

Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

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Thesis submitted to the University of Nottingham

For the degree of Doctor of Philosophy

December 2020

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Abstract

Introduction

Care home residents have a short life expectancy and are more likely to have emergency admissions than people of the same age living in the community. Although such admissions may resolve crises, maintain and restore functional and relieve physical and mental distress, there is evidence that hospital admission may be burdensome or detrimental to the health of older people with severe frailty. Furthermore, admission may not reflect their wishes, or those of their families. Advance care planning is a means by which care home residents can express their health care preferences, not only regarding admission to hospital, but also their choices in relation to other aspects of their care.

I conducted a systematic review which found that some research studies showed that advance care planning for care home residents was associated with reduced hospital admissions and increased proportions dying in the care home. The evidence appeared stronger for advance care planning educational interventions than interventions delivered by specialist teams, but there was much less evidence as to whether these findings could be replicated in routine practice.

Aims

The research questions this thesis asked was whether Advance Care Plans (ACPs):

- could be implemented in unselected care homes
- were acceptable to care home residents
- were associated with reduced hospital admissions
- were associated with more residents dying in their preferred place of care.

Methods

To test this research question, a service was implemented and evaluated in Lincoln, UK. The intervention involved a multidisciplinary team trained in comprehensive geriatric assessment and the use of ACPs and led by me. The effect of this service on hospital admissions was evaluated using

a step wedge randomised control designed study, under clinical governance, using routine hospital and mortality data. The extent to which the intervention was delivered was evaluated using routine service records. A trustworthiness framework was used to justify the credibility, dependability, confirmability, transferability and authenticity of the use of field notes, multidisciplinary team meetings and diary records, and reports from residents' electronic primary care records obtained during the implementation and delivery of the service and the results of the quantitative study to formulate retrospectively a synthesis using soft systems methodology and a widely used framework for understanding service implementation, the Consolidated Framework for Implementation Research.

Results

I found that:

- Advance care planning could be implemented in 68% of care homes
- ACPs were acceptable to almost 80% of residents, similar levels to research trials
- the intervention did not lead to a reduction in hospital admissions, but rather a trend towards increased admissions
- Possession of an ACP was associated with a greater chance of dying in the care home which, for most residents, was their preferred place of care
- Residents were more likely to opt for active medical treatment while their function remained good, whereas residents with greater frailty were more likely to emphasise preference for palliative care

The synthesis illustrated that, in implementation of the project, multiple interfaces needed to be considered, including individual residents, their families, care homes and general practices, local health and social care organisations, and the wider context of a whole system experiencing increasing financial constraint and organisational change.

Discussion

This service successfully delivered ACPs alongside a comprehensive geriatric assessment, although not all care home managers co-operated. Most residents in whom ACPs were put in place opted for their preferred place of death to be the care home, and having an ACP increased the likelihood of doing so. However, hospital admissions were not reduced.

Although advance care planning is not a new concept to palliative care in the UK, most NHS staff, and the Lincolnshire population, were unfamiliar with the concept. Thus, implementation of a relatively novel concept for residents of care homes in Lincoln presented challenges.

Importantly, care home residents were able to have their choices formalised and communicated to stakeholders, including primary care and out of hours services. The failure to demonstrate a reduction in admissions was likely to reflect several factors, including residents' choice for active intervention, and lack of community services to support implementation of ACPs. However, in a climate of economic austerity, no reduction in admissions has implications for future funding and sustainability of advance care planning. The importance of proactive use of implementation science models for future implementation is proposed.

Acknowledgments

I was responsible for design and implementation of the project and leadership of the multidisciplinary team. I undertook Comprehensive Geriatric Assessments and advance care plans, reviewed all the electronic primary care records and collated and analysed the results.

I would like to acknowledge and thank the following people:

- the project team: Lindsey Mills, Donna Readman, Lesley Storey and Graham Wilson, who also undertook CGAs and advance care plans
- Adeela Usman Mohammed (AUM), who opened my eyes to the complexity of step wedge randomised cluster data analysis and who undertook statistical analysis of admission data
- The Lincoln general practitioners and their practice managers
- The care home managers, their staff, residents and families, without whose cooperation, the project could not have been implemented
- Mr Olu Adeyemi, Associate Medical Director, United Lincolnshire Hospitals Trust, and Honor Green, information analyst, who provided all the admission data
- Dr Sunil Hindocha and Sarah Jane Mills at Lincolnshire West Clinical Commissioning Group
- All the staff at St Barnabas Hospice, who were wonderfully hospitable, but especially, Drs Georgina Keenleyside and Adam Brown, Consultants in Palliative Care, and Chris Wheway, Chief Executive
- The trustees of the Bromhead Medical Charity who funded the project

I am profoundly grateful for the support from my supervisors, Professors John Gladman, Tom Dening and Adam Gordon, from whom I have learned so much. They have guided me patiently, never once showing exasperation at my naivety or pace.

Lastly, to my husband, David, whose life would have been so much easier had I never embarked on this journey, I owe an enduring debt for his belief in me and the importance of the project, and his unwavering love throughout.

in memory of

Sue Pieniak

without whom this journey would not have started

and

Josh

who taught me about the importance of choice,

and that there is still a long way to go

Glossary of abbreviations

Abbreviation		
A&E	Accident and Emergency Department	Emergency department in UK hospitals
ACP(s)	Advance Care Plan(s)	Formal statement of a person's choices for their care in the event of loss of Mental Capacity. In Lincolnshire, ACP is used for people with Mental Capacity to make decisions about their future care
AnCP(s)	Anticipatory Care Plan(s)	Form of advance care plan used in Lincolnshire for people without Mental Capacity to make decisions about their future care
ADRT	Advance Decision to Refuse Treatment	Legally binding formal document signed by an independent witness which states what treatments a person does not wish to receive in the event of loss of Mental Capacity to make decisions about care
AMED	Allied and Complimentary Medicine Database	Database produced by the British Library designed for physicians, therapists, medical researchers, historians and clinicians wishing to learn more about alternative and allied therapies and related subjects
BGS	British Geriatrics Society	Professional body of specialists in healthcare of older people in the UK
BNI	British Nursing Index	Database for support of practice, education and research for nurses, midwives and health providers in the UK
CCG	Clinical Commissioning Group	Group responsible for the commissioning of most hospital, mental health and community services in a specific geographical area
CGA	Comprehensive Geriatric Assessment	A multidisciplinary diagnostic process intended to determine a frail older person's medical, psychosocial and functional capabilities and limitations in order to develop an overall plan for treatment

CINAHL	Cumulative Index to Nursing and Allied Health Literature	Database indexing top nursing and allied health literature available including nursing journals and publications from the National League for Nursing and the American Nurses Association (EBSCO.com. accessed 4.12.2020)
CPR	Cardiopulmonary Resuscitation	Process of applying basic life support in event of cardiac or pulmonary arrest
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation	Formal document used in the UK to state that CPR should not be performed based on a person's wishes, futility, or likelihood of poor quality of life following a cardiopulmonary arrest. Although a medical decision, it should be discussed with the person concerned and family
EMBASE	<i>Excerpta Medica</i> Database	Biomedical and pharmacological bibliographic database produced by Elsevier containing published literature from more than 8,500 journals
GRADE	Grading Recommendations Assessments, Development and Evaluation working group	Working group developed in 2000, which has developed common and transparent approach to grading quality of evidence and strength of recommendations. It is now considered the standard in guideline development
GSF	Gold Standards Framework	Framework used by many general practices, care homes and hospitals in the UK to enable earlier recognition of patients with life-limiting conditions, helping them to plan to live as well as possible right to the end
IMCA	Independent Mental Capacity Advocate	Person whose role is to support and represent a person in the decision-making process, making sure that the Mental Capacity Act is being followed
LCHS	Lincolnshire Community Health Services NHS Trust	Health service organisation providing community services for the people of Lincolnshire
LECCG	Lincolnshire East Clinical Commissioning Group	Clinical Commissioning Group covering Boston, East Lindsey and part of South Holland
LSTP	Lincolnshire Sustainability and Transformation Partnership (formerly Plan)	The joining together of NHS organisations and local councils to develop proposals for improved health and care

LWCCG	Lincolnshire West Clinical Commissioning Group	Clinical Commissioning Group covering Lincoln, West Lindsey and North Kesteven
MDT	Multidisciplinary Team	The team of health care staff involved in this project comprising nurses, a physiotherapist, an occupational therapist, and a doctor
MRCP	Member of the Royal College of Physicians	Possessor of postgraduate qualification of the Royal College of Physicians designed to test the skills and knowledge of doctors training in medicine
NHS	National Health Service	Publicly funded healthcare systems in the United Kingdom
NICE	National Institute for Health and Care Excellence of Clinical Excellence	Executive non-departmental public body of the Department of Health in England which publishes guidelines in the use of health technologies within the NHS, clinical practice, guidance on health promotion and guidance for social care services and users
OPTIMISTIC	Optimising Patient Transfers, Impacting Medical Quality, Improving Symptoms, Transforming Institutional Care	An American programme funded by the Centers for Medicare and Medical Services
PARiHS	Promoting Action on Research Implementation in Health Sciences	Determinant framework proposed by Kitson et al 1998
PICOS	Participants, Intervention, Comparison, Outcomes and Studies	Mnemonic used in evidence -based practice to frame and answer a clinical or healthcare-related question. It can also be used to develop literature search strategies for systematic reviews
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses	Evidence-based minimum set of items for reporting systematic reviews and meta-analyses
PROSPERO	Prospective Register of Systematic Reviews	International database of prospectively registered systematic reviews in health and social care
PsycINFO		Database of abstracts of literature in the field of psychology produced by the American

		Psychological Association
PubMed		Free search engine accessing primarily MEDLINE database of references and abstracts on life sciences and biomedical topics. Maintained by the United States National Library of Medicine
RCT(s)	Randomised Controlled Trial(s)	Scientific experiment which aims to reduce bias, when testing a hypothesis, by randomly allocating subjects to two or more groups, which are treated differently, and their responses compared.
RECIPE	Residential Care Intervention program in the Elderly	A service based in outer metropolitan Melbourne, Australia providing expert comprehensive assessment and management by geriatricians and aged care nurse specialists to individuals living in residential care facilities who are imminent risk of requiring acute care management
	St Barnabas Hospice	An independent charity providing inpatient and community palliative care for Lincolnshire
SD	Standard deviation	Statistical term to quantify the degree of variation of a set of data
UK	United Kingdom	Sovereign realm of United Kingdom of England, Northern Ireland, Scotland and Wales
ULHT	United Lincolnshire Hospitals NHS Trust	Hospital trust providing acute care in Lincolnshire
USA	United States of America	Republic made up of 50 federal states covering part of North America and Hawaii

Chapter 1 Introduction

1.1 Introduction

People in care homes in the UK have a relatively short life expectancy; more than a quarter will die within a year (Shah et al 2013). However, they also have 40 to 50 percent more emergency admissions than the general population aged 75 and older (Smith et al 2015). Although admission to hospital might offer access to the benefits of modern medicine, those who die in hospital may spend the last days of their life in a noisy, alien environment, cared for by strangers and separated from those who love them or know them. Decisions to send care home residents to hospital instead of providing home based, conservative and palliative care may not reflect their wishes or be in their best interests: 60-70% of respondents said they would like to die at home if circumstances allowed (Gomes et al 2011). Not only may hospital admission be unwanted, futile, and hazardous for this group, they are costly (National End of Life Intelligence Network 2012). Services offering alternatives to hospital admission, therefore, might represent cost-effective interventions and could provide more choice for care home residents. Advance care planning is a potential intervention that could help.

Well-conducted scientific studies in care home residents did not implement advance care planning as part of a holistic intervention such as Comprehensive Geriatric Assessment (Molloy et al 2000; Caplan et al 2006). They showed that residents often preferred to be managed in the care home rather than be admitted, and that offering advance care planning to all residents reduced hospital admissions without increasing mortality. However, the single intervention in these trials does not reflect common clinical practice, where advance care planning is part of the wider process of health and social care. It is the translation of the research findings to advance care planning in routine practice that is crucial, if widespread implementation in routine practice is to be successful and sustainable. Therefore, this thesis asks: **Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical**

service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

To answer the thesis question requires consideration of the context: the characteristics of care home residents; the nature of the care homes in which they live; and the current pattern of healthcare use of this population. The nature of advance care planning and its role in CGA need further description to appreciate the rationale for the project which underlies this thesis.

1.2 Care homes

Care homes provide “accommodation together with nursing or personal care for persons who are or have been ill, who have or have had a mental disorder, who are disabled or infirm, or are or have been dependent on alcohol or drugs” (Department of Health 2001b). In England and Wales, care homes are registered to provide different levels of care; those which deliver solely personal care are often termed residential homes, whereas those delivering nursing care in addition to personal care are termed nursing homes, and a third group have beds for residents needing only personal care, as well as beds for residents requiring nursing care.

1.3 Care home residents

Approximately 410,000 people live in care homes registered for the care of older people in England and Wales (Competition and Markets Authority 2017). Public expenditure on adult social care of all types has been under pressure; cuts to council budgets in the past decade have resulted in reduced funding available for social care. Expenditure declined in real terms by 8% between 2009/10 and 2015/16 in England (Institute of Fiscal Studies 2017). However, the UK population is ageing; by 2050 one in four of the population will be 65 or older, and a 36% growth in persons aged 85 or greater between 2015 and 2025, from 1.5 million to 2 million is predicted (Office of National Statistics, 2019). The combination of an ageing population, more care provided at home and diminishing social

care resources, is likely to result in an increasingly frail care home population, with limited life expectancy.

1.3.1 Prognosis of care home residents

The overall prognosis of care home residents is poor. Shah et al reported a one-year mortality rate of 26.2% in care home residents in England and Wales compared with 3.3% in community residents.

The prognosis of care home residents was by no means uniform, however; standardised mortality ratios were 419 for nursing home residents and 284 for residential home residents (Shah et al 2013).

The overall rates were similar to other studies (Dale et al 2001; McCann et al 2009). In Shah's study, people with a diagnosis of dementia in nursing and residential homes had lower standardised mortality rates of 309 and 218 respectively, whereas care home residents taking more classes of medication, or having more primary care contacts had higher mortality rates (Shah et al 2013).

Another paper reported the median time from admission to a care home to death in England was 462 days (15 months), but 27% lived for more than three years (Forder and Fernandez 2011). An

American study (Kelly et al 2010) showed that the median length of stay in a nursing home was five months, with 65% dying in the first year. The same paper reported a gender difference, with men having a median survival of three months. A clearer picture of prognostic indicators in care home residents is emerging from the literature suggesting that clinical instability, related to frailty, rather than age, is the most important factor (Hirdes et al 2003; Shah et al 2013).

Despite the changes faced by care homes, it is incontrovertible that most care home residents are in the last years of life, during which time their health will deteriorate, so their choice of healthcare, and where they receive it, is pertinent.

1.3.2 Healthcare for care home residents

Care home residents have high levels of frailty and dependency (Gordon et al 2014). In the UK in recent years, there have been innovative health care initiatives for care home residents, such as the NHS Care Home Vanguard (NHS England 2016). By the end of the NHS Care Home Vanguard project in participating care homes, residents had weekly access to multidisciplinary teams, and

there were NHS appointed clinical champions (personal correspondence Gordon 2020). Prior to the advent of the Covid pandemic, NHS England was preparing to implement the early phases of its enhanced health in care homes strategy, which advocates wholesale revision of care to include person-centred change, integration, and joint working of the care home sector with health, local government, community and voluntary sectors (NHS England 2016).

