the geriatrician there probably would be” (AHP05)

Contrary to the allied health participants perception that communication with the GP did not improve, the GPs on the other hand identified that inclusion of the allied health professionals provided an opportunity to develop this interprofessional contact which would otherwise not be possible.

“There was more involvement of allied health people, um, on top of my looking after her. Probably it made it easier for me to access people like that.” (GP4)

All the GPs also indicated they developed a relationship with the specialist and the clinics that allowed them to follow up on patient care and on the implementation of the care plan.

“I think it enhanced it, you know. The other thing that happened was because I had a connection to the specialist and those clinics and things like that I was emailing them saying ‘What’s happened to this? Have you been able to, or we haven’t had any feedback about this!’ and then I was getting some feedback from that.”

The GPs also identified positive outcomes for the patients, with one GP also noting that whilst there was not an improvement for one of their patients, due to deteriorating condition, there was an improvement for the carer.

“Among my patients I feel it made a better difference, a bigger difference for (patient 1) than for (patient 2). But (patient 2)’s situation is a bit different because, I think, he has a lot of other physical issues as well and he is not doing well at all. So within the limitations of this study and case conferences and stuff I think it has at least, not for (patient 2) himself but for his wife, it has made life a bit easier.” (GP2)

Overall the health professionals indicated that the case conference was acceptable. The health professionals reported benefits to the case conference including that they were more familiar with the health needs of their patients and their patients' wishes in relation to their care, providing a patient-centred care experience. Communication was improved between the GPs, the hospital-based health professionals, the community-based health professionals and the patients and carers. The benefits perceived by the health professionals indicate the acceptability of the case conference as an intervention for frail older people.

7.5.2 Patients and carers

Acceptability for patients and carers addressed satisfaction with the case conference process and any perceived benefit, indicating a willingness to participate in case conferences. Overall patients and carers liked the case conference process. All but one of the carers found the case conference reduced the burden of caring and provided additional services

“Yes, it did, it did. Because I’m not doing this just alone, where before, (GP name)’s great, you guys are great and whatever else but, you know, (GPs name) got to see the next patient and she’s not going to be sitting there thinking about me and whatever else and you guys. Now, It’s like, alright this is what [carer name] and [patient name] this is what we think we need to do, so. Then [GP name] speaks up and says ‘Right, well I’m going to take care of this for you. I’m going to do this’ and you say ‘I’m going to do this’ and I’m going ‘Wow, this is fantastic’ because it takes off a lot of pressure. And I’ve had a lot of follow up phone calls from people to see how things are going and all that.” (Carer 17)

Carers found that relationships with hospital staff were improved. The extract below shows that although the case conference was demanding for the carer, the carer felt that it was worth it so that the patient's views were accounted for as part of the process.

“Yeah, I think it was good, you know, because I met the doctor in Ipswich hospital after that and she said I remember you and I said I remember you. I was shaking when it was all over, you know. But I thought that was a good idea because usually as patients aren’t involved in the medical side at all, you know.” (Carer 13)

One carer explained the importance of good relationships with those caring for her mother and the impact those relationships can have on how they engage with the health service.

“No it’s a relationship. It’s how I get treated at the same time. Because if I’m not treated well by you, by the doctors, whatever else, then I’m going to take it [mum’s care] all onto myself again. What everyone else does has a massive impact on me and for my mum. So, you know, how we’re treated and how, you know, just being relaxed and whatever, you know. I can have my cry and things like that and its okay. You know, you’re not just computers walking in on two legs. And off you go again.” (Carer 17)

And they identified that the case conference was responsible for additional services.

“Em, [community nursing service’s] been very good, you know. And we’ve had ACAT [Aged Care Assessment Team] out last week speaking to both of us.” (Carer 13)

There was one carer that participated in the case conference who perceived very little benefit and who was unsatisfied with the case conference. This carer identified that the case conference revolved around the patient’s recent admission. They felt the GP received some benefit from the case conference, but that because the patient had straightforward care issues the case conference was not beneficial for this patient.

“Not really, because they were talking about the hospital stay mainly and they gave the information to the doctor that he can refer us straight into the ward if necessary, which is what he never, he didn’t know he could do, so he got that out of it. But I was discussing with him, myself about the case conference and as he said, she’s such low care, she’s not got any ongoing major health issues apart from the ones that manifest themselves, so we just really didn’t get a lot out of the case conference.” (Carer 23)

The patients and carers considered the case conference model to be a satisfactory model with some benefits for the patient.

Overall, the case conference was considered an acceptable intervention by the health professionals and most carers.

7.6 Discussion

This chapter has explored feasibility from the perspectives of health professionals and patients. In this study the topics were implementation, practicalities, acceptability and demand. Health professionals were given time and reminders to complete preparation, but, the preparation was not completed prior to the case conferences. Although the GPs felt prepared for the case conference as they were familiar with the patients, the hospital-based health professionals felt underprepared. It is possible that preparation could have improved the quality of the case conference. The hospital-based health professionals agreed that preparation would also improve the efficiency of the case conference. Implementation could be improved with the sharing of information prior to the case conference and this could be facilitated as part of the booking process

The participants found the proforma useful as a prompt or reminder of areas to discuss and it served to focus the conversation. However, the end-of-life sections within the proforma were not used much and participants perceived that patients were reluctant to discuss these issues. The sections of the proforma relating to physical health were completed well, as detailed in chapter 6. Care plans were successfully created from the proforma notes and followed, resulting in additional services provided for patients and carers. Although implementation was not completed as prescribed by the study, implementation can be considered successful, with care plans created as part of the case conference being followed through from the patient and carer perspective. However, there was uncertainty in the minds of hospital-based specialists whether the plans had been fully implemented. Further correspondence between participants, relating to the completion of care plan items may increase the health professionals' confidence in the process and improve the likelihood of case conferences being implemented successfully.

Case conferences in this study were not implemented without outside intervention. Although the mix of participants was considered appropriate and the timing of case conferences could be managed to facilitate everyone's involvement, in this study GP practices were not equipped with the appropriate technology to enable participation in case conferences. All the case conferences were held within a region which does not receive any support from the government for telehealth, which provides financial support to upgrade technology to facilitate video conferencing in designated rural areas, aged care facilities and aboriginal health services.(205) If practices are unwilling or unable to provide suitable devices (eg laptops, tablets, phones) it may be possible the GP, patient or carer may have devices capable of video conferencing, thus providing a possible solution. However, software

would have to be approved by the district health service to ensure security. The provision and use of information technology is an area that requires deliberate and further exploration.

Funding was a considerable concern for the hospital-based participants. To enable health care professionals to participate in case conferences additional staff would be necessary to provide support for the involved professionals. There is also an argument to be made that administrative support should be funded to facilitate the case conference process. The case conference is cost-effective when considering staff time, as discussed in chapter 6. However, there are concerns about how the departments are funded within the hospital system. Current rules mean that while the extra costs of case conferences would be borne by the ward, the cost benefits are only appearing in other departments. There would need to be recognition within the budget that there is an additional cost to the ward to provide this service, with the knowledge that the financial benefit is seen elsewhere within the hospital. Some of these concerns can be overcome with discussions with hospital management overseeing different hospital budgets and providing the additional resources where required. The health system uses activity-based funding, which benefits from activity within the system and does not reward efficiencies. This can lead to early discharge of patients, increased readmission to hospital, increased patients discharged to post-acute care services, sick patients discharged to ill-prepared community settings and a focus on acute care rather than the more complex patients.(206-208) Activity-based funding currently provides funding for case conferences to GPs, however, the same level of funding is not available at the hospital level.

Concerns were also raised that uptake for case conferences would be high and that to manage the uptake only complex patients would be referred for case conferences. Previous research has shown multidisciplinary case conferences promoting integrated end-of-life care provided for a substantial saving in advanced heart and lung disease patients.(16) This would be considered an efficient use of resources with a case conference taking roughly the same amount of time for a complex patient as a non-complex patient. There are probably more savings in reduced hospital admissions by creating a care plan for the complex patient.

This model of palliative care planning for frail older people, was generally acceptable, although there are significant barriers to the feasibility of the model. The health professionals were satisfied with the case conference model and identified benefits to the patients and to themselves and other health professionals. Health professionals also identified that the process provided them with an understanding of the patients' wishes allowing for patient centred care to be provided. Likewise,

carers also indicated that the case conference was acceptable with patient benefits identified.

However, the evidence also supports the need to adapt the model locally to improve feasibility and more so, to strengthen the opportunity for it to become part of routine practice. A critical aspect of this involves addressing the funding models that would likely impede implementation and change longer-term.

Chapter 8 Discussion and Conclusion

In this chapter, the key findings from each phase of the study will be summarised. The findings from Phase 1 will be related to the development of the model of integrated palliative care and the findings from Phase 2 will be discussed in relation to the aims of the study. This is followed by a discussion of the findings in the context of the relevant literature and the implications for health policy and clinical practice. Finally, the strengths and the limitations of the research design and the implications for future research are discussed.

8.1 Summary of key findings

The first phase of the study explored health professionals' experiences and perceptions in caring for frail older people at the end-of-life and in providing palliative care to patients. Further, views were sought of a proposed model of integrated palliative care, identified through the systematic review, in order to explore how the model could be modified and adapted for the current health system. The systematic review identified that engaging GPs in palliative care with relevant specialised secondary services reduces hospital use and improves patient outcomes (pain management, symptom control and functional status). A case conference model between GPs, specialist secondary services and the patient was successful in reducing hospital use, improving pain control and improving patients' functional status, and this model was presented to participants in Phase 1 of the study.

Phase 1 found that identifying frail older patients was complex. In the primary care setting frail older patients can present themselves in a positive light, putting on 'their best face for the doctor', hiding or downplaying multiple comorbidities. Whereas, in the secondary system, the patient's complex health needs can be overlooked when the focus is on the acute medical issue that the patient presented with at the ED. Health professionals indicated that the disease trajectory for frailty is complex with no clear clinical indicators that would indicate a high risk of death, making identification of those patients who would benefit from palliative care challenging. This finding of a complex trajectory from Phase 1 indicated the case conference model required a system of screening or case finding to be included to identify frail patients with palliative care needs.

Furthermore, health professionals are reluctant to use the term palliative care with their patients as this can cause distress, and that some patients are not ready or unwilling to accept palliative status. They emphasised that sensitivity is required to negotiate these conversations with patients. This

finding is in accordance with the literature. Previous studies confirm that health providers perceive that the term palliative care causes distress to patients and families.(173) Thoosen and colleagues(209) found that even when trained to identify patients in need of palliative care and provided a structure for anticipatory care planning, GPs are reluctant to initiate an appropriate conversation about proactive palliative care. Phase 2 of the study adjusted the language used in the information sheet and consent forms to reflect the concerns of the health professionals from Phase 1, referencing supportive care, rather than palliative care.

Phase 1 of the study also indicated that not only GPs, geriatricians, and allied health professionals, but also the patient and/or family should be invited to participate in a model of integrated palliative care. Further, it was decided by the health professionals including palliative care specialists, that a palliative specialist was not a necessary participant and could be consulted if required. Several barriers to an integrated model of palliative care were identified, with poor communication between the primary and secondary health services, and constraints on time and funding identified by the health professionals as significant issues to resolve. To alleviate any time and funding constraints for the purpose of the study, the researcher provided the administrative support required to implement the multidisciplinary case conference model of palliative care for frail older people in the community.

Phase 2 of the research was a small pilot study of the multidisciplinary case conference model of integrated palliative care for frail older people based in the community. The aim of Phase 2 was to determine the feasibility and acceptability of multidisciplinary case conferences for frail older people at the end-of-life and to estimate the effects of the intervention on health service utilisation, patient outcomes and carer outcomes. The model was implemented in clinical practice and evaluated using quantitative and qualitative methodology using a comprehensive set of questionnaires for patients and/or carers and individual face-to-face interviews with each case conference participant, including health professionals.

Patients involved in the pilot study demonstrated an improved mental health, alongside physical decline, over three months. Carers experienced an increase in carer strain, although both physical and mental wellbeing, showed improvement. The results showed a promising decrease in emergency department visits, the total days in hospital and the average days per admission despite increasing physical frailty. Although encouraging, given the small sample size and non-randomised

design, these findings were only indicative of those patients and carers in this pilot study, but are important in informing future research and the development of the model of care.

Health professionals did not strictly adhere to the design of the model during implementation. Specifically, health professionals identified that whilst preparation would have been useful, often the preparation required prior to the case conference was not completed. Care plans were created for each patient as designed and the care plans were followed.

Patients, carers, GPs, specialists and allied health professionals all indicated that the model of care was acceptable. The model of palliative care improved communication between the primary and secondary care providers and communication with the patient and family. It provided direct benefits for the patients in the way of improved mental health and increased use of community-based services (e.g. meals on wheels). Carers also derived benefit from the case conferences, feeling involved in the process of care. The research found the model of care was acceptable and feasible clinically, but financial barriers and time constraints within the health system would need to be addressed to make multidisciplinary case conferences a sustainable model of palliative care for frail older people in the community.

8.1.1 Impact of a Model of Integrated Care

According to the literature, engaging GPs in palliative care with relevant specialised secondary services is effective and provides positive outcomes for the hospital (reduced readmissions, shortened length of stay), improved communication between services and for the patient (pain management, symptom control, functional status) (101, 107-109, 130, 135, 139, 141), particularly in patients with end stage cancer, cardiac and respiratory disease.(107, 130)

The model of care in this study reduced hospitalisations and better maintained mental health. As frailty is a leading cause of death, this study sought to develop and implement multidisciplinary case conferences as an integrated model of palliative care for frail older people in the community.

In the model, the patient's GP, hospital specialist and at least one other health professional, often an allied health provider at the hospital participated in the case conference. The patient and/or their carer were also asked to participate if they wished, as were any community-based health providers. The patients and carers were pleased to be involved, which the health professionals found positively added to the case conference. However, most health professionals also expressed the view that they

were unable to talk as freely with the patient/carer there. Hence, although the doctors were committed to patient-centred care, they felt time to discuss issues frankly without the concern of how the patient/carer would react would be useful. There were concerns about the patient/carer dynamic and the relationship with the health professional and that any underlying conflict present may frustrate constructive dialogue and meaningful discussions. This concern speaks directly to the structure of the case conference used in the study. The dissonance between allowing free communication without the patient and family present, and the desire to provide patient-centred care was emphasised.

There is (or can be) tension between a paternalistic view of health care where decisions are made by the professionals, and an autonomous view, where the patient has the main medical decision-making role. There are many alternate theories of medical care that attempt to define the working relationship between the health professional and the patient.(175, 210) Some theories place a patient's choice and autonomy above those of the health professional, with an emphasis on providing the competent patient the information required to make their decision and advocating for this choice, whether the health professional believes it is acceptable or appropriate.(211) Most identify that although choices made by the patient should be supported there are complexities that limit autonomy, including competence, mental illness, the imbalance in the relationship structure, the imbalance of knowledge between the health professionals and the patient, shock and distress experienced by patients and families or, at times, decisions made by patients or families to access a treatment the doctor considers inappropriate or illegal.(175, 212, 213) Inviting patients and carers to participate in the case conference enhances patient-centred care and autonomy. Although this may cause inefficiencies in the case conference process, it empowers patient and carers to choose their level of involvement in the patient's medical decisions. The model of case conferences for frail older people at the end-of-life should retain an invitation for the patient / carer to participate if they wish.