However, at the inception of this project, the prevailing mode of healthcare delivery for care home residents was as part of the General Medical Services contract with general practitioners working together with community health services. This system has managed the (predictable) health crises of care home residents reactively, and up to 75% are admitted to hospital each year (Vossius et al 2013).

Whilst admission to hospital might resolve crises, hospital outcomes for care home residents are very poor (Dwyer et al 2014). Dwyer's systematic review reported higher rates of investigation and intervention than for community dwelling older people. They also experienced more in hospital complications, such as pressure damage, than their community dwelling counterparts, high rates of delirium, a threefold increase in hospital acquired infection, increased antibiotic resistance and further functional decline. Residents with pre-existing cognitive impairment, fractured hip, stroke, and septicaemia were particularly vulnerable to functional decline as measured by the minimum data set activity of daily living score (Dwyer et al 2014).

In addition, mortality in this group was higher than those admitted from the community. Between 1% and 5% died in the emergency department, and between 5% and 34% died in hospital, most within the first week of admission, and up to half in the first 3 days. Death following discharge from hospital was also high with up to 52% dying within three months of acute hospital admission (Dwyer et al 2014).

Thus, although acute hospital admission maybe important for management of crises and may confer health gain following CGA or rehabilitation, it is associated with poor outcomes. With increasing

frailty, increasing risks associated with hospitalisation may not justify diminishing benefits.

Furthermore, decisions to send residents to hospital instead of providing home-based, conservative, and palliative care may not reflect their wishes, or be in their best interests. There is an important and growing qualitative literature about the preferences and experiences of older people and their families relating to health outcomes at the end of life. Despite the preference of many older people to die at home if circumstances allowed (Musa et al 2015), the reality is that not everyone has that opportunity; a substantial proportion of care home residents die in hospital (Gomes et al 2011) and not all those who die at home have a “good” death (Pollock 2015). Reality, therefore, may not match aspiration, and so what solutions might offer better care and increase the opportunity to die in the preferred place of care for care home residents?

1.4 Proposed solutions

1.4.1 Advance care planning

Advance care planning enables people to state their preferences for care in the event of deterioration in health. These preferences may range from avoidance of intervention and hospitalisation to access to hospital in all circumstances. Advance care planning is now widely recognised as good practice and there is a body of research evidence demonstrating the benefits of advance care planning for care home residents, which is discussed in the systematic review in Chapter 2. There is a discrepancy however, between what happens to people at the end of life, and their choice of care at the end of life and place of death. As stated in Section 1.1, it is important to know whether the findings from well-controlled research studies and small-scale service interventions can be replicated in everyday practice, and what challenges arise from large-scale implementation.

The term advance care planning has been used to describe processes of varying complexity and formality. These have included single issues, such as tube feeding or cardiopulmonary resuscitation, in which case the term advance directive is often used; discussion of a person’s wishes, but no

documentation; Advance Decision to Refuse Treatment (ADRT) when a person wishes a legally binding document refusing a specific intervention, and complex ACPs involving a formal process of discussion and documentation of complex choices for care in the event of deteriorating health. In this thesis I have used the term ACP to describe the latter, to distinguish it from an advance directive or an ADRT.

In my clinical role as a liaison psychiatrist, I have assessed many care home residents admitted to hospital, often in the last days of life, who did not appear to benefit from investigation and intervention, however well-meaning. The distress I witnessed led me to question whether the best interests of these patients were being served, and whether there might be alternatives to hospital care. I discovered that my observations resonated with a large literature on this subject. The seminal paper which inspired me to set up services for care home residents in Boston, UK, and later in Lincoln UK, and to embark on this thesis was published by Molloy and his colleagues (2000). This group undertook a randomized controlled trial of residents in Canadian nursing homes which implemented an advance directive system, Let Me Decide (Molloy and Mepham 1992). Healthcare use was lower in the intervention group than the control group, with significantly fewer residents from the intervention homes being hospitalised. A later controlled study in Australia (Caplan et al 2006) and service evaluations in the UK (Garden et al 2016) and Ireland (O'Sullivan et al 2016) also reported a reduction in admissions to hospital and reduced healthcare use associated with advance care planning for residents of care homes. These studies are described in greater detail in the next chapter which reports the results of a literature review on the evidence for Advance Care Plans (ACPs) impacting on health care use in care home residents.

1.4.2 Optimal care

Optimal care for care home residents should be holistic, that is comprehensive assessment and management of multiple health conditions. Comprehensive Geriatric Assessment (CGA) offers such a process. It is defined as a multidisciplinary diagnostic process intended to determine a frail older person's medical, psychosocial, and functional capabilities and limitations in order to develop an

overall plan for treatment (Rubenstein et al 1989). Importantly, CGA places the patient and their supporters at the heart of care. As part of this, the term psychosocial is expanded to specify psychological, socioeconomic, and environmental issues, which affirms the importance of a multi-agency partnership. Optimisation emphasises the potential for improvement, and patient-centred escalation plans acknowledge the inevitability of future crises.

Given the nature of the care home population, application of CGA to the care home setting was a logical development. Gordon's doctoral thesis "Does Comprehensive Geriatric Assessment (CGA) have a role in UK Care Homes" (Gordon 2012) concluded that there was a role for CGA in UK care homes, but there were caveats. Delivery was sparse across the UK; there was substantial variability amongst care homes and care home residents; different delivery models might equally well accomplish the goals of CGA; and further research was required to establish which healthcare models deliver the best outcomes. Since then a realist review of the role of CGA in care homes has been published. The review concluded that the evidence indicated a multidisciplinary team was required to deliver core components of CGA, which included a structured or standardised approach to assessment, followed by communication within a multidisciplinary team and coordination of care delivery activities (Chadborn et al 2019).

1.4.3 Relevance to healthcare systems

In the UK currently, and in many other health systems, costs, affordability, and cost-effectiveness are important. A large proportion of the NHS budget is spent on acute hospital care (Office of National Statistics 2020). A reduction in admissions, resulting from advance care planning, together with possible benefits for end of life care, might justify the cost of advance care planning interventions. Therefore, the question of whether research findings can be put into practice as part of usual care is important.

1.5 Research question

Thus, there existed a research evidence-base for advance care planning, and a vehicle, CGA, in which to deliver advance care planning. However, what I wished to examine is whether this project could deliver similar results to the research studies in routine practice.

Currently, in the UK, costs, affordability, and cost-effectiveness are important, as is reducing admissions to hospitals. Therefore, although reducing admissions may or may not be a consequence of better end of life care, doing so will help justify the costs of advance care planning.

Therefore, the research question this thesis examines is “Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment?”

In this thesis I:

- review the evidence base of studies that have shown ACPs to be effective
- discuss why the findings of these experimental studies may not translate to usual practice
- describe a new service providing ACPs (alongside optimising care using a CGA-inspired process)
- present the methods, methodology and results of a service evaluation of this new service
- critique the findings in the light of implementation theory
- conclude by drawing lessons about how the benefits of ACPs, as seen in experimental studies, could be realised in usual care

The outcomes of this project would be measured by:

- the extent of participation of unselected care homes
- the acceptability of advance care planning to care home residents
- a reduction in healthcare use associated with ACPs
- residents with advance care plans dying in their preferred place of care

The thesis plan is summarised in Table 1.1.

Table 1.1 Thesis plan

Chapter 1 Introduction	Introduction of research question <ul style="list-style-type: none"> • Definition of research question and objective
Chapter 2 Systematic review	Rationale for literature review Application of ACP to frail older people Effect of ACP on: <ul style="list-style-type: none"> • healthcare use • place of death
Chapter 3 Intervention	ACP as an intervention in routine practice Proposal of intervention Justification for intervention Research questions about implementation
Chapter 4 Implementation methods	Methodology <ul style="list-style-type: none"> • service evaluation designs • implementation science Methods <ul style="list-style-type: none"> • Lincoln care home project implementation • Healthcare & place of death measurement • Application of Soft Systems Methodology and the CFIR
Chapter 5 Results of service evaluation	Baseline outcomes Results of healthcare use Results of place of death
Chapter 6 Implementation science	Comparison with research methodologies Analysis of results with reference to: <ul style="list-style-type: none"> • Soft Systems Methodology • The Consolidated Framework for Implementation Research
Chapter 7 Discussion	Summary of principle findings Strengths and limitations Relationship between findings and context Relevance of findings to stakeholders

1.6 Summary

The research question this thesis examines is “Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale

clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment?”

This chapter has set out the background to the study presented in this thesis and has stated the main research question in the previous section. In summary, the purpose of this service evaluation was to establish whether:

- advance care planning, shown to be effective in reducing healthcare use in research studies, can be implemented as part of a routine service in the UK for care home residents
- observed outcomes of ACPs embedded in a routine service are compatible with outcomes reported in the research trials of ACPs in care home residents
- deficiencies or challenges arise in implementation of advance care planning on a large scale

In summary, the research in this thesis sought to address the research question by means of providing a new service in care homes to promote optimal care and advance care planning. The evaluation of implementing this service forms the core of this thesis.

Chapter 2 Systematic review

2.1 Introduction

The justification for the thesis question is outlined in Chapter 1. Two well-controlled research studies and two service evaluations were quoted, but the wider evidence for the benefits of advance care planning on the healthcare use and place of death of care home residents warranted further review to establish exactly what remained unknown, and what I would hope to replicate.

2.1.1 Rationale

Although there have been several research studies, and three reviews of the effects of ACPs, to set the backdrop for my research, it was necessary to review the relevant literature, with reference to findings that were relevant to my research question.

2.1.2 Objectives

The objectives of this systematic review were to examine whether there is evidence from randomised controlled trials and other published studies that advance care planning for care home residents was associated with more people dying in their preferred place and that hospital admissions were reduced.

2.2 Methods

The PRISMA checklist was used to structure this systematic review (Moher et al 2009). This review was not published or registered. In the event of being unable to perform a meta-analysis, it was intended to do a synthesis without meta-analysis (SWiM) (Campbell et al 2020).

2.2.1 Eligibility criteria

The acronym PICOS (Participants, Intervention, Comparisons, Outcomes, Study design) was used to define eligibility criteria. All citations fulfilling the following inclusion and exclusion criteria were eligible for scrutiny and inclusion in the review:

Inclusion criteria:

- Studies reporting on the outcome of advance care planning or equivalent intervention (I) in care home residents (P) with respect to healthcare use (O)
- Studies published in English
- Studies with a group comparison (C), including parallel randomised groups, parallel non-randomised groups, and pre-post intervention studies where there was a historical comparison (S)
- Studies published in peer reviewed journals
- Systematic reviews reporting the effects of advance care planning

Exclusion criteria:

- Studies based on advance directives for single interventions e.g. tube feeding

2.2.2 Information sources and search strategy

I searched the electronic databases, AMED, BNI, CINAHL, EMBASE, Medline, Pub Med and PsychINFO until July 2020.

To refine the search for studies, I identified search headings most closely related to the subject using **Medical Subject Headings**, the system used by MEDLINE and PubMed, and EMTREE, the thesaurus used for EMBASE. The search terms were applied to both title and abstract.

Care homes are described variously in the literature: The following are MeSH and EMTREE terms:

Residential home, Nursing home, Residential facilities, Long term care and Residential care. For this literature review, all the above terms were included if residents were living in accommodation where they were in receipt of 24-hour care. Studies examining residents of sheltered accommodation, or warden-controlled accommodation, were not searched for.

The term Advance Care Plan is included in the MeSH and EMTREE thesaurus and is widely used across the world, but other terms can be used synonymously such as “anticipatory care plan”, “escalation plan”, “palliative care plan”, “end of life care plan” and “treatment escalation plan”. The MeSH and EMTREE headings for ACP also include “advance directives” and “living wills”.

2.2.3 Search strategy

2.2.3.1 *Data management*

Electronic copies of papers were stored on my computer and paper copies printed, which together with other paper articles were filed alphabetically.

2.2.3.2 *Selection process and data collection process*

I conducted the selection process and read abstracts of citations yielded from the electronic search. Of those which might meet the inclusion criteria, complete citations were obtained electronically, or paper articles requested from the professional library at Lincoln County Hospital. All complete citations were scrutinised, and citations not meeting the eligibility criteria discarded. The remaining studies were included in this systematic review. I conducted the data collection. I did not have an independent collector.

2.2.4 Data items

The data items were:

- Care home residents (participants)
- Advance care planning (intervention)
- Control groups or pre-intervention period (comparisons)
- Healthcare use (outcomes)
- Randomised controlled trials, non-randomised controlled trials and pre-post intervention studies (study design)

2.2.5 Outcomes and prioritisation

My research question was: Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment? The question states a clear intervention: advance care planning conducted as part of CGA. The benefits, or outcomes, require greater clarification and encompass:

- whether the choices made by care home residents and their families about place of care and place of death can be fulfilled by advance care planning delivered in routine practice
- whether these preferences affect healthcare and overall resource use.

2.3 Data synthesis

A table was drawn up to collect papers to be reviewed containing the first author’s name, year, location of study, aims, study methodology and GRADE (discussed in section 2.5), sample size, study duration and follow-up period, intervention carried out and outcomes.

To enable quantitative synthesis and exploration of consistency, using the methods recommended by Ryan et al (2016), I prepared data extraction templates for hospital admissions, hospital bed days and deaths. Separate templates were prepared for RCT and pre-post intervention studies to enable pooling of data where possible. I planned to conduct additional analyses, such as sensitivity and subgroup analysis, if indicated.

If meta-analysis were impossible, I would undertake a Synthesis without meta-analysis (SWiM). This is a nine-item checklist developed using a best practice approach which involved extensive consultation and formal consensus (Campbell et al 2020). Table 2.1 illustrates the checklist.

Table 2.1 Synthesis without meta-analysis checklist

<p>1. Grouping studies for synthesis:</p> <p>a) Provide a description of, and rationale for, the groups used in the synthesis (e.g., groupings of populations, interventions, outcomes, study design)</p> <p>b) Detail and provide rationale for any changes made subsequent to the protocol in the groups used in the synthesis</p>
<p>2. Describe the standardised metric and transformation methods used: describe the standardised metric for each outcome. Explain why the metric(s) was chosen and describe any</p>

methods used to transform the intervention effects, as reported in the study, to the standardised metric, citing any methodological guidance consulted

3. Describe the synthesis methods: describe and justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates

4. Criteria used to prioritise results for summary and synthesis: where applicable, provide the criteria used, with supporting justification, to select the particular studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (e.g. based on study design, risk of bias assessments, directness in relation to the review question)

5. Investigation of heterogeneity in reported effects: state the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity

6. Certainty of evidence: describe the methods used to assess the certainty of the synthesis findings

7. Data presentation methods: describe the graphical and tabular methods used to present the effects (e.g. tables, forest plots, harvest plots) Specify key study characteristics (e.g. study design, risk of bias) used to order the studies, in the text and any tables or graphs, clearly referencing the studies included

8. Reporting results: for each comparison and outcome, provide a description of the synthesised findings and the certainty of the findings. Describe the result in language that is consistent with the question the synthesis addresses, and indicate which studies contribute to the synthesis

9. Discussion: limitations of the synthesis. Report the limitations of the synthesis methods used and/or the groupings used in the synthesis and how these affect the conclusions that can be drawn in relation to the original review question

2.4 Meta-analysis

I planned to undertake a meta-analysis if the studies identified by the search were suitable. To undertake a meta-analysis, more than one adequately controlled trial would be required with similar interventions and outcomes presented in the same way, from which effect sizes could be calculated and combined.