Multidisciplinary case conferences are the start of an ongoing process of integrated specialist and community care. The initial case conference allows a shared care plan to be developed with the input of all concerned parties. The development of the relationship between the primary care service professionals and hospital-based specialists provides a point of contact for future discussion about the changing health care requirements of the patient, and carer support. Additional conversations between the health professionals should be encouraged, allowing updates and

amendments to the care plan to meet changing patient and carer needs as frailty progresses, and if required, frank discussions without the concern of impacting the patient/doctor dynamic.

The series of multidisciplinary case conference discussions focused on the physical symptoms and the social support needs of the patients and carers, and most actions taken were in response to these physical symptoms and social support needs. The health professionals involved in the case conferences identified that more complex patients would benefit the most from the case conference model. In New Zealand, Stewart and colleagues(141) developed and implemented a primary secondary integration project in palliative care and found that over time the service had a reduction in referrals with a corresponding increase in complexity of the cases referred. This suggests that in a real-world setting, health professionals will prioritise the more complex cases to an integrated service. Although all the aspects of palliative care of the patient were not discussed in all of the case conferences, each element of a comprehensive palliative care plan was at least considered. Case conferences were an acceptable and worthwhile model of care planning and subsequent care delivery for frail older people with complex medical and social needs, and to support carers.

8.1.2 Barriers to the Implementation of the Model of Care

The health professionals identified time and funding as barriers to implementing multidisciplinary case conference as a model of palliative care for frail older people.

The funding for the universal health service in Australia is split between state and federal governments. The federal government provides a scheme – Medicare- which covers most of the costs for out-of-hospital medical services, such as GP consultations, specialist consultations, radiology and pathology, with some contribution from the patient. As part of the federal system, GPs are funded to prepare for and participate in multidisciplinary case conferences. The states provide funding for public hospitals, where all Australian citizens and permanent residents are entitled to free care. For this reason, reducing hospitalisations and increasing the number of GP visits for a patient, moves the funding burden from the state to the federal government. Reducing costs from the hospital system may please the states, however, provides further burden on the federal budget. This is true in reverse, with additional hospital visits putting further pressure on state funds.

Additionally, within each hospital, funding is organised in discrete units, with each unit managing a budget. For example, the emergency room budget is quite separate to the paediatric budget or the

geriatric budget. When additional resources are required to implement an intervention on the geriatric ward the increased costs are borne by that ward. If the intervention reduces the number of emergency room visits by a patient, the savings derived from the intervention are made in the emergency area's budget. The mindset of protecting each unit's budget mitigates against system change. To overcome this obstacle, an administrative change to a centralised budget may encourage better system outcomes, rather than punish individual units. This change could be a mechanism to alleviate these budgetary concerns.

These funding pressures are relevant to the time pressure that hospital-based staff expressed. The hospital-based staff liked the concept of the case conference and attempted to find a solution that provided benefit to the patients of the unit. They expressed the view that while their time on case conferences is worthwhile and that although all patients could benefit from case conferences, the most benefit would derive from conducting case conferences on the most complex cases, reducing admissions and time involved. This reflects previous research that indicates the most complex cases were the cases referred to an integrated palliative care service in New Zealand.(141)

This model of integrated palliative care shows a decrease in health service utilisation at the hospital level, with a decrease in ED visits, a decline in hospital admissions and reduced length of admission. With the estimated staff cost of conducting a case conference less than the cost of a day of hospitalisation, efficiencies can be realised. However, hospitals in Australia are under considerable funding pressure and are struggling to meet patient demand, with capacity falling behind demand.(214) Any efficiencies gained from providing integrated care are unlikely to be visible when demand is high. However, establishing the cost-saving to the health service of any efficiency delivered from integrated care is vital for a publicly funded health service.

Australian hospitals are currently funded using an activity-based funding model whereby they are paid for the number of patients they treat.(215) There are some allowances built into the funding model for the treatment of complex patients, however any efficiencies gained through innovation do not provide any additional funds to the hospital. There are concerns internationally that activity-based funding can lead to the early discharge of patients, which can lead to patients discharged to community settings while still sick, an increase of patients accessing post-acute care settings and increased hospital readmissions.(206-208) Evidence does support a substantive increase in post-acute care use,(208) shifting the costs of care to another sector of the health system. However, this

pilot study found no substantive increase in patients accessing community-based care, including no increased visits to their GP.

There are also concerns that service providers may attempt to circumvent the funding model by incorrectly coding services provided and focusing on those patients and procedures that provide more funding.(207, 216, 217) However, in Australia, there are incentives built into the funding model to reduce readmissions and penalties for subverting the system.

Within the activity-based funding model, there is little financial incentive to provide a model of integrated palliative care for frail older people. Importantly funding is available at the primary care level to compensate for the additional time required to participate in case conferences, however, the same level of funding is not available to the hospital for the staff time required. The argument can be made that communication with GPs is a requirement of the hospital-based staff, mostly done by discharge report, and the case conferences are a different way of achieving this. However, extra time and resources are required to organise and conduct a case conference, and it is disingenuous to suggest that it is comparable to practice as usual. The extra time and resources required can be justified in the potential of better patient outcomes and reduced ED visits, reduced hospital readmissions and length of stay.

The outcomes from the pilot study suggest that even with the funding restrictions of the health system, small changes at a local level could provide potential efficiencies to the system as a whole. The pilot study also showed that although patients' physical health continued to decline, as expected, and caregiver strain increased over the same time period, there were improvements in mental wellbeing for both the patient and the caregiver. The reasons for this have not been identified in this research but may be due to a sense of being supported by the medical community. Being included in care decisions potentially give patients and carers a feeling of empowerment, knowing what is happening, and proactive planning.

There was also a high degree of acceptability of the model of care by the patients and the caregivers. Most participants experienced positive outcomes from the case conference, such as improved access to services and feeling a part of the process. The health professionals also found the case conferences acceptable, as they improved communication between providers and familiarity with patients' wishes in relation to their care. However, a model of integrated care that does not receive funding specific to that activity is unlikely to be sustainable in the current system.

Policy change to recognise that case conferences between GPs and specialists is a legitimate clinical activity and should attract activity-based funding at both the primary and secondary service level.

8.2 Implications

This research has shown that the development and evaluation of a model of integrated palliative care for frail older people based in the community has some positive outcomes for the patient and their carer. The model was acceptable to the patients and most of the caregivers and resulted in an increase in services for most of the patients. Health professionals from multiple disciplines indicated that the model was acceptable and resulted in improved services for most patients (as reported by the health professionals). There was also a benefit to the health system with a reduction in health service utilisation, resulting in cost efficiencies for the health service.

It can be argued that increased integration of the primary and secondary health services and the reduction of fragmentation in the provision of care for frail older people is worth the additional effort. The savings for the health service that could be realised through an integrated model of care are worth pursuing. The efficiencies gained through reduced health service utilisation improve the effectiveness of the system to meet increased patient demand.

However, the feasibility of the model of integrated care may be impeded due mainly to issues of funding. Currently this form of communication is not considered as fundable activity therefore, time taken to participate in a case conference has an opportunity cost. Without appropriate funding to support the intervention, staff at the hospital may be providing time to collaborate with the other service providers at a considerable cost to their department. The demands on staff time also suggest that without an administrative assistant within the hospital to coordinate the case conference process, the intervention would not be sustainable. Funding at a health service level would need to be allocated specifically to the integration of health services to allow staff to be appointed to manage the case conference process without impacting on departmental resources required to provide current service levels. Additionally, Medicare funding for conducting a case conference is only available to GPs in this instance and it would be more equitable for this funding to be available to all medical specialists.

The ageing population will bring an inevitable increase in demand for health services. Health services will need to be delivered using the skill sets of all health professions to deliver the greatest

effect. Integration of care is an essential element of providing a comprehensive boundary-less package of care to frail older people.

8.3 Study Strengths and Limitations

This study had a number of strengths. The study was based on the MRC model of development and evaluation of health interventions, so it was conducted using best practice methods. It was a mixed-methods design and sought input from multiple stakeholders. The triangulation of the data that this represents means that the conclusions are robust.

Phase 1 of the trial was a series of focus groups with health professionals. Phase 1 had some limitations: the selection of the sample was purposive, rather than random, and; there was a small sample size. As a result, the findings may not be transferable to other settings.

Phase 2 of the study saw the study design altered due to significant recruitment and retention difficulties. During the first stage of recruitment the study was a randomised controlled trial. However after the first 12 patients were recruited the study was altered from an RCT to a pre-post design, with enrolled control group participants receiving the intervention. The first stage of the recruitment saw all but one of the six patients randomised to the intervention group withdrawn from the trial or ineligible, either because the patient was discharged to permanent residential care rather than the community, or the patient's GP declined to participate. Lower than anticipated recruitment rates limited the ability to conduct the trial as initially planned. The decision was made to return to ethics and request a change to the study design to a pre-post design, where all patients received the intervention of an integrated model of care. This change allowed the study to continue so that feasibility and acceptability could be assessed. The comparator instead became service use by the participating individuals in the twelve months prior to the case conference, a historical control. These changes reduced the ability to attribute the findings to the model of care compared to usual care alone. The small sample size also meant due to lack of statistical power that effectiveness could not be assessed, and the sample may not be representative of all frail older people in the community approaching end-of-life.

Previous research into case conferences(107, 130) did not have the same issue in recruiting GPs to participate in the study. This may have been due to nurses, acting as case managers, in previous studies asking GPs to participate. In the current study, the Ethics committees required that the PhD student invite the GPs to participate on behalf of the patient. Previous studies conducted in GP

populations show that there are far more effective recruitment processes in primary care research.(218) However, recruitment difficulties may also have occurred as the project was completed in an area of relative workforce shortage, as suggested by overwork of a GP being given as a reason for non-participation. Previous studies were done in capital cities rather than a regional city with a relative oversupply of GPs. Alternatively, GPs may have been willing to accept case conferences in previous research as the disease trajectories that were the subject of the research (end-stage heart and lung disease) were often more clinically challenging than frailty and aged care. GPs may be more familiar and comfortable managing these and therefore saw less need to accept specialist support.

Patient recruitment occurred through the geriatricians at the hospital, so there may have been an element of gatekeeping, where not all eligible patients were made aware, or only those the staff deemed likely to be compliant with the study were approached to participate. While this was mitigated by having a researcher on-site, it was probably not eliminated. During the study, the geriatricians became more considered about which patients to recruit to the trial, with only the patients the geriatricians considered most frail approached, potentially excluding patients that could have been eligible for the study.

The inclusion criteria were restrictive. The frailty measure used was a phenotype frailty measure based on the decline in physical function. This was chosen as it was a simple, validated measure to use on the ward and required the least additional work for the ward staff to complete as it included routinely assessed measures as part of usual care. The geriatricians would identify patients they considered were frail, but many of these patients would not meet the physical frailty criteria for inclusion in the trial. In particular, the grip strength was surprisingly good for this population and may be reflective of their history of manual and farming work by many in the West Moreton Health District. An index method of frailty, including physical decline, functional disability and cognitive function may have been more sensitive within the geriatric ward. However, it was more time consuming to complete in a busy environment with competing demands, as it included measures not collected routinely.

The inclusion criteria also required patients to be community-based on discharge. If a patient entered hospital from the community but was permanently discharged to an aged care home, they were not eligible to participate. This was due to patients in the community being different to those patients in aged care, and that the population of interest for the model in clinical practice are

community-based patients. Patients in residential aged care facilities receive several services automatically that are often not routinely accessed by the community-based patients in the study, for example meals services, cleaning services and nursing services. Patients within an aged care facility are supervised by staff and staff can contact medical professionals for assistance when required. Community-based patients may only be able to organise nursing assistance at home on a limited basis and must make appointments with their medical professionals (eg GP, dietician). Frequently, participants who agreed to participate and who were initially returning home had complications after discharge prior to a case conference where permanent residential aged care placement was necessary, rendering a large proportion of frail older people at the end-of-life ineligible for the study.

The current study was not designed to assess whether frail older patients at the end-of-life, living in aged care homes, would have improved outcomes or reduced hospitalisations if their GP and their hospital-based specialist participated in case conferences.

The ethics committee directed that the researcher was not to attend the case conference in order to preserve patient confidentiality. Therefore, the researcher relied on detailed notes from the health professional participants for information on the case conference. For this reason, the researcher was unable to indicate if the case conferences adhered to the structure provided. The researcher could not directly observe the dynamics of the case conference and make any comments or recommendations on the actual conduct of them.

Both phases of the trial were conducted within the one health area. The health area covers a large rural area as well as a regional urban area, so the findings may not be reflective of health areas in a large city.

8.4 Future Research

This study was the first to design and test an integrated model of palliative care for frail older people based in the community. The systematic review will require updating as more studies come to light to inform the design and implementation of the model of care. The pilot study found that the aspects of the model related to the very end-of-life were not as well implemented as other areas of the case conference, although the model was well received. Future research should change the focus from the end-of-life to the complexities of multiple conditions with advancing age.

The benefits of providing quality palliative care have been well established, however, with few frail patients being referred to palliative care, it is unknown whether the palliative needs of frail patients are being met. A qualitative study to identify the specific palliative care needs of frail older people, living in the community, aged care facilities, and hospice services would be valuable. Particularly, if this was from the patient's perspective.

This research suggested that case conferences would provide benefits to complex frail older patients and their families and would reduce hospitalisations. Although the research aimed to provide palliative care for frail older people, the preliminary evidence from this study suggests that providing comprehensive integrated care for complex patients, irrespective of palliative needs would be beneficial. Health professionals indicated that case conferences would assist in the management of complex cases. Therefore, a study to identify the level of complexity that would justify a case conference should be undertaken. The restrictive inclusion criteria and difficulty in recruiting doctors impacted on the feasibility of the case conferences. A substantial redesign of the trial to account for recruitment, preparation, communication and technology would be needed to improve the feasibility. Then, a multi-site randomised controlled trial of case conferences as a model of integrated primary and secondary care for complex cases would provide robust and generalisable evidence for the efficacy of the intervention. A rehabilitative palliative care model (219) could align with the case conference model to improve the primary-secondary interfaces as a health service worth considering for future research.

The current research identified that workload and funding are barriers to the implementation of a model of integrated palliative care. Further research should include an economic evaluation (cost benefit analysis) of the randomised controlled trial especially given the potential to reduce hospital readmissions, and to provide evidence on the provision of funding needed from government. Additional research could assess different funding models within health services for the implementation of integrated care models for frail older people, including the administrative costs required to support widespread primary-secondary care integration should be investigated.

8.5 Conclusion

This research aimed to develop an integrated model of palliative care for frail older people in the community. The study was a mixed-method, two-phase sequential design with two components in the second phase of the study. Initially a systematic review was conducted which identified models of integrated palliative care. The first phase of the study explored health professionals' experience

of working with frail older people with palliative and supportive needs to inform the design and implementation of an integrated model of palliative care. The second phase of the study assessed the feasibility and acceptability of case conferences as a model of integrated palliative care for frail older people in the community.

The research was unique in the provision of integrated palliative care for a population of frail older people. The model of integrated palliative care was acceptable and indicated the potential to improve outcomes for frail older people in the community and to improve the outcomes for the patients' carers. The model of care was well utilised, although adaptations were made by the health professionals during implementation. It could be expected that further adaptations would be made if implemented across the health service, to tailor the intervention specific to their needs and to prioritise those patients they determine would receive the most benefit. The research also suggested that health service utilisation would decrease, creating cost-efficiencies for the health system overall. However, in the current system, without specific funding allocation, it is unlikely that the intervention would be feasible.