2.5 Confidence in cumulative evidence

The GRADE working group (2004) has devised a grading system used by international bodies including the Cochrane Collaboration and NICE. The system for down and upgrading papers is detailed in Tables 2.2 and 2.3 (Higgins and Green 2011). The following principles apply:

- randomised controlled trials without important limitations provide high quality evidence
- observational studies without special strengths or important limitations provide low quality evidence
- limitations or special strengths can modify the quality of evidence of both randomised trials and observational studies
- non-randomised experimental trials without important limitations can also provide high quality evidence but are automatically downgraded because of limitation in design such as lack of concealment of allocation
- observational studies only investigate patients exposed to the intervention
- case studies and case reports are observational studies that investigate only patients exposed to an intervention. Since the source of the control group is unclear, they usually are downgraded from low to very low-quality evidence

Table 2.2 Levels of quality of a body of evidence in the GRADE approach

Underlying Methodology	Quality Rating
Randomised trials or double-upgraded observational studies	High
Downgraded randomized trials or upgraded observational studies	Moderate
Double-downgraded randomized trials or observational studies	Low
Triple-downgraded randomised trials or downgraded observational studies	Very low

Table 2.3 Factors that may increase or decrease the quality level of a body of evidence

D E C R E A S E	Limitations in the design & implementation of available studies suggesting high likelihood of bias
	Indirectness of evidence (indirect population, intervention, control, or outcomes)
	Unexplained heterogeneity or inconsistency of results (including problems with subgroup analysis)
	Imprecision of results (wide confidence intervals)
	High probability of publication bias
I N C R E A S E	Large effect
	Dose-response
	All plausible residual confounding would reduce the demonstrated effect or would suggest a spurious effect if no effect was observed

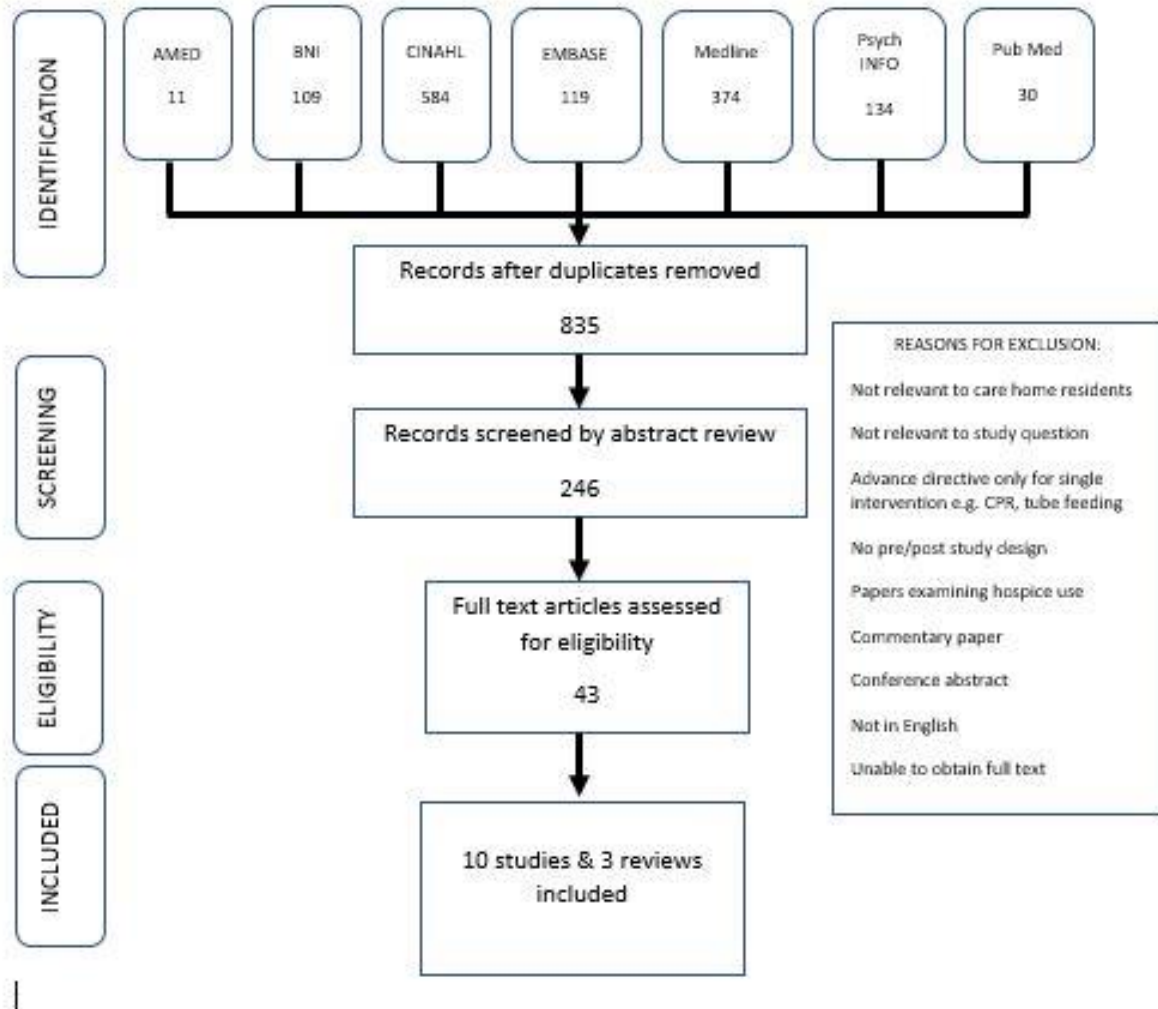
2.6 Results

2.6.1 Study selection

The process of study selection is illustrated in Figure 2.1. The electronic search of advance care planning in care home residents yielded a total of 24,181 citations for advance care planning or equivalent search terms and 347,543 citations for care homes or equivalent terms from all the databases searched. The number of citations containing both terms in the title or the abstract was 1,362. This number contained 527 duplicates. The abstracts of 835 citations yielded from the electronic search were all read, of which 43 were relevant to my review question. A further 31

citations were discarded as they did not meet the eligibility criteria. Ten studies and three systematic reviews met criteria to be included in the systematic review.

Figure 2.1 Study selection process



2.6.2 Quality appraisal and risk of bias within studies

Using the GRADE criteria (Higgins and Green 2011), I examined the eligible studies individually for limitations or bias in study design; inconsistency or heterogeneity; indirectness; imprecision in the number of events, participants and confidence intervals; publication bias and quality. These findings are illustrated in Table 2.4.

Table 2.4 Evaluation of Studies using the GRADE criteria

Authors	Limitations	Inconsistency	Indirectness	Imprecision	Publication Bias	Quality
Molloy et al 2000	Moderate	Little or no	Little or no	Little or no	No	Moderate
Morrison et al 2005	Moderate	Little or no	Little or no	Little or no	No	Moderate
Caplan et al 2006	Minor	Little or no	Little or no	Little or no	No	Moderate
Levy et al 2008	Moderate	Little or no	Little or no	Little or no	No	Low
Finucane et al 2013	Serious	Little or no	Little or no	Little or no	No	Low
Livingston et al 2013	Serious	Little or no	Little or no	Little or no	No	Low
Harvey et al 2014	Minor	Little or no	Little or no	Little or no	No	Moderate
Garden et al 2016	Serious	Little or no	Little or no	Little or no	No	Low
O’Sullivan et al 2016	Serious	Little or no	Little or no	Little or no	No	Low
Hickman et al 2018	Moderate	Little or no	Little or no	Little or no	No	Moderate

2.6.3 Study characteristics

2.6.3.1 Participants

The participants in all studies were care home residents with considerable variation in both the number of care home residents (range 72 -1482) and the number of care homes (range 1-121/unspecified). The study with the smallest sample was of 72 residents from one care home (Levy et al 2008), whilst the sample in Hickman’s study (2019) was the largest, involving 1482 nursing home residents from nineteen care homes. Two papers examined only the outcomes for those who died (Levy et al 2008; Finucane et al 2013). One paper reported only on care home residents with dementia (Livingston et al 2013).

The study participants appear to have been a heterogeneous group in terms of medical stability and thus future risk of hospitalisation and death during follow-up. Morrison's study looked at newly admitted residents to a long-term skilled nursing facility (Morrison et al 2005), but there was no specification of whether they were admitted from hospital, home or another care home. Harvey et al (2014) examined care home residents discharged from hospital to a care home. In other studies residents identified as being at high risk of death were included (Levy et al 2008), whereas Hickman's study (2019) only included residents admitted a minimum of 100 days.

2.6.3.2 Care home settings

Seven studies reviewed described the establishments their subjects lived in as nursing homes (Molloy et al 2000; Morrison et al 2005; Caplan et al 2006; Levy et al 2008; Finucane et al 2013; Livingston et al 2013; O'Sullivan et al 2016). One study used the term "long-stay nursing facility" (Hickman et al 2019); an Australian study used the term "residential facility" (Harvey et al 2014), and one UK service was delivered to residents of both nursing and residential homes (Garden et al 2016). The nursing homes in the Scottish study (Finucane et al 2013) had participated in the Gold Standards Framework (GSF) Care Home project (National GSF Centre 2017), and the London study was conducted in a well-staffed, single, large nursing home with weekly GP on-site clinics (Livingston et al 2013).

2.6.3.3 Intervention

Advance Care Plans were the intervention in all ten studies. Three studies used the same "Let Me Decide" ACP program (Molloy et al 2000; Caplan et al 2006; O'Sullivan et al 2016). Complex ACPs were used in five other studies (Morrison et al 2005, Livingston et al 2013; Finucane et al 2013; Garden et al 2016; Hickman et al 2019). The ACP intervention used in Harvey's study (2014) was part of comprehensive geriatric assessment but the format of ACPs was not described.

2.6.3.4 Comparisons

Five studies used control groups for comparison (Molloy et al 2000; Morrison et al 2005; Caplan et al 2006; Livingston et al 2013 and Harvey et al 2014). Four studies used the pre-intervention period as

a comparator (Levy et al 2008; Garden et al 2016; O’Sullivan et al 2016; Hickman et al 2019). One paper had no comparator (Finucane et al 2013).

2.6.3.5 Study design and follow up

Three studies were RCTs (Molloy et al 2000; Morrison et al 2005; Harvey et al 2014); one was a controlled trial (Caplan et al 2006); one was a non-randomised mixed methods study (Livingston et al 2013); one was a retrospective chart review pre/post intervention (Levy et al 2008); one was a pre-post non-randomised cohort study (Hickman et al 2019) and three were service evaluations (Finucane et al 2013; Garden et al 2016; O’Sullivan et al 2016). Table 2.5 illustrates the study characteristics.

Table 2.5 Study characteristics

Authors, year & origin	PICOS
Molloy et al 2000 Canada	Participants: 1133 residents in 6 match-paired nursing homes Intervention: “Let Me Decide” education programme delivered by nurses to care home staff, residents & families Comparisons: 527 intervention, 602 control residents Outcomes: admissions reduced Study design: RCT with 18-month follow up
Morrison et al 2005 USA	Participants: 139 nursing home residents Intervention: implementation of ACP Comparisons: 43 residents received intervention; 96 control residents Outcomes: admissions reduced Study Design: RCT with 6-month follow up
Caplan et al 2006 Australia	Participants: 34 nursing homes Intervention: “Let Me Decide” ACP Training by Clinical Nurse Specialists for care home carers, residents, and their families Comparators: 21 nursing homes in intervention group; 13 nursing homes in control group Outcomes: admissions reduced Study Design: controlled trial with 36- month follow up
Levy et al 2008 USA	Participants: 72 residents in one nursing home Intervention: ACP intervention, Making Advance Planning a Priority Comparisons: before and after intervention Outcomes: no reduction in hospital days but reduction in hospital deaths Study Design: retrospective chart review pre-post intervention with 18-month follow up
Livingston et al 2013 UK	Participants: residents with dementia in one nursing home Intervention: ten session manualised interactive staff training programme Comparisons: deaths in nursing home v hospital Outcomes: hospital days reduced; deaths in care home increased Study Design: non-randomised mixed methods with 12-month follow up

Finucane et al 2013 UK	Participants: residents in 7 nursing homes Intervention: training from palliative care nurses Comparisons: deaths in nursing home v hospital Outcomes: overall increase in hospital deaths Study Design: retrospective mixed methods service evaluation with 12-month follow up
Harvey et al 2014 Australia	Participants: 116 residential care facility residents Intervention: geriatric-led supported discharge service Comparisons: 57 residents receiving intervention v 59 controls Outcomes: no significant change in hospital bed days Study Design: RCT with 6-month follow up
Garden et al 2016 UK	Participants: 107 residents in 7 care homes with 283 places Intervention: ACP intervention delivered by specialist nurses Comparisons: pre-intervention v post-intervention admissions to hospital Outcomes: admissions reduced Study Design: pre-post intervention service evaluation with 36-month follow up
O’Sullivan et al 2017 Ireland	Participants: 304 residents in 3 nursing homes Intervention: “Let Me Decide” ACP training programme delivered by senior nurses Comparisons: pre-intervention v post-intervention admissions to hospital Outcomes: admissions reduced; decrease in hospital bed days; increase in length of stay; decrease in hospital deaths Study Design: pre-post intervention service evaluation with 24-month follow up
Hickman et al 2019 USA	Participants: 1482 residents in long-stay nursing facilities Intervention: ACP intervention delivered by specialist nurses Comparisons: pre-intervention v post-intervention admissions to hospital Outcomes: no significant change in admissions Study Design: non-randomised cohort study with 12-month follow up

2.7 Results of individual studies

2.7.1 Overall outcomes

The outcomes measured included number of hospitalisations and place of death, and the main findings are summarised in Table 2.6.

Table 2.6 Study outcomes

Study	Outcomes
Molloy et al 2000	Admissions reduced Hospital days reduced
Morrison et al 2005	Admissions reduced
Caplan et al 2006	Admissions reduced Hospital days reduced 100% residents died in their preferred place of death

Levy et al 2008	No change in hospital days Reduction in deaths in hospital
Livingston et al 2013	Hospital days reduced Deaths in care home increased
Finucane et al 2013	Overall increase in hospital deaths
Harvey et al 2014	No significant change in hospital days
Garden et al 2016	Admissions reduced 98.5% died in their preferred place of care, which was the care home
O’Sullivan et al 2016	Admissions reduced Decrease in hospital bed days Increase in length of stay Decrease in hospital deaths
Hickman et al 2019	No significant change in admissions

2.7.2 Hospital admissions

The Molloy (2000) and Caplan (2006) studies both reported significant reductions in hospital admissions in their intervention groups. Molloy performed an inception cohort parallel group RCT (Molloy et al 2000), whereas Caplan used a parallel geographical control method comparing admission rates between geographical control areas during a one-year period (Caplan et al 2006). However, Caplan did not specify the number of residents. Close interpretation of the results reveals that the numbers of residents in the two geographical areas varied over time periods, and the size of the control group must have increased over the follow up period. This observation means that there are other possible explanations for difference in admission rates between the intervention and study groups than the use of ACPs alone. This was not explained in the paper.

As noted in 2.3, the studies also reported different periods of follow up. To enable comparison, I calculated the mean differences in admission during 2001-2 and 2002-3 from Caplan’s study (0.12 admissions avoided/resident/12 months) and then multiplied this by 1.5 to produce a mean difference of 0.19 admissions avoided/resident/18 months. This is very close to 0.2 admissions avoided/resident/18 months seen in Molloy’s study (2000). The confidence intervals for these studies were not reported. Of note is a greater effect with time with the follow up period in Caplan’s study (2006) being twice the length in Molloy’s study (2000).