References

1. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings, 2015. (cat no. 4430.0). Canberra: Australian Bureau of Statistics; 2018.
2. Australian Bureau of Statistics. Census of population and housing: Reflecting Australia - stories from the Census, 2016. (Cat no. 2071.0). Canberra: Australian Bureau of Statistics; 2017.
3. Australian Institute of Health and Welfare. Australia's health 2016. Australia's health series no. 15. Cat no AUS 199. Canberra: AIHW; 2016.
4. Fried LP, Tangen CM, Walston J, Newman AB, Hirsch C, Gottdiener J, et al. Frailty in older adults: Evidence for a phenotype. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences*. 2001;56(3):M146-M56.
5. Santos-Eggimann B, Cuenoud P, Spagnoli J, Junod J. Prevalence of frailty in middle-aged and older community-dwelling Europeans living in 10 countries. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences*. 2009;64(6):675-81.
6. Salinas-Rodríguez A, Manrique-Espinoza B, Heredia-Pi I, Rivera-Almaraz A, Ávila-Funes JA. Healthcare costs of frailty: Implications for long-term care. *Journal of the American Medical Directors Association*. 2019;20(1):102-3.e2.
7. Orlando S, Gilardi F, Scarcella P, Morbidelli S, Tersigni I, Asta F, et al. Cost of older adults' hospital care according to the level of frailty in Lazio region, Italy. *European Journal of Public Health*. 2018;28(suppl_4).
8. Comans TA, Peel NM, Hubbard RE, Mulligan AD, Gray LC, Scuffham PA. The increase in healthcare costs associated with frailty in older people discharged to a post-acute transition care program. *Age and Ageing*. 2016;45(2):317-20.
9. Simpson KN, Seamon BA, Hand BN, Roldan CO, Taber DJ, Moran WP, et al. Effect of frailty on resource use and cost for Medicare patients. *Journal of Comparative Effectiveness Research*. 2018;7(8).
10. Australian Institute of Health and Welfare. Australia's health 2018. Australia's health series no. 16. AUS 221. In: Welfare AIoHa, editor. Canberra2018.
11. Department of Health. Home care packaged program: Data report 2nd quarter 2017-2018. Canberra: Australian Government; 2018.
12. Palliative Care Australia. National palliative care standards. 5th ed. Canberra, ACT: Palliative Care Australia; 2018.
13. Australian Institute of Health and Welfare. Palliative care services in Australia 2014. Canberra: AIHW; 2014.

14. Starks H, Wang S, Farber S, Owens DA, Curtis JR. Cost savings vary by length of stay for inpatients receiving palliative care consultation services. *Journal of Palliative Medicine*. 2013;16(10):1215-20.
15. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews*. 2013(6):1-285.
16. Hollingworth S, Zhang JZ, Vaikuntam BP, Jackson C, Mitchell G. Case conference primary-secondary care planning at end of life can reduce the cost of hospitalisations. *BMC Palliative Care*. 2016;15(1):84.
17. Mason A, Weatherly H, Spilsbury K, Arksey H, Golder S, Adamson J, et al. A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technology Assessment*. 2007;11(15):1-157.
18. Palliative Care Australia. Submission to the Australian Senate Standing Committee on community affairs inquiry into palliative care in Australia. ACT, Australia: Palliative Care Australia; 2012.
19. Palliative Care Australia. Palliative care service development guidelines. Canberra: Palliative Care Australia; 2018.
20. Australian Medical Association. Palliative approach in residential aged care settings. Canberra: AMA; 2015.
21. Tapsfield J, Hall C, Lunan C, McCutcheon H, McLoughlin P, Rhee J, et al. Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners. *BMJ Supportive & Palliative Care*. 2016:bmjspcare-2015-001014.
22. World Health Organization. WHO Definition of Palliative Care 2013 [Available from: <http://www.who.int/cancer/palliative/definition/en/>].
23. Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. *Palliative Medicine*. 2013;27(2):101-2.
24. Murray SA, Firth A, Schneider N, Van den Eynden B, Gomez-Batiste X, Brogaard T, et al. Promoting palliative care in the community: production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care. *Palliative Medicine*. 2014;29(2):101-11.
25. Murray SA, Kendall M, Mitchell G, Moine S, Amblas-Novellas J, Boyd K. Palliative care from diagnosis to death. *British Medical Journal*. 2017;356.

26. Koller K, Rockwood K. Frailty in older adults: implications for end-of-life care. *Cleveland Clinic Journal of Medicine*. 2013;80(3):168-74.
27. Covinsky KE, Eng C, Lui LY, Sands LP, Yaffe K. The last 2 years of life: functional trajectories of frail older people. *Journal of the American Geriatrics Society*. 2003;51(4):492-8.
28. Butters E, Higginson I, George R, McCarthy M. Palliative care for people with HIV AIDS - views of patients, carers and providers. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*. 1993;5(1):105-16.
29. Gibbs LME, Addington-Hall J, Gibbs JSR. Dying from heart failure: lessons from palliative care - Many patients would benefit from palliative care at the end of their lives. *British Medical Journal*. 1998;317(7164):961-2.
30. Andrews PA. Palliative care for patients with terminal renal-failure. *Lancet*. 1995;346(8973):506-7.
31. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*. 2017;15(1):102.
32. United Nations Department of Economic and Social Affairs, Populations Division. *World population ageing 2017*. New York: United Nations; 2017.
33. House of Lords Select Committee on Public Service and Demographic Change. *Ready for ageing? Report*. London: Authority of the House of Lords; 2013.
34. European Union. *EU employment and social situation quarterly review March 2013 - special supplement on demographic trends*. Luxembourg: Publications Office of the European Union; 2013.
35. Anderson GF, Hussey PS. Population aging: a comparison among industrialized countries. *Health Affairs*. 2000;19(3):191-203.
36. Vincent G, K, Velkoff V, A. *The Next Four Decades. The older population in the United States: 2010 to 2050*. Washington DC: US Census Bureau; 2010.
37. Australian Institute of Health and Welfare. *Older Australia at a glance. Cat no: AGE 87. 5th ed*. Canberra: Australian Institute of Health and Welfare; 2018.
38. Australian Bureau of Statistics. *Population by age and sex, Australia, States and Territories, Cat no 3101.0*. Canberra: ABS; 2013.
39. The Treasury Australia. *Intergenerational report 2010: Australia to 2050: future challenges*. Canberra: The Treasury Australia; 2010.
40. World Health Organization. *The World Health Report 2004 - changing history*. France: World Health Organization; 2004.

41. Australian Bureau of Statistics. Australian social trends 2006:chronic conditions and disability. Canberra: Australian Bureau of Statistics; 2006.
42. Australian Bureau of Statistics. National health survey 2004-2005: summary of results. Cat. no. 4363.0. Canberra: Australian Bureau of Statistics; 2006.
43. Strandberg TE, Pitkala KH, Tilvis RS. Frailty in older people. *European Geriatric Medicine*. 2011;2(6):344-55.
44. Sternberg SA, Schwartz AW, Karunanathan S, Bergman H, Clarfield AM. The identification of frailty: A systematic literature review. *Journal of the American Geriatrics Society*. 2011;59(11):2129-38.
45. Sourial N, Bergman H, Karunanathan S, Wolfson C, Payette H, Gutierrez-Robledo LM, et al. Implementing frailty into clinical practice: A cautionary tale. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences*. 2013;68(12):1505-11.
46. St John PD, Tyas SL, Montgomery PR. Life satisfaction and frailty in community-based older adults: cross-sectional and prospective analyses. *International Psychogeriatrics*. 2013;25(10):1709-16.
47. Rodriguez-Manas L, Feart C, Mann G, Vina J, Chatterji S, Chodzko-Zajko W, et al. Searching for an operational definition of frailty: A delphi method based consensus statement. The frailty operative definition-consensus conference project. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences*. 2013;68(1):62-7.
48. Fried L, P, Ferrucci L, Darer J, Williamson JD, Anderson G. Untangling the concepts of disability, frailty and comorbidity: Implications for improved targetting and care. *Journal of Gerontology*. 2004;59(3):255-63.
49. Rockwood K, Stolee P, McDowell I. Factors associated with institutionalization of older people in Canada: Testing a multifactorial definition of frailty. *Journal of the American Geriatrics Society*. 1996;44(5):578-82.
50. Rockwood MRH, Hubbard RE, Eeles E, Mitnitski A, Rockwood K. Use of a frailty index based on a comprehensive geriatric assessment in an acute care setting. *Age and Ageing*. 2012;41:73-.
51. MacKnight C, Merry H, Rockwood K. A brief clinical frailty scale: Validity in the Canadian national population health survey. *Gerontologist*. 2002;42:171-2.
52. Evans S, Mitnitski A, Rockwood K. Use of the Frailty Index to evaluate the risk of death in older patients presenting to hospital. *Journal of the American Geriatrics Society*. 2012;60:S58-S.
53. Johns D, Rockwood K, Jones D, Song X, Mitnitski A. Operationalizing a frailty index from clinical and performance based measures. *Gerontologist*. 2004;44:11-.

54. Rockwood K, Hogan DB, MacKnight C. Conceptualisation and measurement of frailty in elderly people. *Drugs & Aging*. 2000;17(4):295-302.
55. Song X, Macknight C, Mitnitski A, Latta R, Rockwood K. Frailty and the survival of rural and urban older adults in the Canadian study of health and aging. *Gerontologist*. 2004;44:7-.
56. Mitnitski AB, Graham JE, Mogilner AJ, Rockwood K. Frailty, fitness and late-life mortality in relation to chronological and biological age. *BMC Geriatrics*. 2002;2(1):1.
57. Rockwood K, Mitnitski A. Frailty in relation to the accumulation of deficits. *The journals of gerontology Series A, Biological sciences and medical sciences*. 2007;62(7):722-7.
58. Blodgett J, Theou O, Kirkland S, Andreou P, Rockwood K. Frailty in NHANES: Comparing the frailty index and phenotype. *Archives of Gerontology and Geriatrics*. 2015;60(3):464-70.
59. Woo J, Leung J, Morley JE. Comparison of frailty indicators based on clinical phenotype and the multiple deficit approach in predicting mortality and physical limitation. *Journal of the American Geriatrics Society*. 2012;60(8):1478-86.
60. Cesari M, Gambassi G, van Kan GA, Vellas B. The frailty phenotype and the frailty index: different instruments for different purposes. *Age and Ageing*. 2014;43(1):10-2.
61. Boyd CM, Xue QL, Simpson CF, Guralnik JM, Fried LP. Frailty, hospitalization, and progression of disability in a cohort of disabled older women. *American Journal of Medicine*. 2005;118(11):1225-31.
62. Barreto PdS, Greig C, Ferrandez AM. Detecting and categorizing frailty status in older adults using a self-report screening instrument. *Archives of Gerontology and Geriatrics*. 2012;54(3):e249-e54.
63. Woods N, LaCroix A, Gray S, Aragaki A, Cochrane B, Brunner R, et al. Frailty: emergence and consequences in women aged 65 and older in the Women's Health Initiative Observational Study. *Journal of the American Geriatrics Society*. 2005;53:1321-30.
64. Jones DM, Song XW, Rockwood K. Operationalizing a frailty index from a standardized comprehensive geriatric assessment. *Journal of the American Geriatrics Society*. 2004;52(11):1929-33.
65. Mitnitski AB, Mogilner AJ, MacKnight C, Rockwood K. The mortality rate as a function of accumulated deficits in a frailty index. *Mechanisms of Ageing and Development*. 2002;123(11):1457-60.
66. Fassbender K, Fainsinger RL, Carson M, Finegan BA. Cost trajectories at the end of life: The Canadian experience. *Journal of Pain and Symptom Management*. 2009;38(1):75-80.

67. World Health Organization. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization; 2018.
68. National Health Service (UK). End of Life Issues 2012 [Available from: <http://www.nhs.uk/CarersDirect/guide/bereavement/Pages/Accessingpalliativecare.aspx>.
69. Department of Health (Australia). Palliative Care 2013 [Available from: <http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative+Care-1>.
70. Queensland Government (Australia). Palliative care: care for the terminally ill 2013 [Available from: <http://www.qld.gov.au/health/support/palliative-care/index.html>.
71. Lewis MJ. *Medicine and Care of the Dying. A Modern History*. New York: Oxford University Press; 2007.
72. Daughters of Charity of St Vincent de Paul. *Daughters of Charity: Origin of the company 2014* [Available from: <http://filles-de-la-charite.org/history>.
73. Richmond C. Dame Cicely Saunders. *British Medical Journal*. 2005;331(7510):238-.
74. Shepard DAE. Principles and practice of palliative care. *Canadian Medical Association Journal*. 1977;116(5):522-6.
75. Mount BM. Problem of caring for dying in a general-hospital, palliative care unit as a possible solution. *Canadian Medical Association Journal*. 1976;115(2):119-21.
76. Scala ME. Proposal for a palliative care unit in Rhonde-Island- So-called hospice concept. *Rhode Island Medical Journal*. 1979;62(2):55-7.
77. Saunders C. Palliative care for the terminally ill. *Canadian Medical Association Journal*. 1977;117(1):15.
78. Beszterczey A. Staff stress on a newly-developed palliative care service - Psychiatrists role. *Canadian Psychiatric Association Journal*. 1977;22(7):347-53.
79. Wilson D, C, Ajemian I, Mount BM. Montreal (1975) - Royal Victoria Hospital Palliative Care Services. *Death education*. 1978;2(1-2):3-19.
80. Australian Institute of Health and Welfare. *Cancer in Australia: Cancer series no. 72. (cat. no. CAN69)*. Canberra: AIWH; 2012.
81. Vrinten C, McGregor LM, Heinrich M, von Wagner C, Waller J, Wardle J, et al. What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. *Psychooncology*. 2017;26(8):1070-9.
82. Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser C, Mathers M, et al. *Globocan 2012: Estimated cancer incidence, mortality and prevalence worldwide in 2012*. CancerBase no. 11. Internet: International Agency for Research on Cancer, World Health Organisation; 2012.

83. Australian Institute of Health and Welfare. Cancer in Australia: an overview 2012. Cancer series no. 74. (cat. no. CAN70). Canberra: AIHW; 2012.
84. Teno JM, Mor V, Fleishman J. Preferences of HIV infected patients for aggressive versus palliative care. *New England Journal of Medicine*. 1991;324(16):1140-.
85. Cushen M. Palliative care in severe heart-failure. *British Medical Journal*. 1994;308(6930):717.
86. McCarthy M, Lay M, AddingtonHall J. Dying from heart disease. *Journal of the Royal College of Physicians of London*. 1996;30(4):325-8.
87. Luchins DJ, Hanrahan P. What is appropriate health-care for end-stage dementia. *Journal of the American Geriatrics Society*. 1993;41(1):25-30.
88. Hurley AC, Volicer B, Mahoney MA, Volicer L. Palliative fever management in alzheimer patients - Quality plus fiscal responsibility. *Advances in Nursing Science*. 1993;16(1):21-32.
89. Volicer L, Collard A, Hurley A, Bishop C, Kern D, Karon S. Impact of special care unit for patients with advanced alzheimers-disease on patients discomfort and costs. *Journal of the American Geriatrics Society*. 1994;42(6):597-603.
90. Klang B, Bjorvell H, Cronqvist A. Patients with chronic renal failure and their ability to cope. *Scandinavian Journal of Caring Sciences*. 1996;10(2):89-95.
91. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*. 2010;363(8):733-42.
92. National Health and Hospital Reform Commission. A healthier future for all Australians - final report of the National Health and Hospitals Reform Commission. Canberra: Commonwealth of Australia; 2009.
93. World Health Organization. World health statistics. Italy: World Health Organization; 2013.
94. Senate Community Affairs References Committee. Palliative care in Australia. Report to the Senate, Australian Government. Canberra: Senate Community Affairs References Committee; 2012.
95. Davidson P, Halcomb E, Hickman L, Phillips J, Graham B. Beyond the rhetoric: what do we mean by a 'model of care'? *The Australian journal of advanced nursing : a quarterly publication of the Royal Australian Nursing Federation*. 2006;23(3):47-55.
96. Brereton L, Clark J, Ingleton C, Gardiner C, Preston L, Ryan T, et al. What do we know about different models of providing palliative care? Findings from a systematic review of reviews. *Palliative Medicine*. 2017;31(9):781-97.

97. Higginson I, Gomes B, Calanzani N, Gao W, Bausewein C, Daveson BA, et al. Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries. *Palliative Medicine*. 2014;28(2):101-10.
98. Brown CRL, Hsu AT, Kendall C, Marshall D, Pereira J, Prentice M, et al. How are physicians delivering palliative care? A population-based retrospective cohort study describing the mix of generalist and specialist palliative care models in the last year of life. *Palliative Medicine*. 2018;32(8):1334-43.
99. Wiencek C, Coyne P. Palliative care delivery models. *Seminars in Oncology Nursing*. 2014;30(4):227-33.
100. Evans CJ, Ison L, Ellis-Smith C, Nicholson C, Costa A, Oluyase AO, et al. Service delivery models to maximize quality of life for older people at the end of life: A rapid review. *Milbank Quarterly*. 2019;97(1):113-75.
101. Goldschmidt D, Groenvold M, Johnsen AT, Stromgren AS, Krasnik A, Schmidt L. Cooperating with a palliative home-care team: Expectations and evaluations of GPs and district nurses. *Palliative Medicine*. 2005;19(3):241-50.
102. Brogaard T, Jensen AB, Sokolowski I, Olesen F, Neergaard MA. Who is the key worker in palliative home care? *Scandinavian Journal Of Primary Health Care*. 2011;29(3):150-6.
103. Rabow M, Kvale E, Barbour L, Cassel JB, Cohen S, Jackson V, et al. Moving upstream: a review of the evidence of the impact of outpatient palliative care. *Journal of Palliative Medicine*. 2013;16(12):1540-9.
104. Hui D. Palliative cancer care in the outpatient setting: Which model works best? *Current Treatment Options in Oncology*. 2019;20(2):17.
105. Finlay E, Newport K, Sivendran S, Kilpatrick L, Owens M, Buss MK. Models of outpatient palliative care clinics for patients with cancer. *Journal of Oncology Practice*. 2019;15(4):187-93.
106. Demiglio L, Williams AM. A qualitative study examining the sustainability of shared care in the delivery of palliative care services in the community. *BMC Palliative Care*. 2013;12(1):32.
107. Abernethy AP, Currow DC, Shelby-James T, Rowett D, May F, Samsa GP, et al. Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the "Palliative Care Trial" ISRCTN 81117481. *Journal of Pain and Symptom Management*. 2013;45(3):488-505.
108. Doughty R, Wright S, Pearl A, Walsh H, Muncaster S, Whalley G, et al. Randomized, controlled trial of integrated heart failure management: The Auckland Heart Failure Management Study. *European Heart Journal*. 2002;23:139-46.

109. Mitchell GK, Del Mar CB, O'Rourke PK, Clavarino AM. Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomised controlled trial (ISRCTN 52269003). *Palliative Medicine*. 2008;22(8):904-12.
110. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med*. 2013;368(13):1173-5.
111. Vanbutsele G, Pardon K, Van Belle S, Surmont V, De Laat M, Colman R, et al. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. *The Lancet Oncology*. 2018;19(3):394-404.
112. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, et al. Effects of Early Integrated Palliative Care on Caregivers of Patients with Lung and Gastrointestinal Cancer: A Randomized Clinical Trial. *The oncologist*. 2017;22(12):1528-34.
113. Chater K, Tsai CT. Palliative care in a multicultural society: a challenge for western ethics. *Australian Journal of Advanced Nursing*. 2008;26(2):95-100.
114. Goodwin N, Smith J, Davies A, Perry C, Rosen R, Dixon A, et al. Integrated care for patients and populations: Improving outcomes by working together. A report to the Department of Health and the NHS Future Forum. London: The King's Fund; 2012.
115. Minister for Health. Implementing the New Zealand Health Strategy. Wellington: Ministry of Health; 2013.
116. Canadian Medical Association, Canadian Nurses Association, Health Action Lobby. Integration: A new direction for Canadian Health Care. Ottawa: Strachan Tomlison; 2013.
117. Mur-Veeman I, Hardy B, Steenbergen M, Wisto G. Development of integrated care in England and the Netherlands: managing across public-private boundaries. *Health Policy*. 2003;65(3):227-41.
118. Kodner D. All together now: a conceptual exploration of integrated care. *Healthcare Quarterly*. 2009;13:6-15.
119. Grone O, Garcia-Barbero M. Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. *International Journal of Integrated Care*. 2001;1.
120. Waddington C, Egger D. Integrated Health Services - What and Why? Technical Brief No.1. Geneva: World Health Organisation; 2008.
121. Leichsenring K. Developing integrated health and social care services for older persons in Europe. *International Journal of Integrated Care*. 2004;4(3):1-15.
122. Mitchell G, Del Mar C, Francis D. Does primary medical practitioner involvement with a specialist team improve patient outcomes? A systematic review. *British Journal of General Practice*. 2002;52:934-9.

123. Reed J, Childs S, Cook G, Hall A, McCormack B. Integrated care for older people: Methodological issues in conducting a systematic literature review. *Worldviews of Evidence-Based Nursing*. 2007;4(2):78-85.
124. Critical Appraisal Skills Programme. 10 questions to help you make sense of qualitative research. England: Critical Appraisal Skills Programme; 2010. Available from: <http://www.casp-uk.net/wp-content/uploads/2011/11/CASPQualitativeAppraisalChecklist14oct10.pdf>.
125. The Joanna Briggs Institute. Joanna Briggs Institute Reviewer's Manual: 2011 Edition. Adelaide: Joanna Briggs Institute; 2011.
126. Jadad A, Moore R, Carroll D, Jenkinson C, Reynolds D, Gavaghan D, et al. Assessing the quality of reports of randomized clinical trials: is blinding necessary? *Control Clinical Trials*. 1996;17:1-12.
127. Centre for Evidence Based Medicine. Critical appraisal of a survey. Oxford: Centre for Evidence Based Medicine; 2014.
128. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC Methods Programme Version. Lancaster: Lancaster University; 2006.
129. Moher D, Liberati A, Tetzlaff J, Altman D. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *Public Library of Science Medicine*. 2009;6(6):e10000097.
130. Mitchell G, Zhang J, BurrIDGE L, Senior H, Miller E, Young S, et al. Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: An exploratory pilot study. *BMC Palliative Care*. 2014;13(1).
131. Groot MM, Vernooij-Dassen MJ, Verhagen SC, Crul BJ, Grol RP. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliative Medicine*. 2007;21(8):697-703.
132. Rowlands S, Callen J, Westbrook J. What information do general practitioners need to care for patients with lung cancer? A survey of general practitioners perceptions. *Health Information Management Journal*. 2010;39(1):8-16.
133. Davison G, Shelby-James TM. Palliative care case conferencing involving general practice: An argument for a facilitated standard process. *Australian Health Review*. 2012;36(1):115-9.
134. Mason B, Epiphaniou E, Nanton V, Donaldson A, Shipman C, Daveson BA, et al. Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study. *The British Journal Of General Practice: The Journal Of The Royal College Of General Practitioners*. 2013;63(613):e580-e8.

135. Mitchell G, Cherry M, Kennedy R, Weeden K, Burridge L, Clavarino A, et al. General practitioner, specialist providers case conferences in palliative care--lessons learned from 56 case conferences. *Australian Family Physician*. 2005;34(5):389-92.
136. Norman A, Sisler J, Hack T, Harlos M. Family physicians and cancer care. Palliative care patients' perspectives. *Canadian Family Physician (Médecin De Famille Canadien)*. 2001;47:2009.
137. Street A, Blackford J. Communication issues for the interdisciplinary community palliative care team. *Journal of Clinical Nursing*. 2001;10(5):643-50.
138. Tucker H. Discovering integrated care in community hospitals. *Journal of Integrated Care*. 2013;21(6):336-46.
139. Walshe C, Caress A, Chew-Graham C, Todd C. Implementation and impact of the Gold Standards Framework in community palliative care: A qualitative study of three primary care trusts. *Palliative Medicine*. 2008;22(6):736-43.
140. Brazil K, Howell D, Marshall D, Critchley P, Van den Elzen P, Thomson C. Building primary care capacity in palliative care: proceedings of an interprofessional workshop. *Journal of Palliative Care*. 2007;23(2):113-6.
141. Stewart B, Allan S, Keane B, Marshall B, Ayling J, Luxford T. Palliative Care Partnership: a successful model of primary/secondary integration. *The New Zealand Medical Journal*. 2006;119(1242):U2235-U.
142. Mitchell G, Zhang JZ, Burridge L, Senior H, Miller E, Young S, et al. Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study. *BMC Palliative Care*. 2014;13.
143. Mitchell GK, Burridge L, Zhang JZ, Donald M, Scott IA, Dart J, et al. Systematic review of integrated models of health care delivered at the primary-secondary interface: how effective is it and what determines effectiveness? *Australian Journal of Primary Health*. 2015;21(4):391-408.
144. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: Transformative tools for consumer-centric care. *BMC Medical Informatics and Decision Making*. 2008;8:45.
145. Australian Government Department of Health. My Health Record [July 2016]. Available from: <http://health.gov.au/internet/main/publishing.nsf/Content/ehealth-record>.
146. New Zealand Ministry of Health. Sharing your health information. [July 2016]. Available from: <http://www.health.govt.nz/your-health/services-and-support/health-care-services/sharing-your-health-information>.
147. eHealth Ontario. eHealth Ontario [July 2016]. Available from: <http://www.ehealthontario.on.ca/en/ehrs>.

148. European Commission. eHealth Policy [July 2016]. Available from: http://ec.europa.eu/health/ehealth/policy/index_en.htm.
149. Kaushik V, Walsh C. Pragmatism as a research paradigm and its implications for social work research. *Social Sciences*. 2019;8(9):255-272.
150. Cornish F, Gillespie A. A pragmatist approach to the problem of knowledge in health psychology. *Journal of Health Psychology*. 2009;14(6):800-9.
151. Patton MQ. *Qualitative research and evaluation methods*. 3rd ed. Thousand Oaks, CA: Sage; 2002.
152. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*. 2008;337.
153. City of Ipswich Council. About Us. 2017 [January 2017] Available from: http://www.ipswich.qld.gov.au/about_ipswich/statistics_facts.
154. Lewis J, McNaughton Nicholls C. Design Issues. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice*. 2nd ed. Los Angeles: SAGE; 2013.
155. Royal Australian College of General Practitioners. *General Practice: Health of the Nation 2018*. Melbourne, VIC: RACGP; 2018.
156. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology*. 2009;5:52-7.
157. Gale N, Health G, Cameron E, Rashid S, Resdwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013;13(1):1-8.
158. Greenhalgh T, Robert G, Bate P, Macfarlane F, Kyriakidou O. *Diffusion of innovations in health service organisations: A systematic literature review*. Oxford, UK: Blackwell Publishing Ltd; 2005.
159. Creswell J, Clark V. *Designing and conducting mixed methods research*. Thousand Oaks, California: Sage Publications; 2007.
160. Harris AD, McGregor JC, Perencevich EN, Furuno JP, Zhu J, Peterson DE, et al. The use and interpretation of quasi-experimental studies in medical informatics. *Journal of the American Medical Informatics Association*. 2006;13(1):16-23.
161. Gomez-Batiste X, Martinez-Munoz M, Blay C, Amblas J, Vila L, Costa X. Identification of people with chronic advanced diseases and need of palliative care in sociosanitary services: Elaboration of the NECPAL CCOMS-ICO (c) tool. *Medicina Clinica*. 2013;140(6):241-5.

162. Abernethy AP, Shelby-James TM, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliative Care*. 2005;4.
163. Ware JE J, Kosinski M., Keller. S. A 12 Item Short Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*. 1996;34:220-33.
164. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*. 1983;67(6):361-70.
165. Robinson BC. Validation of a Caregiver Strain Index. *Journal of Gerontology*. 1983;38(3):344-8.
166. The National Gold Standards Framework (GSF) Centre in end of life care. The Gold Standards Framework [July 2013]. Available from: www.goldstandardsframework.org.uk
167. Tabachnick BG, Fidell LS. *Using Multivariate Statistics*. 6th ed. Boston: Pearson; 2013.
168. Raudonis BM, Daniel K. Frailty: An indication for palliative care. *Geriatric Nursing*. 2010;31(5):379-84.
169. Abellan van Kan G, Rolland Y, Bergman H, Morley JE, Kritchevsky SB, Vellas B. The I.A.N.A Task Force on frailty assessment of older people in clinical practice. *The Journal of Nutrition, Health & Aging*. 2008;12(1):29-37.
170. Weil J, Weiland TJ, Lane H, Jelinek GA, Boughey M, Marck CH, et al. What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department. *Palliative Medicine*. 2015;29(4):293-301.
171. Miyashita M, Hirai K, Morita T, Sanjo M, Uchitomi Y. Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis. *Supportive Care in Cancer*. 2008;16(3):217-22.
172. Boldt AM, Yusuf F, Himelstein BP. Perceptions of the term palliative care. *Journal of Palliative Medicine*. 2006;9(5):1128-36.
173. Fadul N, Elsayem A, Palmer JL, Del Fabbro E, Swint K, Li Z, et al. Supportive versus palliative care: What's in a name? *Cancer*. 2009;115(9):2013-21.
174. BurrIDGE LH, Foster MM, Donald M, Zhang J, Russell AW, Jackson CL. A qualitative follow-up study of diabetes patients' appraisal of an integrated diabetes service in primary care. *Health & Social Care in the Community*. 2017;25(3):1031-40.
175. Emanuel EJ, Emanuel LL. 4 Models of the physician-patient relationship. *Journal of the American Medical Association*. 1992;267(16):2221-6.

176. Scholl I, Loon MK-v, Sepucha K, Elwyn G, Légaré F, Härter M, et al. Measurement of shared decision making: a review of instruments. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*. 105(4):313-24.
177. Eccles MP, Mittman BS. Welcome to implementation science. *Implementation Science*. 2006;1.
178. Elwyn G, Legare F, van der Weijden T, Edwards A, May C. Arduous implementation: Does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice. *Implementation Science*. 2008;3.
179. Kennedy A, Rogers A, Chew-Graham C, Blakeman T, Bowen R, Gardner C, et al. Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. *Implementation Science*. 2014;9.
180. Mitchell G, Senior H, Rhee J, Young S, Teo P, Murray S, et al. Using intuition or a formal palliative care needs assessment screening process in general practice to predict death within 12 months: A randomised controlled trial. *Palliative Medicine*. 2018;32(2):384-94.
181. Allen S, Chapman Y, O'Connor M, Francis K. Discourses associated with nursing aged people who are dying in the Australian context: a review of the literature. *International Nursing Review*. 2008;55(3):349-54.
182. Hui D, De La Cruz M, Mori M, Parsons HA, Kwon JH, Torres-Vigil I, et al. Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer*. 2013;21(3):659-85.
183. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A systematic review. *Journal of Pain and Symptom Management*. 2014;47(1):77-89.
184. Bruera E, Hui D. Integrating supportive and palliative care in the trajectory of cancer: Establishing goals and models of care. *Journal of Clinical Oncology*. 2010;28:4013-7.
185. Bélanger E, Rodríguez C, Groleau D, Légaré F, Macdonald ME, Marchand R. Patient participation in palliative care decisions: An ethnographic discourse analysis. *International Journal of Qualitative Studies on Health and Well-being*. 2016;11(1):32438.
186. Zimmermann C. Denial of impending death: a discourse analysis of the palliative care literature. *Social Science & Medicine*. 2004;59(8):1769-80.
187. Zimmermann C. Acceptance of dying: A discourse analysis of palliative care literature. *Social Science & Medicine*. 2012;75(1):217-24.