It is harder to interpret the findings of Morrison's study (2005) because of various methodological problems. These included resignation of one of the social work team leading to removal of some residents, different intervention and control group sizes, and lack of pair-match randomisation, as in Molloy's study (2000), resulting in baseline differences. It is not possible to calculate a comparable rate from this study, although the proportion of residents having one or more admissions during the six-month follow-up period was reported to be 11% lower in the intervention group. The unreliability and incomparability of the results meant that speculation as to the efficacy of Morrison's study, in relation to those of Molloy and Caplan, was unwise.

Harvey's study (2014) did not demonstrate any reduction in admissions, but the intervention differed from that in Molloy's (2000) and Caplan's (2006) studies in that an outreach team was part of the intervention. The results of this study may be incompatible for several reasons, including insufficient follow-up, use of different cohorts or a different intervention package. The follow up period, at just six months, was short and so this finding may have reflected insufficient time for the intervention to be embedded. Incorporation of an outreach team was a more complex intervention than advance care planning alone and may have negated the effect of ACPs. Table 2.7 summarises the findings of the controlled trials.

Table 2.7 Controlled trials analysis for hospital admissions

Study	Eligible Participants		Follow-up period	Admissions Intervention group	Admissions Control Group	Diff
	Intervention	Control				
Molloy et al 2000	527	672	18 months	143 admissions 0.27/resident/18 months Rate: 0.18/resident/12 months	290 admissions 0.48/resident/18 months Rate: 0.32/resident/12 months	Difference: 0.21/resident 0.14 admissions/resident
Morrison et al 2005	43	96	6 months	7 (16%) had one or more admissions	26 (27%) had one or more admissions	Total number of admissions
Caplan et al 2006	1344	523	Three periods of 12 months: 2001-2 2002-3 2003-4	2001-2: 1393 admissions Rate: 1.036/resident/12 months 2002-3: 1198 admissions Rate: 0.891/resident/12 months 2003-4: 1163 admissions Rate: 0.865/resident/12 months	2001-2: 569 admissions Rate: 1.088/resident/12 months 2002-3: 645 admissions Rate: 1.088/resident/12 months 2003-4: 656 admissions Rate: 1.254/resident/12 months	Relative risk of admission 2001-2: 0.99 (95% CI 0.95-1.030) Difference 0.052/resident 2002-3: 0.94 (95% CI 0.9-0.98) Difference: 0.197/resident 2003-4: 0.89 (95% CI 0.85 -0.93) () Difference: 0.389/resident
Harvey et al 2014	57	59	6 months	Readmission rate: 22/6 months 0.39/6 months	Readmission rate: 20/6 months 0.34/ 6 months	Calculated difference: Proportion having one or 0.05/6 months

The two pre-post intervention service evaluations reporting hospital admission reported falls of between 0.13 (O'Sullivan et al 2016) and 0.33 (Garden et al 2016) admissions per resident/12 months. Although these were not RCTs, the results of the former compare closely to the results of Molloy's and Caplan's studies, and both reported a fall in admissions associated with an ACP intervention. It should be noted that the baseline admission rate for residents was much higher in the British study than the Irish study, which may reflect different care home and healthcare provision. O'Sullivan's study was conducted in nursing homes whereas Garden's study included residential homes, which may have less capability to care for ill residents. Table 2.8 summarises the findings of the pre/post-intervention studies.

2.7.3 Hospital bed days

Five of the ten studies reviewed reported hospital bed days (Molloy et al 2000; Caplan et al 2006; Levy et al 2008; Harvey et al 2014; O'Sullivan et al 2016). The data extraction results of hospital bed days are illustrated in tables 2.9 and 2.10. The Molloy and Caplan studies suggest that between 2 to 7 hospital bed days can be saved per resident per annum. Although of poorer study design, the reduction of 1.84 days/resident per annum reported in Levy's study (2008) is comparable. A service evaluation reported a much smaller reduction in hospital bed days of 0.74 bed days/per resident per annum (O'Sullivan et al 2016). The discrepancy between the results of the research studies and the service evaluation may indicate that advance care planning has less effect when implemented in an uncontrolled setting. Another study reported no significant change in of hospital bed days (Harvey et al 2014). The follow-up period for this study was six months and so may have been too short to demonstrate an effect. Alternatively, it is possible that embedding advance care planning in an outreach service may have altered the impact on hospital admissions.

Table 2.8 Pre-post intervention study analysis for hospital admissions

Study	Eligible Participants	Follow up period	Pre-intervention group	Post-intervention	Difference
Garden et al 2016	283	36 months	202 admissions/12 months	Year 1: 138 admissions/12 months Year 2: 92 admissions/12 months Year 3: 92 admissions/12 months	Year 1: -0.22 admissions/resident/12 months Years 2 & 3: -0.33 admissions/resident/12 months
O'Sullivan et al 2016	287/301	24 months	80 admissions/12 months	44 admissions/12 months	-0.13 admissions/resident/12 months

Table 2.9 Controlled trial analysis for hospital bed days

Study	Care home places		Follow up	Intervention group	Control Group	Difference
	Intervention	Control				
Molloy et al 2000	527	606	18 months	1378 days mean 2.61/resident/18 months	3551 days mean 5.85/resident/18 months	Calculated difference: -3.24 days/resident/18 months (p=0.01)
Caplan et al 2006	1344	523	36 months	2001-2: 8878 days 6.61/nursing home bed/12 months 2002-3: 7730 days 5.57/nursing home bed/12 months 2003-4: 7,707 days 5.73/nursing home bed/12 months	2001-2: 5284 days 10.10/nursing home bed/12 months 2002-3: 5669 days 10.84/nursing home bed/12 months 2003-4: 6671 days 12.76/nursing home bed/12 months	Calculated differences: 2001-2: 0.87 -3.49 days/nursing home bed/12 months 2002-3: 0.80 -5.31 days/nursing home bed/12 months 2003-4: 0.74 -7.03 days/nursing home bed/12 months
Harvey et al 2014	57	59	6 months	271 days mean 4.8/resident/6 months	372 days mean 6.3/resident/6 months	Calculated difference: -1.5 days/resident/6 months (p=0.55) -3.0 days/resident/12 months

Table 2.10 Pre-post intervention study analysis for hospital bed days

Study	Eligible Participants	Follow up period	Pre-intervention	Post-intervention	Difference
Levy et al 2008	27/45	12 months	N=27: 139.6 days/12 months	N=45: 149.9 days/12 months	-1.84 days/resident/12 months
O'Sullivan et al 2016	287/301	24 months	561.2 days/12 months	399. days/12 months	- 0.74 days/resident/12 months

2.7.4 Place of death

Place of death was an outcome measure in six studies (Caplan et al 2006; Levy et al 2008; Livingston et al 2013; Finucane et al 2013; Garden et al 2016; O'Sullivan et al 2016). Numbers of residents dying in nursing homes increased by 39.3% ($p < 0.0001$) in the American Study (Levy et al 2008) and 29% ($p < 0.02$) in the Livingston study (Livingston et al 2013). Conversely Finucane et al (2013) reported an 8% decrease in care home deaths, although there was also a 4% reduction in inappropriate hospital deaths. Of note in Finucane's study was that 63% of the deaths were in people expected to live for months or years. Caplan (2006) reported 100% of deaths to be in the preferred place of death after implementation of the ACP program. The service evaluation from Ireland reported a reduction in hospital deaths from 22.9% to 8.4% (O'Sullivan et al 2026) but did not specify that the care home was the preferred place of death. Of 102 residents with ACPs in the Boston service evaluation 98 (96%) residents chose the care home as the preferred place of death. Of the 68 residents who died in the follow up period, all but one (98.5%) died in their preferred place of care, which was the care home (Garden et al 2016).

Table 2.11 Pre-post intervention study analysis for hospital deaths

Study	Eligible Participants	Follow up period	Pre-intervention group	Post-intervention
Levy et al 2008	27/45	12 months	N=27 13 hospital deaths	N=45 4 hospital deaths
O'Sullivan et al 2016	218/166	24 months	8 hospital deaths/ 12 months	7 hospital deaths/ 12 months

2.8 Additional analysis

2.8.1 Results of systematic reviews

During my own review, three systematic reviews on ACP were published. Only one, like mine, specifically addressed the effects of advance care planning interventions on nursing home residents and did not confine the review to RCTs, but unlike mine examined grey literature (Martin et al 2016). The two other systematic reviews examined ACPs in different settings (Brinkman-Stoppelenburg et al 2014; Weathers et al 2016). The former included studies with a broad range of methodologies and included studies examining single-issue advance directives, such as Do Not Resuscitate and Do Not Hospitalise, as well as complex ACPs. The study settings were heterogeneous, with 36 (32%) conducted in care homes (Brinkman-Stoppelenburg et al 2014). Conversely, one review was restricted to examination of RCTs (Weathers et al 2016).

All three reviews used a systematic search process like mine; one was registered with PROSPERO (Martin et al 2016) and only one specified using the PRISMA guidelines, as I did (Weathers et al 2016). Although the most recent review was of studies examining ACPs in nursing homes, in addition to hospitalisation and place of death, unlike mine, it examined outcomes including consistency of actions with ACPs, palliative care and hospice use (Martin et al 2016). None of these systematic reviews included a meta-analysis because of the heterogeneity of study settings and interventions. Comparison of the outcomes of these systematic reviews with mine was limited because of the heterogeneity of their populations, the settings, and the study methodologies they included. Table 2.12 summarises the main findings of the three reviews.

Figure 2.12 Summary of findings of systematic reviews

Authors, date of publication & country of origin	Databases searches & dates	Studies, intervention & outcomes examined, review design	Outcome regarding thesis question	Comments
Brinkman-Stoppelenburg et al 2014 The Netherlands	EMBASE Psych INFO PubMed 2000-2012	Participants: 113 studies; 95% observational, 81% from USA 49% hospital populations: 32% nursing homes Interventions: Do Not Resuscitate (39%) or written advance directives (34%) Outcomes: hospitalisation, hospital deaths, mortality	Do Not Hospitalise orders associated with: - reduction in hospitalisation in 8/9 studies - fewer hospital deaths in 2/2 studies - no report of effect of ACP on mortality	Significant study population heterogeneity
Weathers et al 2016 Ireland	CINAHL PubMed Cochrane databases	Participants: 9 RCTs conducted on 3646 older adults (7 community dwellers, 2 nursing home residents) Intervention: advance care planning Outcomes: hospitalisation, healthcare use and mortality	1 nursing home study reported significant reduction in hospitalisation rates and use of healthcare resources with no impact on mortality	Significant study population heterogeneity
Martin et al 2016 Australia	Embase Medline PsychINFO CINAHL Grey literature Search April 2015	Participating studies: 13 papers Intervention: ACPs for nursing home residents Outcomes: hospitalization, health costs, death in preferred place of care, mortality	ACPs in nursing homes associated with: <ul style="list-style-type: none"> • decreased hospitalisation between 9-26% • significant increase (29-40%) in residents dying in preferred place of death • decrease in hospitalisation not associated with increased mortality (2 studies) 	

2.8.2 Synthesis without meta-analysis (SWiM)

The heterogeneity of the studies in terms of intervention, methods and outcomes prevented meta-analysis and therefore a synthesis without meta-analysis (SWiM) was undertaken.

2.8.2.1 Methods

2.8.2.1.1 Grouping studies for synthesis

Given the question this thesis asked, studies included in this synthesis were restricted to those of care home residents as the population, complex care planning as the intervention, hospital admissions, hospital bed days and place of death as the outcomes, and either randomised controlled trials, controlled trials, or pre-post intervention study designs. There were no changes to the protocol in groups used in this synthesis.

2.8.2.1.2 Description of standardized metric and transformation methods used

The standardised metric for each outcome was number of hospital admissions.

Hospital admission was chosen as the standardised metric because it was a finite number, could be transformed into a rate per annum depending on the length of follow up period by simple multiplication or division, which would allow comparison of studies.

2.8.2.1.3 Criteria used to prioritise results for summary and synthesis

The criteria used to prioritise the results were:

- study design
- directness in relation to the review question
 - ACP implementation
 - Healthcare use as demonstrated by hospital admission

The benefits of using study design were that results could be prioritised by quality with randomised controlled trials and controlled trials providing higher quality of evidence than pre-post intervention studies because of lack of control and confounding variables such as time effect.

Another means of comparison was to prioritise ACP interventions by their directness in relation to the review question. Since this thesis asked the question “Does ACP intervention delivered as part of

CGA demonstrated the same benefits as demonstrated by research studies”, it was logical to prioritise evidence from studies delivering the same or similar interventions. Thus, the outcomes of studies in which the ACP intervention was delivered by specialist healthcare staff were more relevant than those using an ACP education intervention for care home staff.

By using these groupings, prioritising studies using an ACP intervention, delivered by specialist healthcare staff as part of a broader assessment such as CGA, with hospital admission, hospital bed days and place of death provided the greatest direct evidence. Of those studies, the evidence from outcomes of the studies with a randomised controlled trial or controlled trial design was of greater quality than pre-post intervention study design.

2.8.2.1.4 Heterogeneity

It was not possible to undertake a meta-analysis of the three studies because there was marked heterogeneity. Each study came from different countries, Australia (Harvey et al 2014), the UK (Garden et al 2016) and the USA (Hickman et al 2019) with different healthcare systems. Although all three used specialist healthcare staff to deliver the advance care planning intervention, the methods used to deliver the intervention differed with one study implementing advance care planning as part of Comprehensive Geriatric Assessment (Harvey et al 2014). Additionally, the studies were heterogenous in terms of medical stability. In the Harvey study the residents had been discharged recently from hospital (Harvey et al 2014), whereas the residents in the Hickman study were required to have a minimum length of stay of 100 days (Hickman et al 2019) and no length of stay was specified by the UK study (Garden et al 2016). Lastly there was heterogeneity in funding of the studies. The Australian study was an evaluation of the Residential Care Intervention program in the Elderly (RECIPE); the American study was part of the Optimising Patient Transfers, Impacting Medical Quality, Improving Symptoms, Transforming Institutional Care (OPTIMISTIC) funded by the Centers for Medicare and Medical Services, whereas the British study was of a service evaluation initially funded by a local medical charity.

2.8.2.1.5 Certainty of evidence

Evidence from interventions implemented using study designs of greater quality such as RCTs or controlled trials was of the highest quality and thus the greatest certainty for evidence. Evidence from non-randomised or pre-post study design was of poorer quality and the results of less certainty. The GRADE criteria were used to evaluate the quality of evidence: see Tables 2.2 and 2.3.

2.8.2.1.6 Data presentation methods

The results of the synthesis were presented in tabular format with all studies clearly referenced. The studies were ordered into those using RCT or controlled trial study design, those examining ACP intervention delivered by specialist nurses and those reporting hospital admission, hospital bed days and place of death as outcomes assessment such as CGA.

2.8.2.2 Results of synthesis without meta-analysis

2.8.2.2.1 Description of the synthesised findings

Of the ten studies identified by the literature search, in seven the ACP intervention was an educational programme for care home staff (Molloy et al 2000; Caplan et al 2006; Livingston 2013; Finucane 2013, O'Sullivan et al 2016), care home social workers (Morrison et al 2005) or attending physicians (Levy et al 2008), did not answer the review question directly and were discarded from the SWiM. In only three studies was the ACP intervention delivered by specialist health care staff (Harvey et al 2014; Garden et al 2016; Hickman et al 2019). Of these studies only one was a randomised controlled trial (Harvey et al 2014); the other two were pre-post intervention studies. Additionally, one offered an ACP intervention as part of comprehensive geriatric assessment (Harvey et al 2014). All three studies reported admissions, one reported hospital bed days (Harvey et al 2014) and only one reported on place of death, which was the care home for 98.5% of the residents (Garden et al 2016).

Table 2.13 Summary of three studies included in SWiM

<p>Harvey et al 2014 Australia</p>	<p>Participants: 116 residential care facility residents Intervention: geriatric-led supported discharge service Comparisons: 57 residents receiving intervention v 59 controls Outcomes: no significant change in hospital bed days Study Design: RCT with 6-month follow up</p>
<p>Garden et al 2016 UK</p>	<p>Participants: 107 residents in 7 care homes with 283 places Intervention: ACP intervention delivered by specialist nurses Comparisons: pre-intervention v post-intervention admissions to hospital Outcomes: admissions reduced Study Design: pre-post intervention service evaluation with 36-month follow up</p>
<p>Hickman et al 2019 USA</p>	<p>Participants: 1482 residents in long-stay nursing facilities Intervention: ACP intervention delivered by specialist nurses Comparisons: pre-intervention v post-intervention admissions to hospital Outcomes: no significant change in admissions Study Design: non-randomised cohort study with 12-month follow up</p>

Only one of these studies (Garden et al 2016), demonstrated a reduction in admissions associated with an ACP intervention. Although this reduction was sustained and increased over three years with the service in place, it was a pre-post intervention service evaluation of 107 residents with ACPs and was of poor quality. However, it was conducted in an unselected group of care homes in the UK and so had greater generalisability to the UK setting than the studies conducted in Australia (Harvey et al 2014) and the USA (Hickman et al 2019).

The Hickman study was also a pre-post intervention study with 1482 participants and a twelve month follow up period. Although it reported no significant change in hospital admissions between the ACP and no ACP group, the ACP group consisted of a group opting for palliative care and no hospitalisation (492 residents), and a group with no limits on intervention, including hospitalisation (771 residents). It is questionable as to whether comparison of this group with divergent wishes with the group of residents without ACPs was appropriate. The overall hospitalisation incident rate compared to the palliative ACP group, for the ACP group without hospitalisation limits was 1.48 (p=0.009), and for the no ACP group was 1.93 (p=0.001). There was no statistical difference between the no ACP and ACP without hospitalisation limits. However, when adjusted for age, gender, race,

end stage renal disease, cognitive function and functional status, there was no statistically significant difference for any paired comparison ($p>0.094$) (Hickman et al 2019).

The findings of the most methodologically robust of the studies, Harvey’s RCT, found no significant change in hospital bed days, but it was of residents recently discharged from hospital and limited by a short follow up period of six months (Harvey et al 2014). Whilst those residents expected to die during their hospital admission were excluded, the likelihood that this group had great medical instability than cohorts in the other studies cannot be ignored. Medical instability is known to be a risk factor for readmission (Hirdes et al 2003; Shah et al 2013). Additionally, it could not be discounted that implementation of advance care planning as part of CGA impacted on admissions.

Table 2.14 SWiM study outcomes: admissions

Study	Intervention Group & number of places	Control Group	Follow up	Admissions
Harvey et al 2014	57	59	6 months	Control group: readmission rate: 22/6 months 0.39/6 months Intervention group: readmission rate: 20/6 months 0.34/6 months
Garden et al 2016	107 283 places		36 months	Admission rate: Pre-intervention: 0.71/bed/12 months Year 1: 0.48/bed/12 months Year 2 & 3: 0.32/bed/12 months
Hickman et al 2019	1482 Comfort/do not hospitalise: 493 No limits group: 771 No ACP: 218		12 months	No significant difference between ACP group and no ACP group

2.8.2.2.2 The result relating to the question the synthesis addresses

When directness of evidence to the review question is prioritised, only three studies addressed the question because for each the intervention was advance care planning delivered by specialist nurses (Harvey et al 2014; Garden et al 2016; Hickman et al 2019). Of these, two did not demonstrate a significant change in healthcare use (Harvey et al 2014; Hickman et al 2019) with one of these being a randomised controlled trial (Harvey et al 2014). A reduction in healthcare use was reported by the service evaluation (Garden et al 2016), which was implemented in the UK in an unselected healthcare setting for a sustained period, so the findings may have greater transferability. However, the study design and lack of control group were serious limitations.

2.9 Summary of findings from systematic review including synthesis without meta-analysis.

There has been implementation of complex advance care planning methodologies in differing healthcare systems and some evidence of comparable results. Different advance care planning interventions for residents of care homes has been shown to be associated with:

- reduction in hospital admissions (five studies)
- reduction in hospital bed days (four studies)
- increase in numbers of care home residents dying in the care home or preferred place of care (five studies)

Synthesis without meta-analysis prioritised three studies because they examined ACP interventions delivered by specialist healthcare staff, instead of ACP educational interventions. Of these studies, neither the RCT (Harvey et al 2014) nor a large pre-post intervention study (Hickman et al 2019) demonstrated a significant change in healthcare use. The only study to do so was a small pre-post intervention service evaluation of poor quality (Garden et al 2016).

2.10 Discussion

This chapter provides a systematic review of the literature pertaining to the effect of advance care planning for care home residents on healthcare use and a synthesis without meta-analysis.

The ten original studies reviewed were heterogenous in terms of methodology, quality, the ACP intervention used, the nature of care homes, the healthcare system and outcomes studied, which made synthesis of results challenging. Of positive note, is that much of the evidence is relatively recent, which gives it value and applicability to modern health settings.

The papers all come from high-income countries in North America, Australia, and Europe. The findings would not necessarily generalise to low and middle-income countries. In the USA, the Patient Self-Determination Act of 1991, which required that nursing homes reimbursed by Medicare or Medicaid informed all residents upon admission of their rights to enact care directives in the event of terminal illness, appears to have increased research interest in ACPs in the ensuing decade. Interest in northern Europe in recent years may have been stimulated by significant changes in population demographics and health care needs, as people live longer with multiple comorbidities and frailty. In the UK, increasing pressure on the NHS to deliver cost-effective care, and a growing realisation that hospital may be neither the safest environment, nor the preferred place of care for older people with frailty, may have contributed to greater awareness of the potential of advance care planning in the UK to increase the chances of patients dying according to their wishes, whilst reducing healthcare use and costs. The fact that three papers came from the UK and another from Ireland, a country with a largely similar healthcare system is positive, in terms of applicability to the National Health Service.

The subjects of the review were care home residents, but the term care home encompassed a range of establishments with a range of facilities and so there are issues about generalisability. For example, care homes with more than 100 residents are relatively uncommon in the UK; staffing qualifications and levels may differ internationally and there may be differences in the medical interventions that can be administered in different countries.

Within the UK, care homes can be residential homes or nursing homes. There is no requirement for the former to have qualified nursing staff, whereas nursing homes need qualified Registered General

Nurses or Registered Mental Nurses to operate. Unfortunately, few papers detailed the facilities, nursing capabilities or staffing levels of the care homes in their study, so it is difficult to know whether a skilled nursing facility in New York (Morrison et al 2005) is comparable with a nursing home in Colorado (Levy et al 2008), or a long-term nursing facility in Indiana (Hickman et al 2019). Similarly, nursing homes in Ireland (O'Sullivan et al 2016), Australia (Caplan et al 2006; Harvey et al 2014) and the UK (Finucane et al 2013, Livingston et al 2013) may differ substantially in their ability to offer proactive or palliative care to their residents and thus affect the necessity to transfer to hospital.

ACP interventions varied between papers. Molloy has criticised the use of single intervention advance directives because they do not address the decline of older people with frailty (Molloy et al 2000), whose terminal trajectory is one of increasing debility (Thomas and Free 2011). He advocated complex ACPs as being more suitable to address residents' or their families' wishes regarding management of future health problems. An additional consideration is the way in which ACPs were implemented. Five studies delivered training programmes for care home staff (Molloy et al 2000; Caplan et al 2006; Livingston et al 2013; Finucane et al 2013; O' Sullivan et al 2016) or attending physicians (Levy et al 2008) or social workers (Morrison et al 2005), which were reliant upon those individuals having capacity or motivation to deliver ACPs. Only three studies employed specialist nurses to deliver the intervention (Harvey et al 2014; Garden et al 2016; Hickman et al 2019) and thus had the greatest directness to the review question. The only study to examine ACP as part of Comprehensive Geriatric Assessment failed to show a change in healthcare use (Harvey et al 2014). However, the latter examined an ACP intervention in care home residents recently discharged from hospital, and thus those residents might have been at greater risk of readmission because of medical instability. Furthermore, the follow up period in this study was only six months which may have been insufficient to embed the service and to demonstrate change in healthcare use. The authors did acknowledge that recruitment had been slower than anticipated, the study was insufficiently powered therefore, and the failure to demonstrate a change may have reflected this limitation

(Harvey et al 2014). However, it is also possible that ACP delivered by a specialist team has less impact on healthcare use than ACP educational interventions. Outcomes of ACP interventions delivered by specialist nurses might be affected by care home staff adoption or implementation of ACPs, or the specialist service being maintained. Conversely, education interventions requiring care home staff to deliver advance care planning might be constrained by resources and motivation, but education might improve understanding, and thus implementation of ACPs, have a cascade effect upon other carers and family members, and thus have greater sustainability than ACPs delivered by specialist healthcare staff.

Whilst there is research evidence about resource use, such as admission to hospital, and completion of ACPs there is disappointingly little about the quality of life and palliative care of residents (Teno 2000). Palliative care is important to people. Goodman et al (2010) reviewed studies examining decision making at the end of life. Three quarters of those without dementia opted for a more palliative approach to their care. Although two papers reviewed in this chapter did address specific palliative care issues, such as use of an end-of-life pathway (Finucane et al 2013) and referral to palliative care services (Levy et al 2008), there was little or no mention of palliative care in other studies. This omission is an important oversight; although symptoms and suffering in the last six months of life in nursing home residents with dementia have been studied (Mitchell et al 2004; Agar et al 2017), there is less evidence about the experiences of older people with frailty, and specifically, care home residents.

There were several limitations of the systematic review. The search was limited to papers identified by electronic databases. I did not undertake a systematic search of grey literature because of time constraints, and so none was included in my study.

A further limitation was that papers not published in the English language were excluded which may have led to useful studies being overlooked. There were very few papers written in a foreign language and those I found all had English abstracts available and did not meet eligibility criteria.

In comparison with the other systematic reviews, mine was like that of Martin's review (Martin et al 2016) in that it examined the effect of ACPs in a care home population and included research studies other than RCTs. Of the studies reviewed in my systematic review, five were included in that of Martin et al (2016); four in Brinkman-Stoppelenburg et al (2014) and two in Weathers et al (2016). In my systematic review, five of the six studies (83%) examining the effect of ACP on hospital admissions reported a reduction in associated with advance care planning for care home residents, which is comparable to eight out of nine studies (88%) in Martin et al's review (2016), whereas the systematic review examining high quality RCTs found only one of two (50%) RCTs to demonstrate a reduction in admissions (Weathers et al 2016). Regarding reduction of deaths in hospital, the findings of a reduction by two of the systematic reviews (Brinkman-Stoppelenburg et al 2014; Martin et al 2016) were comparable to my review. All the reviews reported significant heterogeneity in the studies, in terms of intervention, methods and outcomes measured, as I had found, and for this reason, a synthesis without meta-analysis (SWiM) rather than meta-analysis was undertaken, which prioritised three studies examining ACP interventions delivered by specialist healthcare staff, instead of ACP educational interventions. Of these studies, neither the RCT (Harvey et al 2014) nor the large pre-post intervention study (Hickman et al 2019) demonstrated a significant change in healthcare use and the only one to do so was a small pre-post intervention service evaluation of poor quality (Garden et al 2016).

2.11 Conclusion

Overall, this review suggests that advance care planning may have an impact on place of death and healthcare use, namely hospitalisation, ambulance transfers and emergency department visits, when implemented as part of controlled research studies or in selected care homes. The evidence for the effect of advance care planning on healthcare use seems stronger for ACP educational interventions rather than advance care planning delivered by specialist nurses but is less strong when

implemented in less controlled settings, raising the question of the effect in routine practice. In addition, none of the studies measured health use in primary care, which is a limitation. There is undoubtedly a lack of studies with rigorous methodology, but it is important to recognise that there are numerous barriers to care home research, which include the high proportion of residents without mental capacity to consent to interventions; fragmentation of service provision; the vulnerability of the care home sector to economic austerity; management change and employee turnover, time-trend bias with new health care policies, and other initiatives being implemented during the research.

Although two of the previous systematic reviews recommended further RCTs, I would argue that the issues described above are challenges faced in routine practice, and that it would be more valuable to demonstrate whether the benefits of ACPs, as demonstrated by research studies, are also seen when implemented as service interventions offering either an educational ACP programme or advance care planning delivered by a specialist team.

Chapter 3 Intervention, service implementation and evaluation

The findings of my systematic review were that, although advance care planning interventions have an impact on place of death and healthcare, when implemented as part of controlled research studies, or in selected care homes, the evidence seems weaker when implemented in less controlled settings and by specialist teams. Complex interventions are context sensitive, with the research setting, personnel, design and practice, all important influences. However, time-effects and sustainability are often not considered in experimental studies and so their findings may not translate to routine practice. Therefore, implementation of a large-scale project offering advance care planning to care home residents in routine practice was justified.

In the first part of this chapter, advance care planning as an intervention and CGA, as a vehicle for advance care planning to be delivered, are discussed. Following this, the Lincoln care home service model is presented, setting out the need to evaluate the use and acceptability of ACPs embedded in CGA. The methods of implementing the project, and its evaluation, are described.

The literature review in the preceding chapter has discussed the strongest evidence for efficacy of ACPs in reducing admission to hospital; a randomised controlled trial (Molloy et al 2000) and a controlled trial (Caplan et al 2006). However, there is only limited evidence from two small service interventions in Lincolnshire and Ireland (Garden et al 2016; O'Sullivan et al 2017) that application to routine clinical practice delivers the same outcomes. These four studies have necessarily tested advance care planning in a stand-alone manner, three delivered as educational interventions and one a nurse led intervention. Rather than supplementing the research evidence for the effects of advance care planning, this project's aim was to close the implementation gap between research and practice by examining whether ACPs could be applied in routine practice in the UK.

3.1 Advance care planning as an intervention

My experience from the Boston care home service was that, whilst advance care planning as a stand-alone intervention was acceptable to many residents, their families, care home staff and general practitioners, the emphasis on death deterred participation of many residents and their families, whereas an overall assessment, of which advance care planning was a part, undertaken to optimise remaining life, might have been more acceptable. Thus, there were potential benefits from integration of advance care planning into a process such as CGA, both in terms of contextualising the ACP, and by increasing acceptability. Furthermore, the advantage of the health professional, who did the assessment, going on to discuss advance care planning, was that they were fully aware of the resident's condition, and during the assessment had opportunity to develop rapport with the resident, their family and care home staff, which was invaluable when discussing sensitive issues as part of the advance care planning process.

Experience from the Boston care home service showed, that to be acceptable to health commissioning organisations, health providers and health professionals in Lincolnshire, care home staff and residents and their families, three different formats of ACP were needed. The Lincolnshire countywide guidelines required ACPs to be drawn up for people with mental capacity to make decisions about their healthcare; Anticipatory Care Plans to be drawn up on a best interests' basis for people lacking mental capacity, and Advance Decisions to Refuse Treatment (ADRTs) for people with mental capacity, who wanted a legally binding document stating specific refusal of treatment(s) in a predefined potential future situation.