188. Claxton J. Paving the way to acceptance. Psychological adaption to death and dying in cancer. *Professional Nurse*. 1993;8(4):206-11.
189. Hunt M. 'Scripts' for dying at home—displayed in nurses', patients' and relatives' talk. *Journal of Advanced Nursing*. 1992;17(11):1297-302.
190. Annas GJ, Healey JM. Patient rights advocate - Redefining doctor-patient relationship in hospital context. *Vanderbilt Law Review*. 1974;27(2):243-69.
191. Stewart M. Towards a global definition of patient centred care - The patient should be the judge of patient centred care. *British Medical Journal*. 2001;322(7284):444-5.
192. Abernethy AP, Currow DC, Shelby-James TM, Rowett D, May F, Williams H, et al. Delivering strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the "Palliative Care Trial". *Journal of Pain and Symptom Management*. 2013;45(3):488-505.
193. Martin GP, Currie G, Finn R. Reconfiguring or reproducing intra-professional boundaries? Specialist expertise, generalist knowledge and the 'modernization' of the medical workforce. *Social Science & Medicine*. 2009;68(7):1191-8.
194. Kislov R, Walshe K, Harvey G. Managing boundaries in primary care service improvement: A developmental approach to communities of practice. *Implementation Science*. 2012;7.
195. Avery J, Dal Grande E, Taylor A. Quality of life in South Australia as measure by the SF12 Health Status Questionnaire: population norms for 2003: trends from 1997 - 2003. South Australia: South Australian Department of Human Service Population Research and Outcome Studies; 2004.
196. Puhan MA, Frey M, Buchi S, Schunemann HJ. The minimal important difference of the hospital anxiety and depression scale in patients with chronic obstructive pulmonary disease. *Health and Quality of Life Outcomes*. 2008;6.
197. Rogers E. *Diffusion of Innovations*, 5th Edition. New York: Free Press; 2003.
198. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. *British Medical Journal*. 2015(350):h1258.
199. National Institute of Health and Research. Feasibility and Pilot Studies 2012 [Available from: <https://www.nihr.ac.uk/funding-and-support/documents/funding-for-research-studies/research-programmes/PGfAR/Feasibility%20and%20Pilot%20studies.pdf>].
200. Bowen DJ, Kreuter M, Spring B, Cofta-Woerpel L, Linna L, Weiner D, et al. How we design feasibility studies. *American Journal of Preventive Medicine*. 2009;36(5):452-7.

201. Bajwah S, Ross JR, Wells AU, Mohammed K, Oyeboode C, Birring SS, et al. Palliative care for patients with advanced fibrotic lung disease: a randomised controlled phase II and feasibility trial of a community case conference intervention. *Thorax*. 2015;70(9):830-9.
202. Furman M, Harild L, Anderson M, Irish J, Nguyen K, Wright FC. The Development of Practice Guidelines for a Palliative Care Multidisciplinary Case Conference. *Journal of Pain and Symptom Management*. 2018;55(2):395-401.
203. Deckx L, Mitchell G, Rosenberg J, Kelly M, Carmont S, Yates P. Understanding general practitioners' clinical practice in end-of-life care: a qualitative study. *BMJ Supportive & Palliative Care*.
204. Chao JT, Lowescher LJ, Soyer HP. Barriers to mobile teledermoscopy in primary care. *Journal of the American Academy of Dermatology*. 2013;69(5):821-4.
205. Australian Government Department of Health. MBS Online Medicare Benefits Schedule 2019 Available from: <http://www9.health.gov.au/mbs/search.cfm?q=Telehealth&Submit=&sopt=S>.
206. Qian X, Russell L, Valiyeva E, Miller J. "Quicker and sicker" under Medicare's prospective payment system for hospitals: new evidence on an old issue from a national longitudinal survey. *Bulletin of Economic Research*. 2011;63:1-27.
207. Ellis R. Creaming, skimping and dumping: provider competition on the intensive and extensive margins. *Journal of Health Economics*. 1998;17(537-555).
208. Palmer KS, Agoritsas T, Martin D, Scott T, Mulla SM, Miller AP, et al. Activity-based funding of hospitals and its impact on mortality, readmission, discharge destination, severity of illness, and volume of care: a systematic review and meta-analysis. *Public Library of Science One*. 2014;9(10):e109975-e.
209. Thoonsen B, Vissers KCP, Verhage S, Prins J, Bor H, van Weel C, et al. Training general practitioners in early identification and anticipatory palliative care planning: a randomized controlled trial. *BMC Family Practice*. 2015;16:126.
210. Marzuk P. The right kind of paternalism. *New England Journal of Medicine*. 1985;313(23):1474-6.
211. Wilson F, Ingleton C, Gott M, Gardiner C. Autonomy and choice in palliative care: time for a new model? *Journal of Advanced Nursing*. 2014;70(5):1020-9.
212. Stirrat G, Gill R. Autonomy in medical ethics after O'Neil. *Journal of Medical Ethics*. 2005;31:127-30.
213. Anyfantakis D, Symvoulakis E. Medical decision and patient's preference: 'much ethics' and more trust always needed. *International Journal of Medical Science*. 2011;8(4):351-2.

214. Australian Institute of Health and Welfare. Emergency department care 2017-2018. Australian hospital statistics. Canberra: Australian Institute of Health and Welfare; 2019. 93 p.
215. Australian Government. National Health Reform Act. Canberra: Federal Register of Legislation; 2011.
216. Dafny L. How do hospitals respond to price changes? *American Economic Review*. 2005;95:1525-47.
217. Newhouse J. Do unprofitable patients face access problems? *Health Care Financial Review*. 1989;11:33-42.
218. Mitchell G, Veitch C, Hollins J, Worley P. General practice research: problems and solutions in participant recruitment and retention. *Australian Family Physician*. 2001;30(4):399-406.
219. Tiberini R, Richardson H. *Rehabilitative Palliative Care. Enabling people to live fully until they die. A challenge for the 21st century*. London: Hospice UK; 2015.

Appendices

Appendix A Ethics approvals

- Approval letter from the Darling Downs Hospital & Health Service Human Research Ethics Committee, reference number HREC/15/QTDD/9
- Approval letter from the University of Queensland's Behavioural & Social Sciences Ethical Review Committee, approval number 2015000217
- Approval letter from the Royal Brisbane & Women's Hospital Human Research Ethics Committee, reference number HREC/16/QRBW/33
- Approval letter from the University of Queensland's Behavioural & Social Sciences Ethical Review Committee, approval number 2016000229
- Approval letter from the West Moreton Hospital and Health Service Research Governance Office, reference number SSA/16/QWMS/6



Queensland
Government

Medical Services

**Darling Downs Hospital
and Health Service**

Enquiries to: Wendy Friend
Telephone: (61 7) 4616 6696
Facsimile: (61 7) 4616 5099
Our Ref: HREC/15/QTDD/9

Mrs Sue-Ann Carmont
Discipline of General Practice
School of Medicine
University of Queensland
Lvl 8, Health Sciences Building
RBWH
HERSTON QLD 4006

Dear Mrs Carmont

HREC Reference number: HREC/15/QTDD/9
Project title: Health professionals' perceptions and experiences of integrated primary and secondary care for frail older people at the end of life: The BASIC Supportive Care Project for Frail Older People.

Thank you for submitting the above project for ethical and scientific review. This project was considered by the Darling Downs Hospital and Health Services Human Research Ethics Committee (HREC).

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Attached is the HREC Composition with specialty and affiliation with the Hospital (Attachment I).

I am pleased to advise that the Human Research Ethics Committee has granted approval of this research project at the following site:

- Ipswich Hospital

The documents reviewed and approved include:

Document	Version	Date
Application	AU/1/385D17	24 Feb 2015
Consent Form	v1.2	19 March 2015
Participant Information Sheet	v1.2	19 March 2015
Response to Request for Further Information		19 March 2015

Medical Services
Pechey Street Toowoomba
PMB 2 Toowoomba
Queensland 4350 Australia
Telephone +61 7 4616 6151
Facsimile +61 7 4616 5099
www.health.qld.gov.au/darlingdowns

ABN 64 109 516 141

Protocol: Protocol and Question Guide for Focus Groups	1.0	11 Feb 2015
Investigator CV: A/Prof Michele Foster CV	1.1	01 Feb 2015
Investigator CV: Prof Keith Mitchell	1.1	27 Jan 2015
Letter of support from organization: Geriatrician - Dr Alison Cutler	1.1	12 Feb 2015

Please note the following conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - Unforeseen events that might affect continued ethical acceptability of the project.
 - Serious Adverse Events must be notified to the Committee as soon as possible. In addition the Investigator must provide a summary of the adverse events, in the specified format, including a comment as to suspected causality and whether changes are required to the Patient Information and Consent Form. In the case of Serious Adverse Events occurring at the local site, a full report is required from the Principal Investigator, including duration of treatment and outcome of event.
2. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC coordinator as per standard HREC SOP. Further advice on submitting amendments is available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp
3. Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office/r (by-passing the HREC).
4. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly to the HREC for review and, once HREC approval has been granted, then submitted to the RGO.
5. Amendments which do not affect either the ethical acceptability or site acceptability of the project (e.g. typographical errors) should be submitted in hard copy to the HREC coordinator. These should include a cover letter from the principal investigator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.
6. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

7. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.
8. The Health Service administration and the Human Research Ethics Committee may inquire into the conduct of any research or purported research, whether approved or not and regardless of the source of funding, being conducted on hospital premises or claiming any association with the Hospital; or which the Committee has approved if conducted outside Darling Downs Hospital and Health Service.

HREC approval is valid for 3 years from the date of this letter.

Should you have any queries about the HREC's consideration of your project please contact Dr Hwee Sin Chong, Chair, Darling Downs Hospital and Health Service Human Research Ethics Committee. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive of that site has been obtained.

A copy of this approval must be submitted to the Research Governance Officer with a completed Site Specific Assessment (SSA) Form for authorisation from the Chief Executive to conduct this research at the site.

Once authorisation to conduct the research has been granted, please complete the Commencement Form (Attachment II) and return to the office of the Human Research Ethics Committee.

The HREC wishes you every success in your research.

Yours sincerely



Dr Hwee Sin Chong MBChB MHM FRACMA
Chair
Darling Downs Hospital & Health Service
Human Research Ethics Committee

So 13 115



**Royal Brisbane & Women's Hospital
Human Research Ethics Committee**

Enquiries to: Ann-Maree Gordon
A/Coordinator
Telephone: 07 3646 5490
Facsimile: 07 3646 5849
File Ref: HREC/16/QRBW/33
Email: RBWH-Ethics@health.qld.gov.au

Ms Sue-Ann Carmont
Discipline of General Practice
School of Medicine
University of Queensland
Level 8, Health Sciences Building
Royal Brisbane & Women's Hospital
Herston Qld 4029

Dear Ms Carmont,

Re: Ref N°: HREC/16/QRBW/33: A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Thank you for submitting the above research project for single ethical review. This project was considered by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (RBWH HREC) (EC00172) at its meeting held on 08 February 2016. The research project meets the requirements of the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*.

I am pleased to advise that the RBWH Human Research Ethics Committee has granted ethical approval of this research project.

The nominated participating site for this project is:

- Ipswich Hospital, West Moreton Hospital and Health Service

This letter constitutes ethical approval only. This project cannot proceed until separate research governance authorisation has been obtained from the CEO or Delegate of the Ipswich Hospital under whose auspices the research will be conducted.

The approved documents include:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		20 January 2016
Application: NEAF (<i>Submission Code: AU/1/04B3212</i>)	2.2 (2014)	25 January 2016

Royal Brisbane & Women's Hospital
Level 7 Block 7
Butterfield Street, Herston Qld 4029
Australia

Telephone +61 7 3646 5490
Facsimile +61 7 3646 5849
www.health.qld.gov.au/rbwh/research/hrec.asp

<i>Document</i>	<i>Version</i>	<i>Date</i>
Protocol	1.1	20 January 2016
Participant Consent Form (Patient)	1	25 November 2015
Participant Consent Form (Substitute Decision Maker)	1.1	20 January 2016
Participant Consent Form (Carer)	1	25 November 2015
Participant Consent Form (Health Professional)	1	25 November 2015
Withdrawal of Participation Form	1	20 January 2016
Letter to Health Professional	1.1	20 January 2016
Qualitative Interview Guide (Patient)	1.1	20 January 2016
Qualitative Interview Guide (Carer)	1.1	20 January 2016
Qualitative Interview Guide (Health Professional)	1.1	20 January 2016
Form A: Eligibility	1	25 November 2015
Form B: Baseline (Patient)	1.1	20 January 2016
Form B2: Follow Up Time 1 (Patient)	1	25 November 2015
Form B3: Follow Up Time 2 (Patient)	1.1	20 January 2016
Form C: Baseline (Carer)	1.1	20 January 2016
Form C2: Follow Up Time 1 (Carer)	1.1	20 January 2016
Form C3: Follow Up Time 2 (Carer)	1.1	20 January 2016
Form Z: Contact Details	1	25 November 2015
NECPAL CCOMS-ICO [®] Tool	1.0	November 2011
Curriculum Vitae of Sue-Ann Sonya Carmont		
Curriculum Vitae of Dr Hugh Senior		
Curriculum Vitae of Geoffrey Keith Mitchell		20 October 2015
Curriculum Vitae of A/Prof Michele Foster		
Response to Request for Further Information		15 February 2016
Participant Information Sheet - Patient	1.2	15 February 2016
Participant Information Sheet - Substitute Decision Maker	1.2	15 February 2016
Participant Information Sheet - Carer	1.2	15 February 2016
Participant Information Sheet - Health Professionals	1.2	15 February 2016
Letter to GP	1.2	15 February 2016

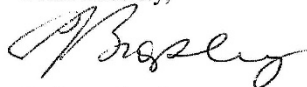
Approval of this project from the RBWH HREC is valid from **26.02.2016** to **26.02.2019** subject to the following conditions being met:

- The Coordinating Principal Investigator will immediately report anything that might warrant review of ethical approval of the project.