The Royal College of Physicians guidelines state that a document is not a requirement for an ACP, unless the patient specifically wishes to record an ADRT refusing life-sustaining treatment (Conroy et al 2009). In practice, in emergency situations it is often impossible for health and social care professionals to ascertain patients' wishes if they have lost mental capacity, and/or their

representatives cannot be contacted. A document is a pre-requisite therefore, to ensure previously stated wishes are made known and acted upon.

3.2 Comprehensive Geriatric Assessment as a vehicle for advance care planning

Comprehensive Geriatric Assessment (CGA) is a multi-disciplinary, multi-agency, holistic assessment of a patient, which places the patient and their supporters at the heart of care. Optimal healthcare for frail older people should encompass multidisciplinary assessment of the person's physical, functional, psychological, socio-economic, and environmental condition, allowing a personalised care plan to be developed in conjunction with the patient and their family, often with escalation plans which may be tailored to the person's wishes and their condition (Figure 3.1). Delivery of such care takes time, and requires good working relationships, both between disciplines and agencies, and for the patient and their family to take ownership of care (British Geriatrics Society 2019).

Figure 3.1 Comprehensive Geriatric Assessment

What is CGA?

Comprehensive Geriatric Assessment (CGA) is a process of care comprising a number of steps. Initially, a multidimensional holistic assessment of an older person considers health and wellbeing and leads to the formulation of a plan to address issues which are of concern to the older person (and their family and carers when relevant). Interventions are then arranged in support of the plan. Progress is reviewed and the original plan reassessed at appropriate intervals with the interventions reconsidered accordingly.

Comprehensive Geriatric Assessment Toolkit for Primary Care Practitioners.

British Geriatrics Society 2019

The concept of holistic assessment for older people with frailty is not new. In the 1940s, Warren and others started the focus on geriatric care in the UK (Warren 1943). During the latter half of the century this process was called CGA, tested, and finally meta-analysed in 1993 (Stuck et al 1993). Since then, there has been more empirical research, more meta-analyses, and CGA has become the leading model of care for older people with frailty. However, whilst there is evidence for its

applicability in hospital (Stuck et al 1993; Ellis et al 2017) and the community (Beswick et al 2008), the evidence for its use in care homes is limited.

Chadborn et al (2019) undertook a realist review using expert opinion and evidence from the literature to develop a programme theory as to how CGA should be applied to care homes. They found that structured and contemporaneous assessment by multidisciplinary teams, as well as setting of patient-centred goals were variable, and there was little literature addressing the views of patients, their relatives and care home staff. The authors concluded that, to be successful in care homes, CGA must have three components: a structured or standardised approach to assessment, communication within a multidisciplinary team and coordination of care delivery activities (Chadborn et al 2019).

CGA does not have to be standardised, but tools can be helpful to develop services and monitor care. In practice in the UK, tools have been used most often to quantify findings, for the purpose of audit or research into CGA. However, the importance of assessment, one of the key objectives of the 1989 White Paper Caring for People (Cm 849, 1989), was reiterated in the National Service Framework for Older People (Department of Health, 2001a), which identified the need for a single assessment process for older people. The National Minimum Standards for Care Homes for Older People (Department of Health, 2001b) specified the key components of comprehensive assessment of residents which would allow service user plans to be drawn up.

Importantly, Chadborn concluded that staff needed to own their individual assessments (Chadborn et al 2019).

The GSF prognostic Indicator guidance was developed in general practice in the UK with the intention of predicting patients' needs, rather than exact prognostication, and has been adopted widely in the UK, with support from the Royal College of General Practitioners (Thomas and Free 2011). A GSF training programme is available for care homes to commission, which leads to GSF accreditation. However, uptake of this training has not been universal, with only 2300 care homes reported to be accredited at the time of writing (GSF 2019).

Under the GSF guidance the combination of three triggers should be considered in determination of prognosis (Thomas and Free 2011). These include:

1. The “Surprise Question” which is “Would you be surprised if this patient were to die in the next few months, weeks or days?”
2. General indicators of decline, which are:
 - decreasing activity as measured by declining Barthel score
 - being in bed or a chair 50% of day
 - increasing dependence for most activities of daily living
 - co-morbidity
 - general physical decline
 - advanced disease
 - decreasing response to treatments
 - choice of no further active treatment
 - progressive weight loss (>10%) in past 6 months
 - repeated unplanned/crisis admissions
 - sentinel events e.g. serious fall, bereavement, transfer to nursing home
 - serum albumin <25g/l
3. Condition-specific indicators. For care home residents the specific indicators for frailty and dementia are the most pertinent and are outlined in Table 3.2.

Table 3.2 Condition-specific GSF prognostic indicators (Thomas and Free 2011)

FRAILITY	DEMENTIA
Multiple co-morbidities with significant impairment of day to day living	Unable to walk without assistance
Deteriorating functional score	Urinary and faecal incontinence
Combination of at least 3 of following:	No consistently meaningful conversation
• Weakness	Unable to do Activities of Daily Living
• Slow walking speed	Barthel Score <3
• Significant weight loss	Plus , any of the following:

<ul style="list-style-type: none"> • Exhaustion 	<ul style="list-style-type: none"> • Weight loss
<ul style="list-style-type: none"> • Low physical activity 	<ul style="list-style-type: none"> • Urinary tract infection
<ul style="list-style-type: none"> • Depression 	<ul style="list-style-type: none"> • Severe pressure sores (Stage 3 or 4)
	<ul style="list-style-type: none"> • Recurrent fever
	<ul style="list-style-type: none"> • Reduced oral intake
	<ul style="list-style-type: none"> • Aspiration pneumonia

3.3 Service implementation methods

The aim of this study was to explore whether previous research findings as reviewed in Chapter 2 could be replicated in routine practice in a UK setting. In order to do this, the first step was to establish a care home service.

There was an earlier project in Boston, funded by the Bromhead Medical Charity and led by me. The service involved introduction of ACPs for residents with dementia in seven care homes and was associated with reduction in admissions of 37% in the first year of service and 55% in the second and subsequent years (Garden et al 2016). The Bromhead Medical Charity is a Lincolnshire-focused organisation with the objectives to “prevent, relieve and cure sickness and ill health of every kind and to promote health in any way which shall be for the time being charitable in law” (Bromhead Medical Charity 2020). The positive outcomes of the Boston service led the charity to wish to fund a larger-scale care home service in Lincolnshire under the same leadership. I agreed to develop a business case for such a service on condition that advance care planning was integrated into a system, such as CGA, in order to provide a more holistic service.

3.3.1 The Lincoln care home project

I submitted a business case to the Bromhead Medical Charity to deliver a care home service in Lincoln on 13th May 2014, and a grant for up to £450,000 was awarded. I designed the service protocol under the supervision of my academic supervisors: two academic geriatricians and an academic old age psychiatrist. I too am an old age psychiatrist, but had trained formerly in medicine, possessed MRCP and had extensive experience in the physical and mental healthcare of older people. As mentioned previously, I had developed a care home service in Boston delivering ACP. I

was seconded from my post at Pilgrim Hospital, Boston, to undertake this role. The other members of the team were recruited on fixed-term contracts. They were expected to be able to practice autonomously, with supervision from me, following training in CGA and advance care planning, and so were appointed at Band 6, the level of a deputy ward manager. The positions were open to applications from allied health professionals as well as qualified nurses with a view to developing a multidisciplinary team. In addition to myself, the Lincoln care home project team comprised initially of a physiotherapist, two registered nurses and an occupational therapist. All had extensive experience in the healthcare of older people. The team underwent an induction and training period in September and October 2015. This period consisted of theoretical teaching for two weeks delivered by a geriatrician, a nurse consultant, an academic nutritionist, and me. Thereafter, a period of clinical training was conducted in the designated pilot care home to give the best possible opportunity to deliver a consistent quality of care to the other care homes, which had been randomised to be included in the step wedge randomised cluster service. Following this, team members were allocated residents to assess in each care home. One member of the team was designated as the key worker for each care home: it was their responsibility to follow-up and reassess residents, and to undertake CGA of new residents once the team had moved to the next randomised care home. All members of the team underwent regular supervision sessions and appraisal with me. The team helped me with data collection, as well double-checking data entry to ensure accuracy.

Comprehensive Geriatric Assessment was undertaken on all residents referred by their general practitioners, who agreed to participate. For each resident agreeing to CGA, a member of the project team was identified as the lead, but other members of the multidisciplinary team were involved in the assessment. CGA encompassed assessment of mobility, falls risk, continence, and mental health as well as potential for rehabilitation, diagnostic assessment, and medication review, which led to formulation of a management plan discussed at the weekly multidisciplinary meeting and documented in the primary care electronic record, SystemOne, irrespective of whether the resident

chose to go on to have an ACP. CGA was operationalised using tools agreed at a countywide frailty summit, with the intention that the same well-validated tools, readily applicable to everyday practice, would be adopted by community and secondary care frailty services across Lincolnshire.

The tools agreed were the Edmonton Frail Scale as a screening tool (Rolfson et al 2006), the Barthel Index to assess activities of daily living (Mahoney and Barthel 1965), the Montreal Cognitive Assessment to assess cognitive function (Nasreddine et al 2005) and the Malnutrition Universal Screening Tool to assess nutritional status (BAPEN 2003).

CGA also involved an estimate of prognosis using the Gold Standard Framework (GSF) Prognostic Indicators Guidance, since a GSF register was incorporated in SystemOne in Lincolnshire.

All residents who had agreed to CGA were offered advance care planning. The advance care planning process involved discussion of the resident's present condition, their prognosis, health crises which might arise, possible interventions and locations of care which might be available. These meetings included specific discussion of cardiopulmonary resuscitation, artificial feeding and hydration, treatment of sepsis, myocardial infarction, stroke, and falls with suspected fracture.

Although residents with mental capacity had a right to have advance care planning discussions on their own, we encouraged these discussions to be held with as many family members as possible.

There were several reasons for this decision. Relatives would be contacted by care home or healthcare staff, in the event of deterioration in residents' health. Some residents might have Lasting Power of Attorney for health and welfare, with their relatives as attorneys. Lastly a person's death has many repercussions for family members, and my experience from the Boston service, showed that helping families' understanding of their loved one's condition and preferences was often empowering, reduced uncertainty, and helped them support implementation of the advance care plan. Most families communicated with each other and attended meetings together, but in some instances several meetings needed to be held. For some patients and their families, an ACP could be drawn up after a single meeting; others required a period of reflection and further discussion. In

some instances, for patients with mental capacity, a decision to apply for Lasting Power of Attorney for health and welfare resulted. Appendix 1 contains an Advance Care Plan template

For those people who lacked mental capacity to have these discussions, a best interests meeting was held with family members or proxies. A very small number of residents had no advocate, in which case a referral was made to an Independent Mental Capacity Advocate. In all instances, ceilings of care were discussed, and if the resident or their family wished, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms were completed, and advance care planning offered.

Using recommendations from the Royal College of Physicians guidance (Conroy et al 2009), electronic documents were drawn up which included an administrative section, a mental capacity section, a section giving background details about the person and their medical condition and a section containing detailed information about the person's wishes with specific reference to admission to hospital, cardiopulmonary resuscitation, artificial feeding, treatment of sepsis and other conditions such as myocardial infarction and stroke.

3.3.2 Identification and randomisation of care homes and recruitment of residents

Care homes registered to provide for people with old age and dementia in the Lincoln area were identified from the Lincolnshire County Council Care Services Directory.

Randomisation of participating homes was carried out by an experienced member of the Department of Research and Development at United Lincolnshire Hospitals NHS Trust (UHLT). The individual was asked to generate a random allocation sequence of the order in which the care homes would receive the service, and to retain the list, to which just one other member of the department had access. Neither played any other part in the project. The name of the next randomised care home was released two weeks before the service would be introduced, so that meetings could be held with the care home manager to establish with which general practices residents were registered, and to ask the general practitioners to refer the residents for assessment.

The registration status, number of places, corporate status and nature of the premises were tabulated to illustrate the nature of the settings in which the intervention was carried out.

All permanent residents of the participating care homes, from the date of first contact until the service ceased in January 2018, were offered advance care planning following CGA.

3.3.3 CGA and ACP data management

In addition to paper records of the CGA and ACP, the outcomes were recorded electronically in SystemOne for general practitioners, community services staff and out of hours teams to view.

Residents who fulfilled GSF criteria as probably being in the last six months of life were entered on the integrated GSF register, together with details of preferred place of care and death, and resuscitation status. The ACP and DNACPR form were attached to the electronic record and a high priority notification was added to alert all health professionals involved in residents' care to the presence of these documents. The original DNACPR form, ACP and an information pack summarising the outcomes of CGA were retained in residents' care home records.

3.4 Comparison of the care home project to RCTs

This project used a step wedge randomised cluster design, which has been advocated for research studies examining the effects of an intervention which cannot be introduced at a single time, for reasons such as logistical implementation or funding.

3.4.1 Similarities to RCTs

The reason why evidence gained from a randomised controlled trial is considered so valuable is that as many factors are controlled as possible to avoid bias and confounding results. A step wedge randomised cluster study design requires randomisation of the care homes (clusters) identified to participate as would be done in RCTs.

Like RCTs, the project used the same assessments and tools in all the care homes participating in the service, so that all participating residents would receive the same intervention. Consequently, the

project had two different arms: those who received the intervention (ACP) and those who did not, which, like RCTs, would allow statistical comparison of the two groups.

Inclusion of care homes in a specific geographical area with one acute hospital, one ambulance service and one out of hours service in the project controlled as far as possible for variations in emergency care, which were a feature of earlier RCTs examining this subject.

Protection of identity and confidential information of patients is a fundamental requirement in any healthcare setting. Anonymisation of subjects and use of a number or code enables confidentiality with a document with codes and identities retained in a secure place. For this project, all data collected for the purpose of the project evaluation were anonymised as would be implemented in RCTs.

3.4.2 Differences from RCTs

RCTs are undertaken to establish evidence of an intervention, either where no evidence exists, or to replicate evidence derived from another trial. Subjects are randomised to an intervention group or a control group which run in parallel. Research ethics committee approval is required to ensure that the methods proposed for the trial are appropriate, there is good cause to conduct the trial, participants are protected from burden or harm from research, and there is data security.

Research ethics committee approval was not required for this project since it was implementing ACPs as part of CGA for care home residents, processes for which there was well-established evidence and using a step wedge study design would enable all care homes in the specific health system to participate. The clinical data collected was done so as part of participating residents' assessments, did not pose a burden upon them and was collected and protected by Caldicott Guardian clinical governance arrangements applicable to any routine service. Clinical governance and ethical approval were obtained from the Medical Director of ULHT and the Director of Nursing at Lincolnshire West Clinical Commissioning Group and subsequently from individual general practice Caldicott Guardians.

Routine practice differs from research studies, which are often delivered by highly skilled and/or highly motivated researchers, and thus results of experimental studies may not be replicated when implemented as a service evaluation in whole health system setting by clinicians, not researchers.

Greater experimental control could have been achieved by limiting the care homes to those with a specific registration category; care homes which volunteered to participate; or those which had achieved a certain standard in inspection by organisations, such as the Care Quality Commission. By adopting these measures, RCTs can reduce confounding factors, but in doing so they tend to cherry pick care homes which have volunteered, which may make them unrepresentative of the populations to which the results will be applied, thus limiting the applicability of findings to routine practice. Given the purpose of this study was to examine the effects of ACPs in routine care, it would have been inappropriate to have selected care homes.