- The Coordinating Principal Investigator will notify the RBWH HREC of any event that requires a modification to the protocol or other project documents and submit any required amendments in accordance with the instructions provided by the HREC. These instructions can be found at <http://www.health.qld.gov.au/rbwh/research/hrec.asp>.
- The Coordinating Principal Investigator will submit any necessary reports related to the safety of research participants in accordance with the RBWH HREC policy and procedures. These instructions can be found at <http://www.health.qld.gov.au/rbwh/research/hrec.asp>.
- In accordance with Section 3.3.22 (b) of the National Statement the Coordinating Principal Investigator will report to the RBWH HREC annually in the specified format, the first report being due on **26.02.2017** and a final report is to be submitted on completion of the study. These instructions can be found at http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp.
- The Coordinating Principal Investigator will notify the RBWH HREC if the project is discontinued before the expected completion date, with reasons provided.
- The Coordinating Principal Investigator will notify the RBWH HREC of any plan to extend the duration of the project past the approval period listed above and will submit any associated required documentation. Instructions for obtaining an extension of approval can be found at <http://www.health.qld.gov.au/rbwh/research/hrec.asp>.
- The Coordinating Principal Investigator will notify the RBWH HREC of his or her inability to continue as Coordinating Principal Investigator including the name of and contact information for a replacement.
- A copy of this ethical approval letter together with completed Site Specific Assessment (SSA) and any other requirements must be submitted by the Coordinating Principal Investigator to the Research Governance Office at West Moreton Hospital and Health Service in a timely manner to enable the institution to authorise the commencement of the project at its site.
- Should you have any queries about the RBWH HREC's consideration of your project please contact the HREC Coordinator on 07 3646 5490. The RBWH HREC's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from <http://www.health.qld.gov.au/rbwh/research/hrec.asp>.

The RBWH HREC wishes you every success in your research.

Yours sincerely,



Dr Conor Brophy
Chairperson RBWH Human Research Ethics Committee
Metro North Hospital and Health Service
26.02.2016

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*. The processes used by this HREC to review research proposals have been certified by the National Health and Medical Research Council.



THE UNIVERSITY OF QUEENSLAND
Institutional Human Research Ethics Approval

Project Title: A Randomised Controlled Trial of a Model of Supportive Care for Frail Older People in the Community Through Multidisciplinary Collaboration and Integration Across the Primary and Secondary Interface - a Pilot

Chief Investigator: Mrs Sue-Ann Carmont

Supervisor: Prof G. Mitchell, Dr H. Senior, Dr M. Foster

Co-Investigator(s): None

School(s): Discipline of General Practice, School of Medicine

Approval Number: 2016000229

Granting Agency/Degree: NHMRC

Duration: 31st October 2017

Comments/Conditions:

Expedited review on the basis of approval from the Royal Brisbane and Women's Hospital HREC dated 26/02/2016 (HREC/16/QRBW/33)

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

**Name of responsible Committee:
Medical Research Ethics Committee**

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:

**Dr Jennifer Paratz
Acting Chairperson
Medical Research Ethics Committee**

Signature

Date

2/3/2016



Research Governance Office
The Park – Centre for Mental Health
Level 2 Dawson House
Locked Bag 500
Archerfield
QLD 4108

5 May 2016

Enquiries to:
Phone: **07 3271 8656**
Fax: **07 3271 8634**
Our Ref: **07-16**
E-mail: Sharleen.Young@health.qld.gov.au

Ms Sue-Ann Carmont
Discipline of General Practice
Level 8, Health Sciences Building
School of Medicine
Royal Brisbane and Women's Hospital
Herston QLD 4053

Dear Ms Carmont,

HREC reference number: HREC/16/QRBW/33

SSA reference number: SSA/16/QWMS/6

Project title: A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site(s):

Ipswich Hospital

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

CONDITION OF COMMENCEMENT

As a condition of approval, the investigators and research staff must abide by the:

1. [National Statement on the Ethical Conduct in Human Research 2007\(updated May 2015\)](#)
2. [Australian Code for the Responsible Conduct of Research 2007](#)
3. [ICH-GCP](#)
4. [Hospital and Health Boards Act 2011](#)
5. [Any other policy, procedure, law or legislation relevant to the research](#)

IMMEDIATE NOTIFICATION

As a condition of approval, the Principle Investigator must promptly report anything which might affect the ongoing acceptability of the study to the WMHHS Research Ethics and Governance Officer, this includes:

- Proposed amendments to the research protocol or conduct of the research which affects the ongoing acceptability of the project at WMHHS sites;

- Any other amendments to the research protocol as approved by the reviewing HREC, conduct of the research and unforeseen events that might affect continued ethical acceptability of the study to include, serious adverse effects on participants and complaints or expressions of concern made in relation to the study

The Principle Investigator is also responsible for notifying the Research Ethics and Governance Officer of the date of commencement and date of completion at site.

DATA COLLECTION

When conducting research within West Moreton Hospital and Health Service facilities:

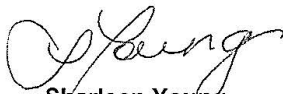
- You are required to have this letter in your possession, as it is validation of research approval.
- An ID needs to be worn.
- The first point of contact on commencing research is the senior clinical staff person in the facility area.

MONITORING AND REVIEW

In accordance with the NHMRC requirement that institutions through their research governance processes and ethics committees monitor approved research:

- **When ready to start please complete and return the 'Notification of Commencement of Research Protocol" via email. By doing so it is considered acceptance of the conditions of approval.**
- Please ensure that a final report and a copy of any publication or thesis is forwarded to the WMHHS Research Governance Office at the end of the study.
- If the project is going to continue beyond the original date of completion, please contact the WMHHS Research Ethics and Governance Officer to discuss.
- The delegated Research Ethics and Governance officer may choose to conduct an audit of your research during or following completion of the project.

Yours sincerely,



Sharleen Young
A/Research Ethics and Governance Officer

Appendix B Search strategy for systematic review

Systematic Review Medline Search Strategy

ID	Search Term
1	(MH "Advance Care Planning") OR (MH "Advance Directive Adherence") OR (MH "Terminal Care") OR "advance care plan*"
2	(MH "Palliative Care") OR "palliative care" OR (MH "Hospice and Palliative Care Nursing") OR (MH "Terminal Care")
3	(MH "Terminal Care") OR "terminal care" OR (MH "Terminally Ill")
4	1 OR 2 OR 3
5	(MH "Primary Health Care") OR "primary health care" OR (MH "Physicians, Primary Care")
6	(MH "General Practitioners") OR (MH "General Practice") OR "general practitioner*" OR "Family Practitioner*" or "Family Physician*"
7	(MH "Family Practice") OR (MH "General Practice") OR (MH "Physicians, Family") OR (MH "Private Practice")
8	5 OR 6 OR 7
9	4 AND 8
10	(MH "Delivery of Health Care, Integrated") OR (MH "Systems Integration") OR (MH "Integrative Medicine")
11	(MH "Case Management") OR (MH "Managed Care Programs")
12	(MH "Continuity of Patient Care")
13	(MH "Interdisciplinary Communication")
14	10 OR 11 OR 12 OR 13
15	9 AND 14

Appendix C Information Sheets and Consent Forms

- Phase 1 Participant Information Sheet
- Phase 1 Consent Form
- Phase 2 Health Professionals' Information Sheet
- Phase 2 Health Professionals' Consent Form
- Phase 2 Patient Information Sheet
- Phase 2 Patient Consent Form
- Phase 2 Substitute Decision Maker Consent Form
- Phase 2 Carer Information Sheet
- Phase 2 Carer Consent Form

Health professionals' perceptions and experiences of integrated primary and secondary care for frail older people at the end of life: The BASIC Supportive Care Project for Frail Older People

Chief investigator: Ms Sue-Ann Carmont, PhD scholar, School of Medicine

Co-investigators: A/Prof Michele Foster, School of Social Work and Human Services
Prof Geoffrey Mitchell, School of Medicine
Dr Hugh Senior, School of Medicine

Contact: Sue-Ann Carmont
07 3365 5014; 0404 289 186
s.carmont@uq.edu.au

Why is this research important?

Australia has an ageing population and is facing increased pressure on its health system from a population with increasing prevalence of chronic conditions and co-morbidities late in life. Frailty is also likely to increase with an increase in the number of older Australians. Frailty is predictive of disability, hospitalisation and death.

Palliative care is an approach that improves the quality of life of patients and their families as patients approach the end of their lives. This involves providing care which prevents and relieves symptoms associated with their illness, such as pain, physical symptoms, psychosocial and spiritual support. As frailty is predictive of death, then it follows that frail patients should be identified and provided with palliative care. Research into the effectiveness of palliative care for frail older people has been negligible.

Palliative care is provided in a multitude of settings in Australia including:- hospital, hospice, aged care, and home. However there is a finite number of specialist palliative care services available. Researchers have been investigating the effectiveness of shared care models and models that integrate the primary care (general practitioner) and secondary care (specialist services) to improve patient care and quality of life. However, these models have not been developed and assessed for a frail older population.

What does the study aim to achieve?

This studies aims to explore, through health professionals' experience working with frail older people at the end of life, how acceptable and workable a shared model of care which integrates primary and secondary care services might be in their local context.

This research aims to inform a pilot study of a shared model of care which integrates primary and secondary care services.



What does the study involve?

The project involves participating in a focus group discussion with peers for 60-90 minutes which will be audio recorded. The location of the focus group discussions will be one of convenience to attendees and suitable for purpose.

Are there any risks?

If you experience any distress or conflict in the workplace due to participation in the focus group, please contact the Queensland Health Employee Assistance Program, provided by Optum. This confidential service is available 24 hours a day 7 days a week and provides short term professional counselling. They can be contacted on 1800 604 640. This program is also available if you experience any distress from issues arising in the focus group. Where appropriate, the lead investigator will follow up to ensure participants receive any help they require.

What measures will be taken to ensure my privacy is protected?

The information collected during focus group discussions will be de-identified. Participant names or details that could be used to identify individuals that are captured during audio recordings will be deleted from the transcript to protect the privacy of the person(s) involved.

Data collected will be stored in a secured filing cabinet under the care of the principal researcher (or their nominee). Any electronic data generated will be stored on a secure password protected server for the duration of the project. Only the researchers (or their nominee) will have access to the information. No data will be published that may identify individuals participating in the research program in any way.

How will feedback about this project be made available to me should I desire it?

A summary of the research results will be available to all participants at the end of the trial.

Do I have to participate?

Your participation in this project is voluntary, and you can choose not to participate in part or the entire research project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way. If you have any queries, please contact Sue-Ann Carmont: ph 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au.

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (contactable on 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924.

Version 1.2 19/03/15



Consent Form

Title: **Health professionals' perceptions and experiences of integrated primary and secondary care for frail older people at the end of life:- The BASIC Supportive Care Project for Frail Older People**

Chief investigator: Ms Sue-Ann Carmont, PhD scholar, School of Medicine

Co-investigators: A/Prof Michele Foster, School of Social Work and Human Services
Prof Geoffrey Mitchell, School of Medicine

Dr Hugh Senior, School of Medicine

Contact: 07 3365 5014 s.carmont@uq.edu.au

I consent to participate in the above University of Queensland research project.

I have:

- Read and understood the information sheet, which I will keep for my records;
- Had any questions or queries answered to my satisfaction;
- Agreed to take part in the focus group discussion, and in the unlikely event that further clarification is required, to being contacted after the event for this purpose;
- Understood the focus group discussion will be audio taped and transcribed;
- Been informed that confidentiality of the information provided will be maintained and safeguarded. Data will be de-identified and will not be provided to a third party;
- Understood that information may be disclosed by others in the focus group and that I agree to respect the privacy of any confidential or sensitive information that may be revealed during the course of the meeting.

I also understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

Signature:

Name (please print)

Date: / /

Version 1.2 19/03/15



Participant Information Sheet

Health Professionals

Title: A pilot trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface

Principal investigator: Sue-Ann Carmont, PhD student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

You are invited to take part in this research project, as the General Practitioner, Allied Health Practitioner or a staff member of the Older Person Evaluation Review and Assessment (OPERA) unit at West Moreton Hospital and Health Service (WMHHS) of a patient who is participating in this research. The project is testing a new model to provide supportive care for frail older people. Supportive care actively manages the patient's current frailty while providing the opportunity to plan for potential future issues such as management of acute symptoms, whom to call for advice out of hours, and advance care planning. This Information Sheet explains the research project, so that you will understand what is involved before you decide whether to participate in the research. Please read this information carefully. Your decision whether to participate in this research will be voluntary. If you choose to participate, you will be asked to sign and return the attached consent form.

What is the purpose of this research?

The aim of this project is to test the hypothesis that for frail older people, case conferences between health professionals across the primary and secondary interface, in addition to usual care, will reduce the incidence of hospital admissions, as measured by health service utilisation. This study will contribute to a PhD.

What does the study involve?

Frail older patients of the WMHHS OPERA unit will be identified.

Patients will have their GP, Geriatrician from OPERA and any other relevant health professional involved in the patient's care hold a structured case conference to provide a care plan for each patient. The patient and the patient's carer will also be able to participate in the case conference if they wish. The case conference will be held via video conference where possible and tele conference when video conference facilities are unavailable. The case conference will take approximately 30 minutes. Patients and carers will be asked to attend the GP's office or the hospital to be involved in the case conference.



Patients will complete questionnaires at 3 time points – at the start, 4-6 weeks later and then 14-16 weeks later. These questionnaires should take 15-20 minutes each time. Questions will include quality of life, mood, service utilisation and carer strain. Patients will also allow access to their health records, so researchers can assess health service use and adherence to the care plan created during the case conference. Some patients and carers will also be asked to participate in a semi-structured interview conducted face to face, to provide their experience of participating in the intervention.

Health professionals will be asked to participate in the structured case conference. Health professionals, specifically the geriatrician and the GP will facilitate access for the researcher to the patient's records (hospital and GP records) to audit the adherence to the care plan initiated during the case conference and to assess health service utilisation. This audit does not collect data about quality of care.

Health professionals will also be asked to participate in a semi-structured interview to be conducted face to face, to provide their experience of participating in the case conference. Interviews will be recorded and transcribed. The transcript is available to the participant to verify accuracy. Health professionals are able to decline to participate in the semi-structured interview.

What are the possible benefits of participating in this research?

We cannot guarantee that you will receive any direct benefit from this research. However, it will enable you to focus on and plan for your patient's complex needs in collaboration with other clinicians in a case conference which engages the combined expertise of those who participate in it. The care plan which results from the case conference may enhance the patient's quality of life. It is hoped that the information gained will assist in the future care of others.

Are there any risks?

If you experience any distress or conflict in the workplace due to participation in the trial, please contact the Queensland Health Employee Assistance Program, provided by Optum. This confidential service is available 24 hours a day 7 days a week and provides short term professional counselling. They can be contacted on 1800 604 640. This program is also available if you experience any distress from issues arising from the research. Where appropriate, the lead investigator will follow up to ensure participants receive any help they require.

What measures will be taken to ensure my privacy is protected?

The information collected will be de-identified. Data will be kept in locked filing cabinets, only accessible by study staff on a secure floor at The University of Queensland. Records from the study will be maintained for 15 years after the study completion, once the waiting period is complete, we will shred any paper copies, including the master list linking participant name and treatment number. Electronic files will be kept in de-identified form indefinitely on a secure server at The University of Queensland. Only the researchers (or their nominee) will have access to the information. No data will be published that may identify individuals participating in the



research program in any way. The de-identified data may be used in future research projects which would be approved by a Human Research Ethics Committee at that time.

How will feedback about this project be made available to me should I desire it?

A summary of the research results will be available to all participants at the end of the trial.

Do I have to participate?

Your participation in this project is voluntary, and you can choose not to participate in part or the entire research project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way. You will be asked to complete a withdrawal form. If you have any queries, please contact Sue-Ann Carmont: ph 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au.

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (contactable on 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924.