3.5 Important changes to methods after start of project

Care home 12 had an extension built after the service was planned, which doubled the number of places in the care home. Initially this care home was designated as a separate entity, but the residents shared the same facilities and staff. Given that we were undertaking a whole system service, and not a research study, I felt it would be irrational, on clinical grounds, to exclude residents from the extension, and so all residents were assessed and offered advance care planning. Subsequently the two care homes officially merged and adopted the same name.

In addition, there were changes in team personnel; one member resigned, and two others were appointed after a vacancy period necessitated by ULHT human resource procedures. One team member underwent a disciplinary procedure, during which time they could not work, and on return was required to work with another team member for two months. In addition, because of the uncertain fate of the service, three members of the team left early to take up permanent positions.

3.6 Outcome measurement

3.6.1 Measuring admissions in care home residents

Information about hospital admissions of residents from the care homes participating in the project were part of the routine data collected by the hospital informatics department. This information included dates of admission and length of stay.

3.6.2 Deaths and place of death

For the Boston service, care homes were the most reliable source of information about deaths. Since each care home in the Lincoln project would have a key worker, part of their role was to collect information about deaths and place of death weekly. After cessation of the project, for the duration of the follow up period, I was responsible for collecting this information.

3.7 Data analysis

The aim of the analysis was to answer the research question: Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

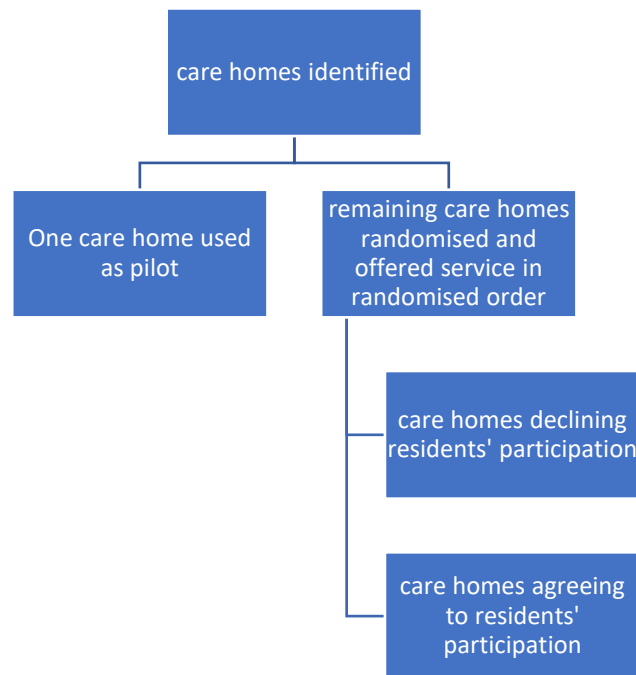
The objectives of the project were to establish:

- the extent of participation of unselected care homes
- the acceptability of advance care planning to care home residents
- whether there was a reduction in healthcare use associated with ACPs
- whether residents with advance care plans died in their preferred place of care

3.7.1 Care home participation

The extent of participation of care homes in the project would be recorded in a flowchart (Figure 3.2). Characteristics of the care homes, in terms of registration to provide personal care or nursing care, number of places, ownership and nature of premises would be determined from individual care home websites.

Figure 3.2 Flow chart for care home participation in the project

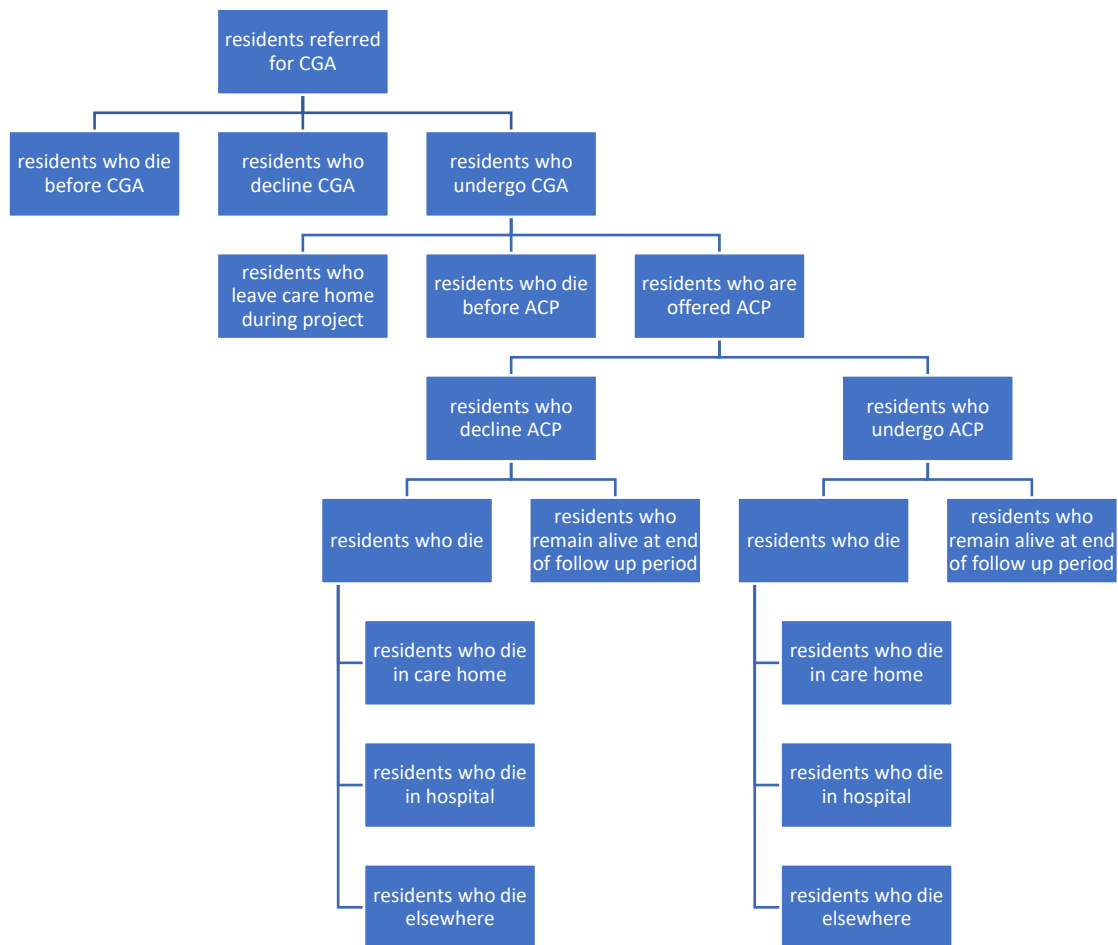


3.7.2 Care home resident participation and characteristics

Recruitment of care home residents to the project, their participation in CGA and advance care planning and their outcomes, including place of death, would be illustrated in a flow chart (Figure 3.3). This information would indicate acceptability of advance care planning and CGA to care home residents, and the place of death of residents with, and without ACPs.

The mean scores of the tools use for CGA would be recorded for the whole group, and the groups with and without ACPs, to assess whether there was a difference in severity of frailty between the groups. This information, together with demographic analysis could indicate whether there was a group of residents for whom advance care planning was more acceptable.

Figure 3.3 Flow chart for resident recruitment and participation in the project and outcomes



3.7.3 Healthcare use

Monthly admissions to hospital from each care home were recorded. A medical statistician (AUM) was asked to analyse the data. She used a generalised linear model adjusted for time effects for hospital length of stay and hospital admissions. The immediate effect of the intervention would be assessed by including three-month outcome data after the intervention was implemented in the last care home. The sustained effect of the intervention would be assessed by including ten months outcome data after the intervention was implemented in the last care home.

3.7.4 Place of death

Given that one of the research questions was whether residents with ACPs died in their preferred place of care, the place of death and preferred place of death for residents with ACPs would be compared using appropriate parametric or non-parametric analysis.

3.8 Summary

This chapter described advance care planning as an intervention, and CGA to deliver the intervention. The methods used to implement the Lincoln care home service were outlined, namely:

- the composition of the project team
- identification, randomisation and recruitment of care homes
- enrolment of care home residents
- implementation of advance care planning embedded in CGA
- methods of data collection
- data analysis

The results of these analyses and retrospective application of implementation science to the results of the project are reported in Chapters 5 and 6.

3.9 Conclusion

This chapter discussed justification for embedding advance care planning in Comprehensive Geriatric Assessment as a rational way to implement ACPs in routine practice. The intervention proposed, namely advance care planning, was considered. The rationale for a pragmatic large-scale service, delivering advance care planning, as a means of testing whether findings from research studies could be replicated in routine practice in the UK was given. The conception of the Lincoln care home project, the methods of its delivery, proposals for data collection and analysis were described.

The next chapter will address the methodology of service design and evaluation and implementation science theory and models, with specific reference to Soft Systems Methodology and the Consolidated Framework for Implementation Research.

Chapter 4 Methods

Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

The first part of this chapter describes implementation science theory, specifically Soft Systems Methodology, and implementation science models, and the reasons for using the Consolidated Framework for Implementation Research (CFIR) as a suitable method to evaluate the project.

The next section describes potential service evaluation designs, their strengths and weaknesses, and the justification for the choice of a step wedge randomised cluster design.

4.1 Implementation science

Health and social care services are highly complex systems which involve multiple interactions between different services and within those services. Therefore, application of implementation science theory to these services is potentially helpful in understanding outcomes of a service.

In comparison to RCTs, service interventions are introduced without controlling for other variables to reduce bias, and therefore their implementation and outcomes may be subject to many more confounding factors. However, the purpose of an implementation study is to put things into practice, and achieve the benefits seen in the experimental evidence. The conditions that apply during an experiment do not necessarily apply when an intervention is put into wider practice and discarding these conditions could alter the outcomes. Experimental studies do not answer important questions, such as sustainability beyond the life of the study, or scale issues when an intervention is delivered to a population. The study of these issues is known as implementation science, and the knowledge is called implementation theory.

Implementation science is a developing field, which has evolved to address what is referred to as the implementation gap, that lies between the experimental evidence for an intervention and

implementation in practice. It does so by considering the complex systems into which new interventions are introduced. Implementation science is defined as the scientific study of methods to promote the systematic uptake of research findings, and other evidence-based practice, into routine practice, to improve the quality and effectiveness of health services and care (Eccles and Mitman 2006).

Many of the concepts underlying implementation science were described originally by operational researchers. Operations research is a discipline which applies advanced analytical methods to help make better decisions. Its origin dates to the Second World War when radar was first introduced. Whilst the potential of radar was evident, development of its operational use was critical for success. Winston Churchill recognised that “it was operational efficiency rather than novelty of the equipment that was the British achievement to change the world decision” (Churchill 1948). The term, constrained optimisation, describes how operation science can maximise benefit and minimise the downside of an intervention by development of an understanding of the quality of the data, the system and the context (Blackett 1962).

4.1.1 Soft Systems Methodology

Soft Systems Methodology is a theory, developed in the 1970s, in response to the failure of established methods of system engineering when faced with messy, complex problems. It was developed expressly to cope with human situations in which people in a problem situation perceive and interpret the world in their own ways, and make judgements about it, using standards and values which may not be shared by others (Checkland and Scholes, 1990). It is a means of defining and describing a task in a way that is both flexible, and broadly applicable, to management of real-world tasks, and its use helps to understand better how different individuals and stakeholders involved in a project, or system, influence outcomes.

The methodology used in many studies, based on this theory, is action research, a term first coined in 1944 and described in a seminal paper in 1946 (Lewin, 1946). The rationale is that transformation occurring by action and research conducted simultaneously can be measured and fine-tuned to

make changes in different parts of a system. Checkland and Scholes initially applied Soft Systems Methodology to industry, but later applied it to the Civil Service and the National Health Service, acknowledging the greater complexity of these organisations relative to industry (Checkland and Scholes, 1990).

4.1.2 Implementation science models

A review by Per Nilsen (2015) is helpful in describing implementation theories and discussion of their origins and uses. He identifies several theoretical approaches and four broad categories of use:

- To address challenges associated with application of research to clinical practice
- To avoid implementation of research without underlying theoretical basis
- To understand better the reasons for implementation outcomes
- To develop strategies with better implementation outcomes

Table 4.1 details Implementation science models: process models, determinant frameworks, classic theory, implementation theory, and evaluation frameworks, with examples of each model.

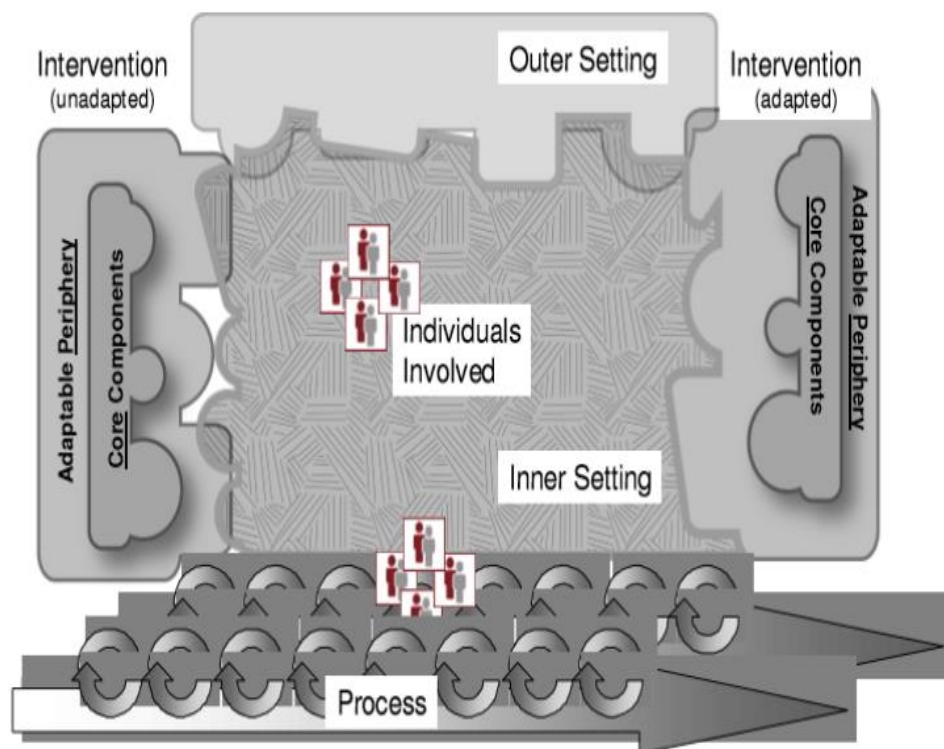
Table 4.1 Implementation Science Models

Model	Examples	Advantages and Limitations
Process Models	Quality Implementation Framework Meyers et al 2012	Stepwise introduction Emphasise good early stage planning Tend to be modelled on ideal conditions, so lack applicability to modern day practice
Determinant Frameworks	Promoting Action on Research Implementation in Health Sciences Kitson 1997	Describe factors which act as barriers & enablers, and which influence implementation outcomes Consider multiple aspects of implementation so useful in complex systems Do not address how change occurs or causal mechanisms
Classic Theory	Theory of Diffusion Rogers 2003	Origins in fields such as psychology, sociology and organisation theory Provide understanding of different organisational cultures & how teams operate Limited applicability to complex implementation studies
	Social Cognitive Theories Bandura 1977	
	Social Capital Theories Grol & Wensing 2004	
Implementation Theories	Implementations Climate Klein & Sorra 1996	Provide understanding and explanation of aspects of implementation Particularly useful to target specific areas of interest.
	Organisational Readiness Weiner 2009	
Evaluation Frameworks	The Reach, Effectiveness, Adoption, Implementation, Maintenance Glasgow et al 1999	Specify aspects of implementation which need to be evaluated to determine implementation success
	Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation Policy, Regulatory and Organisational Constructs Green and Kreuter 2005	
	Consolidated Framework for Implementation Research Damschroder et al 2009	
	Normalisation Process Theory May et al 2009	Explains how new technologies, ways of acting & working, become embedded in everyday practice Applicable to study of implementation processes Uses some of terms in Soft Systems Methodology, such as actors

4.1.3 The Consolidated Framework for Implementation Research

Damschroder et al made a major advance in developing the CFIR (Damschroder et al 2009). They recognised that many of the concepts in previously described implementation theories overlapped, but individual theories did not encompass all aspects of implementation. The CFIR is different, as it allows consideration of multiple aspects of implementation, and therefore is potentially invaluable in complex systems, such as health and social care (Figure 4.1).