This study has been reviewed and approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (EC00172). Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, Human Research Ethics Committee, Royal Brisbane & Women's Hospital, Herston, Qld 4029 or telephone (07) 3646 5490, email: RBWH-Ethics@health.qld.gov.au.

The research has been approved by the West Moreton Hospital and Health Service Governance Office. Should you wish to discuss the study with the Governance Office you may contact the Research and Ethics Governance Officer, West Moreton Hospital and Health Service, The Park-Centre for Mental Health, Locked Bag 500, Archerfield 4108 or telephone 3271 8658, email: Wmhsd_ethics@health.qld.gov.au.



A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Participant Consent Form (Health Professionals)

Principal investigator: Sue-Ann Carmont, PhD Student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

I have read, or have had read to me, and I understand the Participant Information and Consent Form.

I understand the nature and purpose of this study and any risks involved. I have had an opportunity to ask questions, and I am satisfied with the answers I have received.

I acknowledge that my involvement in the study may not be of benefit to me.

I understand that all information collected is strictly confidential. Information used in the project that relates to me will be kept secure and only be accessible to the research team. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I understand that taking part in the study is voluntary, that I am free to withdraw at any time I wish and that this will not have any adverse effects for me.

I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I understand that I will be given a copy of this to keep.

Participant's Name: _____
(please print full name)

Signature of Participant: _____ / / _____
(Date)



Participant Information Sheet

Patient

Title: A pilot trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface

Principal investigator: Sue-Ann Carmont, PhD student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

You are invited to take part in this research project. The project is testing a new model to provide supportive care for frail older people. Supportive care means caring for your current needs, while planning for possible future conditions. This could include planning how to cope with symptoms that may get worse, planning for possible new symptoms, when to go to hospital or the general practitioner and advance care planning – making sure you have your treatment wishes recorded. This Information Sheet explains the research project, so that you will understand what is involved before you decide whether to be involved. Please read this information carefully. Your decision whether to participate in this research will be voluntary. If you choose to participate, you will be asked to sign and return the attached consent form.

What is the purpose of this research?

The aim of this project is to test if for frail older people, case conferences between your General Practitioner, your health care team at the OPERA (Older Person Evaluation, Review and Assessment unit at Ipswich Hospital and other relevant health professionals (e.g. community based nurses or any person paid to provide health care) involved in your care will reduce the number of expected hospital admissions. This study will contribute to a PhD.

What does the study involve?

Your geriatrician may ask you to participate in this research. If you agree, research staff will also ask your carer to participate. Your geriatrician will check that you are eligible to participate. This may involve physical checks for frailty, such as walking a distance of under 5 metres and strength of grip.

You will be asked to provide contact information for your GP so research staff can contact them about the project. They will need to agree to participate for you to continue in the research. We will also ask for contact details for other relevant health professional that cares for you at home. We will invite them to participate. You can remain in the study if they decline to participate.



A case conference about your health need will be conducted by the relevant health professionals involved in your care. This will be your GP, your Geriatrician and other relevant health professionals involved in your care. You and your carer will also be able to participate in the case conference if you want. You do not have to take part if you do not wish to. If you choose to participate, you will be asked to come to the GPs office or the hospital to participate in the video link/teleconference with your GP or geriatrician.

The case conference will take about 30 minutes. It will happen on a video link or over the telephone. The case conference will discuss your care, your current and possible future needs and develop a care plan. You will receive a copy of this. If you do not attend the case conference this plan will be discussed with you and any changes from this discussion will be incorporated.

You and your carer will be asked to complete some questionnaires. These will include questions about your quality of life, mood, and the health services you use. One of the research staff can assist you to complete these questions. They will take about 15-20 minutes to complete. This will happen 3 times. The first time will be shortly after you agree to participate, then 4-6 weeks later and then again 14-16 weeks later. A member of the research team can assist you to complete these. We would also like your permission to look at your health records at the hospital and at the GP office.

You and your carer may also be asked to talk to one of the research team about your experience participating in the intervention. This would be an interview that would take approximately 20 minutes. The interview would be conducted at a place convenient to you, for example, your home or in a private room at the local library. The interview will be recorded and then transcribed (written out). You will be able to check the transcription. You may decline to participate in the interview or stop the interview at any time.

What are the possible benefits of participating in this research?

We cannot guarantee that you will receive any direct benefit from this research. It is hoped that the information gained will assist in the future care of others. You will not receive payment for participating in the research. However, we will reimburse costs involved in travel to the case conference.

What are the possible risks of participating in this research?

There may be some discomfort that occurs from discussions about current and future health needs with several people. To be involved with the trial will require time to complete assessments, participate in the case conference and speak with the researchers. We cannot compensate you for your time. The trial may be an inconvenience at times.

What measures will be taken to ensure my privacy is protected?

The information collected will be kept safe and only accessed by research staff. Data will be kept in locked filing cabinets, only accessible by study staff on a secure floor at The University of



Queensland. Records from the study will be maintained for 15 years after the study completion, once the waiting period is complete, we will shred any paper copies, including the master list linking participant name and treatment number. Electronic files will be kept in de-identified form indefinitely. The de-identified data may be used in future research projects which would be approved by a Human Research Ethics Committee at that time.

The outcomes of the project will be reported in journals and presentations but you will not be identified individually.

How will feedback about this project be made available to me should I desire it?

A summary of the research results will be available to all participants at the end of the trial.

Do I have to participate?

Your participation in this project is voluntary. You can choose not to participate in part or the entire research project. You can withdraw at any stage of the project. You will be asked to complete a withdrawal form. This form will give you option, from withdrawing participation for part of the project up to and including withdrawing permission for data already collected. The decision to withdraw will not affect your medical care and you will not be disadvantaged in anyway.

This study adheres to the Guidelines of the ethical review process of The University of Queensland, and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (contactable on 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924.

This study has been reviewed and approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (EC00172). Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, Human Research Ethics Committee, Royal Brisbane & Women's Hospital, Herston, Qld 4029 or telephone (07) 3646 5490, email: RBWH-Ethics@health.qld.gov.au.

The research has been approved by the West Moreton Hospital and Health Service Governance Office. Should you wish to discuss the study with the Governance Office you may contact the Research and Ethics Governance Officer, West Moreton Hospital and Health Service, The Park-Centre for Mental Health, Locked Bag 500, Archerfield 4108 or telephone 3271 8658, email: Wmhsd_ethics@health.qld.gov.au.



A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Participant Consent Form (Patient)

Principal investigator: Sue-Ann Carmont, PhD Student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

I have read, or have had read to me, and I understand the Participant Information and Consent Form.

I understand the nature and purpose of this study and any risks involved. I have had an opportunity to ask questions, and I am satisfied with the answers I have received.

I acknowledge that my involvement in the study may not be of benefit to me. I understand I will not receive payment to participate.

I understand that all information collected is strictly confidential. Information used in the project that relates to me will be kept secure and only be accessible to the research team. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I understand that taking part in the study is voluntary, that I am free to withdraw at any time I wish and that this will not have any adverse effects for me. My medical care will not be affected in any way if I withdraw.

I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I understand that I will be given a copy of this to keep.

Participant's Name: _____
(please print full name)

Signature of Participant: _____ / / _____

(Date)



Declaration by Geriatrician

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Geriatrician _____
(please print full name)

Signature: _____ /_____/_____
(Date)



A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Participant Consent Form (Substituted Decision Maker)

Principal investigator: Sue-Ann Carmont, PhD Student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

I have read, or have had read to me, and I understand the Participant Information and Consent Form.

I understand the nature and purpose of this study and any risks involved. I have had an opportunity to ask questions, and I am satisfied with the answers I have received.

I acknowledge that the involvement of the person I care for in the study may not be of benefit to them. I understand they will not receive payment to participate.

I understand that all information collected is strictly confidential. Information used in the project that relates to the person I care for will be kept secure and only be accessible to the research team. The researcher has agreed not to reveal the identity or personal details of the person I care for if information about this project is published or presented in any public form.

I understand that taking part in the study is voluntary, that I am free to withdraw consent for the person I care for at any time I wish and that this will not have any adverse effects for them. Medical care will not be affected in any way if I withdraw.

I freely agree to provide consent for the person I care for to participate in this project according to the conditions in the Participant Information and Consent Form.

I understand that I will be given a copy of this to keep.

You are making a decision on behalf of the person for whom you are responsible regarding her/his participation in the above named research project. Your signature indicates that, having read the information provided, you have decided to give permission for him/her to participate.

I am the person responsible for: _____ Relationship: _____
Please PRINT name of person for whom you are responsible, and your relationship to them



Person Responsible: _____
(please print full name)

Signature of Person Responsible: _____ /____/____
(Date)

Witness: _____
(please print full name)

Signature of Witness: _____ /____/____
(Date)



Participant Information Sheet

Carer

Title: A pilot trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface

Principal investigator: Sue-Ann Carmont, PhD student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

The person you care for has agreed to participate in a research project and you are invited to take part. The project is testing a new model to provide supportive care for frail older people. Supportive care means caring for the current needs of person you care for, while planning for possible future conditions. This could include planning how to cope with symptoms that may get worse, planning for possible new symptoms, when to go to hospital or the general practitioner and advance care planning – making sure the person you care for has his or her treatment wishes recorded. This Information Sheet explains the research project, so that you will understand what is involved before you decide whether to participate in the research. Please read this information carefully. Your decision whether to participate in this research will be voluntary. If you choose to participate, you will be asked to sign and return the attached consent form.

What is the purpose of this research?

The aim of this project is to test if for frail older people, case conferences between their General Practitioner, their health care team at the OPERA (Older Person Evaluation, Review and Assessment unit at Ipswich Hospital and other relevant health professional (e.g. community based nurses or any person paid to provide health care) involved in their care will reduce the number of expected hospital admissions. This study will contribute to a PhD.

What does the study involve?

The person you care for has been asked to participate in this research by their Geriatrician. You are also invited to participate.

The GP of the person you care for will be asked to participate. They will need to agree to participate for the research to continue. We will also ask the person you care for to identify other relevant health professionals that care for them in the community and we will then invite them to participate. The research will continue if these additional health professionals decline to be involved.



A case conference about the health needs of the person you care for will be conducted by the relevant health professionals involved in their care; this will be their GP, their Geriatrician and other relevant health professionals named by the person you care for. You and the person you care for will also be able to participate in the case conference if you want. You do not have to take part if you do not want to. If you choose to participate, you will be asked to come to the GP's office or the hospital to participate in the video link /teleconference with the patient's GP or geriatrician.

The case conference will take about 30 minutes. It will happen on a video link or over the telephone. The case conference will discuss the care, current and possible future needs of the person you care for and develop a care plan. The person you care for will receive a copy of this. If you and the person you care for did not attend the case conference this plan will be discussed with you both and any changes due to this discussion will be incorporated.

You and the person you care for will be asked to complete some questionnaires. These questionnaires will include questions about you, your quality of life, your mood, caring duties and there will be questions about the health services the person you care for uses. These will take about 15-20 minutes to complete. This will happen 3 times. The first time will be shortly after you agree to participate, then 4-6 weeks later and then again 14-16 weeks later.

You and the person you care for may also be asked to talk to one of the research team about your experience participating in the intervention. This would be an interview that would take approximately 20 minutes. The interview would be conducted at a place convenient to you, for example, your home or in a private room at the local library. The interview will be recorded and then transcribed (written out). You will be able to check the transcription. You may decline to participate in the interview or stop the interview at any time.

What are the possible benefits of participating in this research?

We cannot guarantee that you will receive any direct benefit from this research. It is hoped that the information gained will assist in the future care of others. You will not receive payment for participating in the research. However, we will reimburse any travel expenses (eg parking costs) to participate in the case conference.

What are the possible risks of participating in this research?

There may be some discomfort that occurs from discussions about current and future health needs with several people. To be involved with the trial will require time to complete assessments, participate in the case conference and speak with the researchers. We cannot compensate you for your time. The trial may be an inconvenience at times.

What measures will be taken to ensure my privacy is protected?

The information collected will be kept safe and only accessed by research staff. Data will be kept in locked filing cabinets, only accessible by study staff on a secure floor at The University of Queensland. Records from the study will be maintained for 15 years after the study completion, once the waiting period is complete, we will shred any paper copies, including the master list linking participant name and treatment number. Electronic files will be kept in de-identified form indefinitely. The de-identified data may be used in future research projects which would be approved by a Human Research Ethics Committee at that time.

The outcomes of the project will be reported in journals and presentations but you will not be identified individually.

How will feedback about this project be made available to me should I desire it?

A summary of the research results will be available to all participants at the end of the trial.

Do I have to participate?

Your participation in this project is voluntary. You can choose not to participate in part or the entire research project. You can withdraw at any stage of the project. You will be asked to complete a withdrawal form. This form will give you options, from withdrawing participation for part of the project up to and including withdrawing permission for data already collected. The decision to withdraw will not affect the medical care of the person you care for and you will not be disadvantaged in anyway.

If the person you care for wishes to participate and you do not, we will proceed with the project, and only talk with him or her and not you.

This study adheres to the Guidelines of the ethical review process of The University of Queensland, and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (contactable on 07 3365 5014; 0404 289 186 or email s.carmont@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924.

This study has been reviewed and approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (EC00172). Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, Human Research Ethics Committee, Royal Brisbane & Women's Hospital, Herston, Qld 4029 or telephone (07) 3646 5490, email: RBWH-Ethics@health.qld.gov.au.

The research has been approved by the West Moreton Hospital and Health Service Governance Office. Should you wish to discuss the study with the Governance Office you may contact the Research and Ethics Governance Officer, West Moreton Hospital and Health Service, The Park-Centre for Mental Health, Locked Bag 500, Archerfield 4108 or telephone 3271 8658, email: Wmhsd_ethics@health.qld.gov.au.



A randomised controlled trial of a model of supportive care for frail older people in the community through multidisciplinary collaboration and integration across the primary and secondary interface – a pilot

Participant Consent Form (Carer)

Principal investigator: Sue-Ann Carmont, PhD Student
Other Investigators: Prof Geoff Mitchell
Dr Hugh Senior
Prof Michele Foster

I have read, or have had read to me, and I understand the Participant Information and Consent Form.

I understand the nature and purpose of this study and any risks involved. I have had an opportunity to ask questions, and I am satisfied with the answers I have received.

I acknowledge that my involvement in the study may not be of benefit to me. I understand I will not receive payment to participate.

I understand that all information collected is strictly confidential. Information used in the project that relates to me will be kept secure and only be accessible to the research team. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I understand that taking part in the study is voluntary, that I am free to withdraw at any time I wish and that this will not have any adverse effects for me. The medical care of the person I care for will not be affected in any way if I withdraw.

I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I understand that I will be given a copy of this to keep.

Participant's Name: _____
(please print full name)

Signature of Participant: _____ / / _____

(Date)



Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher _____
(please print full name)

Signature: _____ /____/____
(Date)



Appendix D Mater focus group question guide for phase 1 study

MASTER Focus Group Question Guide

AIM

To explore, with health professionals' experience working with frail older people with palliative and supportive needs, how acceptable and workable a shared model of care which integrates primary and secondary care services might be in their local context.

Research Questions

What do the experiences of health professionals working with frail older people with palliative and supportive needs reveal about the clinical and professional challenges of providing care to this population?

What value do health professionals attach to a model of care which integrates primary and secondary care services for frail older people at the end of life?

What is the perceived viability of using case conferencing to provide model of care which integrates primary and secondary services and what are likely barriers and facilitators in the local context?

What would be the key features of a model of care which integrates primary services with OPERA/GEM service in the local context?

Introduction/Background for focus group discussions

Frailty is a common syndrome in the community and is leading to increases in hospitalisations. Frailty is also a predictor of mortality. The definition of palliative care suggests that most people with a life-limiting illness could benefit from its holistic scope of practice. However, the extent of research into the effectiveness of palliative care for frail older people is negligible. This research is proposing a model that supports the integration of primary and secondary care, while maintaining the quality of service provision. This research will develop and assess a shared care model on the effectiveness of palliative care for frail older people. The first step in that process it to talk with you today about frailty, palliative care and how a model of integrated care would work for you and your patients.

Hypothetical patient to foster discussion (if required)

As we hold our discussion today it might help to keep in mind Jane. Jane would be 84 years old, living in a granny flat with her daughter. She has mild cognitive impairment but intact insight. She needs help with her finances. Physically she also has long-standing hypertension and had a hospitalisation with heart failure secondary to the H/T about five years ago. She gets breathless when she goes up the steps from the flat to the main house. She also has Osteo Arthritis of the right hip, and the pain of this requires her to take regular panadol osteo. This is not working particularly well and the pain disturbs her sleep. She was overweight (BMI 32 in 2012), but in the last 12 months she has lost weight and it is now BMI 27. She has stage 3b chronic kidney disease. Her appetite has reduced. She appears depressed. Since her husband died two years ago, she seems to have lost her desire to meet with friends and go to church like she used to. She wears hearing aids and has moderately dense cataracts. She is on two medicines for her hypertension, panadol osteo for arthritis, an antidepressant, and pariet for long-standing reflux. Jane is frail and has been deteriorating over some time and expectation is she will likely pass away in the next 12 months.

Version 1.0
11/02/2015

MASTER Focus Group Question Guide

Questions for GP Focus Groups

Question	Clarifications	Rationale/Domain to be explored	Comments
1. When you consider a patient such as Jane, how would you categorise her – palliative, end of life, frail, declining?		Allow participants to own definitions to be used	
1 a) In your experience caring for patients like Jane, what are the main professional/clinical issues that patients present with?		Introductory question. Able to be answered quickly.	Finding common ground.
1 b) To what extent do you see these issues related to her approaching the end of life?	What are the challenges you face as a clinician when caring for a patient such as Jane?	Introducing/highlighting the palliative context	
2. In general, how would you resolve these challenges in caring for the patient?	Specifically you mention _____ as a challenge, what resources would you use Who do you consult with, which services do you interact with when caring for this patient?	Key question Looking at the barriers evident in the current system of care.	Work practices/flow Routine assessment Contact with hospital / other services – is it useful – why/why not Barriers
3. In caring for patients like Jane, to what extent would direct communication with a specialist secondary service resolve some of your challenges or change your approach to care management?	Would this be a logical solution to some of the challenges we have talked about? For which problems would it work best? For which problems would it not work so	Key Question Introducing shared care as a potential	

Version 1.0
11/02/2015

MASTER Focus Group Question Guide

	well?		
Propose case conferences as evidenced by literature. Broad concept – highlight embryonic stage and highlight specifics required by group.		Setting scene – use ‘the case’ to bring discussion back to reality rather than theory	Highlight team, Medicare payment and videoconference potential/teleconference
4. How would you identify the frail older person for this type of intervention?			
5. Very briefly, can you tell me how different this approach (case conferencing) would be to your current practice?			
6. As a clinician/health professional: a) what do you see as the main benefits of this approach? b) What disadvantages, if any, would you envisage with this approach? c) In your view, what would it take from you as a clinician to make this work in your local context?	Value to patients and value to clinicians Any unique practitioner e.g. time issues, resources etc and/or context issues Is this realistic?	Key question Informing phase 3	Challenges/ benefits / who to implement Bring back to ‘Jane’ if getting to far from their practice.
7. In terms of making this multidisciplinary case conference model work what are some of the important considerations?	Who is involved? Who decides involvement? Content of case conference –	Key question Informing phase 3	Content

Version 1.0
11/02/2015

MASTER Focus Group Question Guide

<p>Should Jane and a carer be part of the case conference? Why/Why not?</p>	<p>introduce PEPSI –COLA headings - highlight small amount of time on most sections</p> <p>Who addresses each area of the case conference?</p> <p>Development and implementation of care plan</p> <p>What could be done to make this successful/operational in your practice?</p> <p>Value of her contribution?</p> <p>Difficulty arranging a participation if she had to be there</p> <p>Not being able to discuss some issues in her presence</p>		<p>Communication with patient and carer about plan</p> <p>Patient and carer input – how best achieved?</p>
<p>8. What are the challenges you would anticipate in conducting case conferences with a multi-disciplinary team based in hospital and community settings?</p>		<p>Key question</p> <p>Informing phase 3</p>	<p>Silo theory</p> <p>Trying to get at professional silos reducing/ preventing communication between primary and secondary care, but at a personal, not a system level.</p>
<p>9. In terms of making this model</p>	<p>Some of these we can't</p>	<p>Key question</p>	<p>Organisational</p>

Version 1.0
11/02/2015

MASTER Focus Group Question Guide

<p>work in your local context, what are some of the broader systemic factors that need to be considered?</p>	<p>influence, what factors can we mitigate or work with.</p>	<p>Informing phase 3</p>	<p>Office set up (camera on computer) Support staff Timing Organising case conferences Teleconference as alternative Financial Medicare rebates</p>
<p>10. If our patient Jane was a typical patient Where a case conference was held, what would you anticipate would be her response to a case conference between her GP and her specialist hospital service?</p>		<p>Key question Informing phase 3 Why?</p>	<p>Patient preferences A health professionals' expectation of patient response may influence whether or not they would support case conferences</p>
<p>Summarise discussion (2-3 minutes). Is this an adequate summary?</p>			
<p>Have we missed anything?</p>			

Appendix E Semi-structured case review proforma

DO NOT WRITE IN THIS BINDING MARGIN

Created March 14 / Version 6

		(Affix patient identification label here)	
		URN: Family Name: Given Names: Address: Medicare Number: ID: Expiry Date: Date of Birth: Sex: <input type="checkbox"/> M <input type="checkbox"/> F	
Case Conference : Part 1 – Supportive Care Planning			
Consultant: Phone: General Practitioner: Practice Name: Practice Address: Phone: Chronic Disease Team Clinician: Phone:		Pathology results attached: <input type="checkbox"/> Yes <input type="checkbox"/> No Medication list attached: <input type="checkbox"/> Yes <input type="checkbox"/> No Allergies:	
Diagnosis: Active Problems:		Co-morbidities: Discussion with patient and family about supportive care (Palliation): Date: Notes:	
Support system and service involvement:: Preferred place of care:		AHD <input type="checkbox"/> Yes <input type="checkbox"/> No Legal will <input type="checkbox"/> Yes <input type="checkbox"/> No EPOA <input type="checkbox"/> Yes <input type="checkbox"/> No Funeral Plan <input type="checkbox"/> Yes <input type="checkbox"/> No Death Certificate/Extinction of Life Certificate discussion <input type="checkbox"/> Yes <input type="checkbox"/> No	
Symptom Summary Current Patient Problems: 1. 2. 3. 4. Patient Goals: Psycho-social, emotional and spiritual summary:		Multidisciplinary Team Involvement	

CASE CONFERENCE: PART 1 – CARE PLANNING

Name: _____ Date: _____

Signature: _____

		(Affix patient identification label here)	
		URN:	
		Family Name:	
		Given Names:	
		Address:	
Case Conference : Part 1 – Supportive Care Planning		Medicare Number: ID: Expiry Date:	
		Date of Birth: Sex: <input type="checkbox"/> M <input type="checkbox"/> F	
Action Plan:		Follow up Plan:	
Symptom and problem review Gold Standards – PEPSICOLA			
		Date:	
P – Physical Symptom control Medication – regular & PRN Compliance / stopping non-essentials Complementary therapies	Symptom / Issue / Problem	Plan	Actioned By
E – Emotional Understanding expectations Depression and adjustment Fears / Security Relationships			
P – Personal Spiritual / religious needs Inner journey Quality of life Pt/carer's agenda			
S – Social Support Benefits/Financial Care for carers Practical support			
I – Information / Communication Within Team Between professionals To and from patient To and from carers			
C – Control Choice, dignity Treatment options / Management Plan Advance directive Place of death			
O – Out of Hours / Emergency Continuity Communication to out of hours/pts/carers Carer support Medical support Drugs and equipment			
L – Late End of life/Terminal care Stopped non-urgent Rx Patient and family aware Comfort measure Spiritual care Rattle, agitation			

DO NOT WRITE IN THIS BINDING MARGIN

Name: _____ Date: _____

Signature: _____

		(Affix patient identification label here)	
		URN:	
		Family Name:	
		Given Names:	
		Address:	
Case Conference : Part 1 – Supportive Care Planning		Medicare Number:	
		Date of Birth:	
		ID:	Expiry Date:
		Sex: <input type="checkbox"/> M	<input type="checkbox"/> F
A – Afterwards Bereavement follow-up/others informed Family support Assessment/Audit Support team			
Other issues			

DO NOT WRITE IN THIS BINDING MARGIN

Created March 14 / Version 6

CASE CONFERENCE: PART 1 – CARE PLANNING

Name: _____ Date: _____

Signature: _____

Page 3 of 3

Appendix F Interview guides for phase 2 pilot study

- Patient Interview Guide
- Carer Interview Guide
- Health Professional Interview Guide

Preamble to qualitative interview with patient

- Thank you for giving us your time for this interview. It should take 15-20 minutes.
- We would like to talk with you about your experiences of supportive care since case conference with your health professionals.
- I will be recording our conversation so nothing important is missed, but what you say will be treated as confidential and anonymous, and used only for this research.
- I have a few questions to help guide what we talk about.
- Let me know if you don't understand a question, and I'll rephrase it.
- We can stop for a break during the interview, if you need. Are you comfortable for now?
- Do you want to ask me any questions before we start?

Introduction

We are testing a new way to care for people who are receiving supportive care. Today, we want to talk about your experience of the case conference and about the care you have been received since the case conference happened.

1) Participation:

If yes, **What was your experience during the case conference?**

- What worked well and what would you change to improve information exchange
- A care plan was created during the case conference. What was your experience of creating a care plan and assigning responsibilities as part of the case conference process?
- What worked well and what would you change?
 - Participants
 - Structure
 - technology

If no, would you be comfortable telling me how it came about that you did not attend?

Have you thought since about whether there would have been some benefit in you attending?

2) Expectations:

- What were your expectations in regard to the case conference and your care?
- To what extent were your expectations of the case conference met?

3) Follow up care: Since the case conference, what changes for the better or worse have you noticed in your care since the case conference?

- Were there any gaps in care that were there that have been addressed?
- Have any new services or aids that you did not have before been commenced or supplied since the case conference?
- Are there any new gaps in care that you have noticed?

4) Other thoughts: Is there anything else you would like to say about the supportive care you received that is important to you?

- Have we missed anything?
- If you think of something you want to add after I've gone, you are welcome to phone or email.

Wrapping up

Would it be alright if I needed to get back to you to clarify anything you said today?

Thanks again for your time today. We appreciate your help very much.

Preamble to qualitative interview with carer

- Thank you for giving us your time for this interview. It should take 15-20 minutes.
- We would like to talk with you about your experiences of supportive care since the case conference with the patient's health professionals.
- I will be recording our conversation so nothing important is missed, but what you say will be treated as confidential and anonymous, and used only for this research.
- I have a few questions to help guide what we talk about.
- Let me know if you don't understand a question, and I'll rephrase it.
- We can stop for a break during the interview, if you need. Are you comfortable for now?
- Do you want to ask me any questions before we start?

Introduction

We have been testing a new way to care for people who are receiving supportive care.

Today, we want to talk to you about your experience of the case conference and about the care _____ has been receiving since the case conference was held.

1) Participation:

If yes, **What was your experience during the case conference?**

- What worked well and what would you change to improve information exchange
- A care plan was created during the case conference. What was your experience of creating a care plan and assigning responsibilities as part of the case conference process?
- What worked well and what would you change?
 - Participants
 - Structure
 - technology

If no, would you be comfortable telling me how it came about that you did not attend?

Have you thought since about whether there would have been some benefit in you attending?

2) Expectations:

- What were your expectations in regard to the case conference and _____ care?
- To what extent were your expectations of the case conference met?

3) Follow up care: Since the case conference, what changes for the better or worse have you noticed in _____ care since the case conference?

- Were there any gaps in care that were there that have been addressed?
- Have any new services or aids that _____ did not have before been commenced or supplied since the case conference?
- Are there any new gaps in care that you have noticed?

4) Other thoughts: Is there anything else you would like to say about the supportive care _____ received that is important to you?

- Have we missed anything?
- If you think of something you want to add after I've gone, you are welcome to phone or email.

Wrapping up

Would it be alright if I needed to get back to you to clarify anything you said today?

Thanks again for your time today. We appreciate your help very much.

Preamble to qualitative interview with health professional

- Thank you for giving us your time for this interview. It should take 15-20 minutes.
- We would like to talk with you about your experiences of the case conference recently completed for your patient.
- I will be recording our conversation so nothing important is missed, but what you say will be treated as confidential and anonymous, and used only for this research.
- I have a few questions to help guide what we talk about.
- Let me know if you don't understand a question, and I'll rephrase it.
- We can stop for a break during the interview, if you need. Are you comfortable for now?
- Do you want to ask me any questions before we start?

Introduction

You recently participated in a case conference for one of your patients. Today I would like to talk to you about your experience of that process.

5) Preparation: What was your experience of the preparation for the case conference?

- Tell me about the information received about the agenda and the supporting information from the other participating health professionals and whether it was adequate for negotiating a care plan for the patient?
 - Timing, participants, how to connect (via video-link/ teleconference)
- How do you think preparation could be improved for case conferences?

6) Participation: What was your experience during the case conference?

- What worked well and what would you change to improve information exchange
- What was your experience of creating a care plan and assigning responsibilities as part of the case conference process?
 - What worked well and what would you change?

7) Expectations: What were your expectations in regards to the case conference and to what extent were your expectations met?

8) Follow up care: What was your experience of patient care after the case conference?

- How did your care of the patient change?

9) Is there anything else you would like to say supportive care that is important to you?

- Have we missed anything?
- If you think of something you want to add after I've gone, you are welcome to phone or email.

Wrapping up

Would it be alright if I needed to get back to you to clarify anything you said today?

Thanks again for your time today. We appreciate your help very much.

Appendix G Patient example ‘Jane’

Hypothetical

As we hold our discussion today it might help to keep in mind Jane. Jane is 84 years old, living in a granny flat with her daughter. She has mild cognitive impairment but intact insight. She needs help with her finances. Physically she also has long-standing hypertension and had a hospitalisation with heart failure secondary to the H/T about five years ago. She gets breathless when she goes up the steps from the flat to the main house. She also has Osteo Arthritis of the right hip, and the pain of this requires her to take regular panadol osteo. This is not working particularly well and the pain disturbs her sleep. She was overweight (BMI 32 in 2012), but in the last 12 months she has lost weight and it is now BMI 27. She has stage 3b chronic kidney disease. Her appetite has reduced. She appears depressed. Since her husband died two years ago, she seems to have lost her desire to meet with friends and go to church like she used to. She wears hearing aids and has moderately dense cataracts. She is on two medicines for her hypertension, panadol osteo for arthritis, an antidepressant, and pariet for long-standing reflux. Jane is frail and has been deteriorating over some time and expectation is she will likely pass away in the next 12 months.