Figure 4.1 The Consolidated Framework for Implementation Research



The CFIR comprises five domains:

1. the intervention
2. the inner setting
3. the outer setting
4. the individuals involved
5. the process by which implementation is accomplished

The structure of the CFIR was influenced by earlier implementation science researchers. The interaction between the intervention, inner and outer settings and process of implementation, reflect theories developed by Pettigrew and Whipp (1992) about industrial organisation. Evidence, context, and facilitation are contained in the Promoting Action on Research Implementation in Health Sciences (PARIHS) framework (Kitson et al 1998).

The first domain of the CFIR describes how the intervention is implemented into an organization.

Without adaptation, interventions usually fit poorly into a setting, and an active process is required to engage individuals affected by the intervention, who might otherwise resist the intervention.

Damschroder et al (2009) described internal constructs in each domain, derived from earlier conceptual models. The first domain contains the following constructs:

1. **the intervention source** may originate within an organisation as a solution to a problem, or may be imported because of the reputation of an external body
2. **evidence strength and quality** of the intervention may come from published literature, clinical guidelines, a local pilot study or more anecdotal reports, such as those from patients or colleagues
3. **relative advantage** of the intervention is the stakeholders' view of the intervention's benefits compared with those of another intervention
4. **adaptability** refers to the extent that the intervention can be modified to fit the local needs

5. **trialability** represents the extent to which the intervention can be piloted on a small-scale, allowing expertise to develop which increases the chance of successful implementation
6. **complexity** represents the difficulty of implementation, which can be quantified by the number of steps used in implementing the intervention, and the number of choices at key points
7. **design quality and packaging** represent the presentation of the implementation
8. **cost** comprises the cost of the intervention, and the cost of its implementation, excluding the costs incurred to the inner setting

The intervention can be depicted by shapes of different irregularity. A simple shape could be used to represent an intervention which is relatively straightforward to implement. A complex intervention, with many interacting components, could be shown as an irregular shape.

Furthermore, the nature of the intervention can be shown with core components, representing the essential and indispensable elements, and an adaptable periphery. The latter represents adaptable elements, structures, and systems, which can be modified according to the setting, without undermining integrity of that intervention. For example, depending on the work processes at individual clinics, a clinical reminder could pop up during the patient assessment by a nurse case manager, or when the primary care provider evaluates the patient.

Figure 4.1 delineates the intervention's core components and adaptable periphery. It shows visually that components of the periphery can be modified to a particular setting and vice versa in a co-evolving/co-adaptive way, moving from the left (unadapted intervention and setting) to the right side of Figure 4.1, where both the intervention and setting have changed shapes showing how they evolved or adapted to each other (Damschroder et al 2009).

The inner and outer settings represent the relationships within organisations and between organisations. The outer setting constructs include:

1. **patient need and resources**, which is the extent to which those needs are understood and prioritised by organisations in the outer setting
2. **cosmopolitanism**, which is the degree of networking with other organisations
3. **peer pressure**, which reflects the need to replicate an intervention or to compete with other organisations
4. **external policies and incentives** could feature structural, political, and cultural factors which influence how the implementation will proceed. It is oddly shaped because of the complexities inherent to organisations

The individuals involved with the intervention and/or implementation process form the fourth domain. Individuals, or people, are not passive recipients of innovations, and will respond in different ways. Some will welcome, wish for, understand, and develop innovations, whilst others may be more negative, more concerned, and challenge them. Thus, individuals can make choices, wield power, and influence others, with predictable or unpredictable consequences for implementation. They will also have cultural, organisational, professional, and individual mindsets and affiliations (Greenhalgh et al 2004).

The fifth major domain is the implementation process. Successful implementation usually requires an active change process aimed to achieve individual and organizational level use of an intervention. The implementation process is depicted in Figure 4.1 as an interrelated series of sub-processes that do not necessarily occur sequentially. The multiple series of cycles and shadowed arrows represent the complexity of executing and evaluating implementation because there are often related processes happening simultaneously at multiple levels within the organization. These sub-processes may be formally planned or spontaneous; conscious or sub-conscious; linear or non-linear but, ideally, are all aimed in the same general direction: effective implementation (Damschroder et al 2009).

Although the CFIR was conceptualised to be applied prospectively, a recent review reports that, rather than being used in setting up projects, the CFIR has usually been applied retrospectively to evaluate the implementation process (Kirk et al 2016). Although there is no agreed and tested prospective method for implementation that guarantees success, there is a great deal of knowledge that explains the reasons for failure, and it makes sense to try to avoid making well-known mistakes in implementation. Familiarity with the implementation literature therefore provided important principles to guide to evaluation of this implementation.

4.1.4 Embedding a service in a health and social care system and data acquisition

Whilst choosing a service design offering the best degree of control is important, understanding of the system in which the project is embedded is also relevant.

Models which consider implementation science prospectively can provide a framework to address confounding factors, and thus increase the chance of successful implementation. Health and social care practitioners and managers all too often implement services without robust methods of evaluation, or consideration of confounding factors. The Boston project illustrates this well; implementing ACPs without integration into routine practice reduced potential uptake of advance care planning (Garden et al 2016). My learning from the Boston service led me to use the CFIR as part of the Lincoln service evaluation and doing so could lead to further refinement of advance care planning for care home residents.

The retrospective application of the CFIR to the service outcomes meant that I was unable to use the CFIR Toolkit (<https://cfirguide.org>). Methods of applying the CFIR and soft systems methodology retrospectively, might have included independent third-party analysis, formal thematic analysis, or my own collection of data to populate these models. However, there was no additional funding available for such analyses.

Therefore, to apply both the CFIR and soft systems methodology to the project outcomes, I used observations from field notes, multidisciplinary team meeting records, my diary, information from

the electronic record, SystemOne, written and verbal feedback from residents, their families, care home staff, notes from meetings with West Lincolnshire Clinical Commissioning Group, general practitioners and primary care personnel, as well as my own observations and reflections, and those of the project team. Clearly there were limitations to use of these sources of data. It could be argued that my own observations and reflections and those of the project team were subjective and dependent upon our worldviews and wish for the project to be successful. A similar criticism could be made about use of feedback from the individuals listed above. It is possible that people dissatisfied with the project might be less likely to make their opinions known than those who perceived the project more positively. On the other hand, the converse might be the case and I had no evidence to support either possibility. In support of the validity of feedback from individuals, in particular residents, their families and care home staff, and general practitioners was the frequency and recurrence of the same themes. Given the numbers of individuals from each of these groups likely to be involved in the project, it could be argued that recurrence of similar experiences or views would add strength to their validity.

Some records, such as multidisciplinary team meetings, SystemOne records, email and diary records of meetings cancelled were systematic and made contemporaneously, so were unaffected by retrospective distortion. Whilst clinical records might reflect the perceptions of the record keeper, the content is based on clinical observations and management, and less likely to be subject to bias. In conclusion, it was acknowledged that application of the above sources of information to the CFIR and soft systems methodology were a limitation. Prospective application of the CFIR toolkit, independent third-party analysis or a thematic analysis would have had fewer limitations and thus greater validity.

4.2 Service evaluation designs

As mentioned in Chapter 4.1, service evaluations are conducted without the degree of controlled variables that are employed in research studies to reduce the introduction of bias. Therefore, service

evaluations are subject to many more confounding factors. Nonetheless, it is still possible to include degrees of control to enable more robust evaluation. There are ethical considerations, however. Delivering a service, for which there is already an evidence base, to one group and not another, could be considered unethical and unacceptable to health stakeholders. Conversely, interpretation of the findings of a service without a comparator is of limited value. This problem can be circumvented in several ways, and study evaluation designs, which could potentially have been used for this research, are described in the next sections, together with their advantages and limitations.

4.2.1 Before and after service design

Data about outcomes for the group to whom the service is being delivered could be collected for a period prior to the start of the service, which is known as the before and after design. This design is relatively simple, but there are flaws: if the source of data collection is from electronic information systems, data collected before the service commenced would be difficult to verify whereas data collected during the service could be cross-referenced with information collected both from the team delivering the service and care homes. For example, it would be difficult to identify people admitted to care homes for short periods of respite or for rehabilitation during the pre-intervention period. Furthermore, in a health and social care system with fluctuation in funding, admission criteria, service demand and policies, the findings of a before-after design could be significantly confounded by such changes.

4.2.2 Comparator and criteria population service designs

Comparator and criteria population designs help to address confounding factors such as changes in funding, admission criteria, services demand, and policies. These designs can be useful if the data collected from a service evaluation were also collected regionally or nationally, or if the comparator group is drawn from the same population, in which case changes in the local health and social care systems should have a similar impact on the comparator population. However, variation in the quality of local data fed into bigger systems or local factors, such as differing general practice cover

and the governance policies or nursing/residential mix of care homes, even within a small geographical area, can confound results.

4.2.3 Interrupted time series service design

An interrupted time series service design was another option. Although, it controls for the time trend confounding factors in a before-after service design, given that the interruption for each care home would occur at different times over a two-year period a time trend confounding factor would not be excluded. Additionally, if measurement were not continuous, unless time intervals were chosen carefully, information collected might be incomplete or might not reflect accurately the overall trend.

4.2.4 Step wedge randomised cluster service design

A step wedge randomised cluster (SWRC) design is so called because it is implemented in randomised care homes (clusters) in stages or steps. For the purposes of a service intervention to care homes, a step-wedge randomised cluster design has many advantages. It includes the longitudinal benefits of the before-after design, but also allows direct comparison within the service, because it can be implemented in care homes in stages. Where there is already an evidence base to support the intervention in question, it has an ethical advantage over the comparator population service design because the intention to implement across the entire population is likely to be more acceptable to stakeholders. There are limitations in using this experimental research method for care homes, however:

- if care homes are of unequal size, the steps cannot be uniform which make analysis more complex
- the timing when the first step of the service intervention is complete, particularly if an open cohort model is used, is debatable. Completion date of CGA or meeting date for an ACP are finite, but exactly when an ACP is accepted, and when it is implemented, is more difficult to define

- the design does not control for differences between care homes or for differences within care homes over time. Examples might include:
 - change in care home manager or owner during the project leading to changes in attitudes to advance care planning
 - care home staff turnover affecting the number of staff familiar with ACPs
 - new concepts viewed with initial hostility by staff, who subsequently become more accepting of the concept, may affect implementation rates and impact

4.3 Summary

At the start of this chapter, the evolution of implementation theory, the development of implementation science and Soft Systems Methodology were discussed. The types of implementation models were outlined. The domains of the CFIR were discussed in detail, and application to the Lincoln care home project was justified.

The second half of the chapter addresses service evaluation design models which might be used to implement the intervention, finishing with a description of the step wedge randomised cluster service design.

Chapter 5 Results of service evaluation

Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

The quantitative results, which related to the objectives of the project are reported in this chapter.

The objectives were to establish:

- the extent of participation of unselected care homes
- the acceptability of advance care planning to care home residents
- whether there was a change in healthcare use associated with ACPs
- whether residents with advance care plans died in their preferred place of care

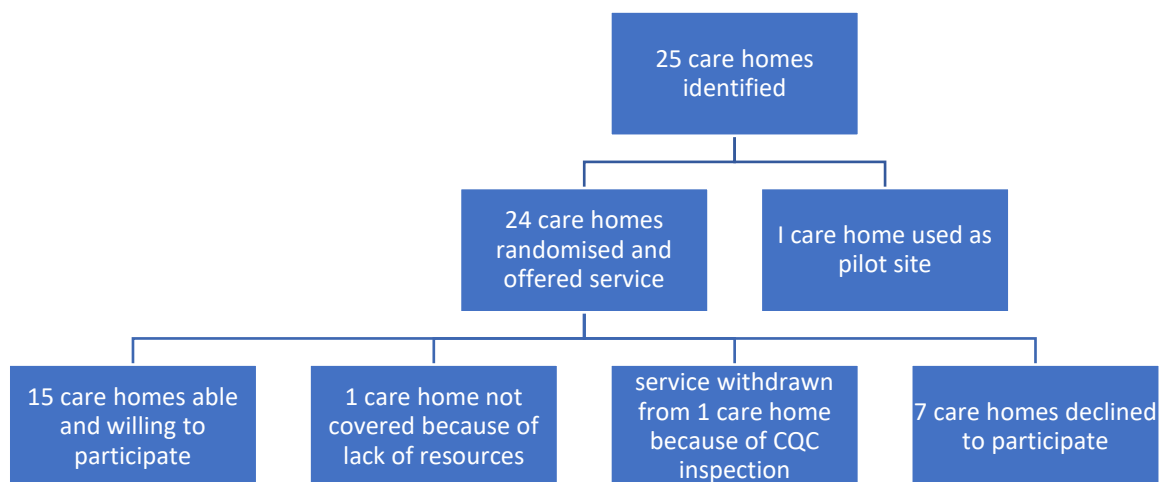
The results of the study addressing each of these objectives will be reported:

- care home participation, randomisation and characteristics
- recruitment of residents, their demographic and clinical characteristics, and numbers who underwent advance care planning
- results of healthcare use, as measured by hospital admission
- the residents' place of death and the relationship between preferred place of death and actual place of death for residents with ACPs

5.1 Baseline results

Twenty-five care homes were identified in the Lincoln area. One care home was used as a pilot site and the remaining 24 were randomised. The service was withdrawn from one of these because of an unannounced and intensive Care Quality Commission inspection which made implementation impossible. One care home could not be covered because of lack of resources at the end of the project, and seven (28%) declined to participate (Figure 5.1).

Figure 5.1 Flowchart for care homes participating in the project



Of the participating homes, seven were registered to provide personal care, five registered for residential and nursing care and three registered for nursing care.

Table 5.1 Characteristics of care homes participating in the project

Care Home	Registration	Places	Corporate status	Building
1	Residential	23	Large corporate	Purpose Built
2	Residential	50	Single home	Purpose built
3	Dual	22	Large corporate	Purpose built
4	Residential	50	Large corporate	Purpose built
5	Dual	48	Large corporate	Purpose built
6	Residential	44	Large charitable	Purpose built
7	Residential	33	Medium corporate	Converted
8	Dual	46	Large corporate	Purpose built
9	Residential	18	Small corporate	Converted
10	Dual	54	Large corporate	Purpose built
11	Nursing	24	Small corporate	Converted
12	Nursing	50	Small corporate	Converted
13	Nursing	40	Small corporate	Converted
14	Residential	30	Single home	Converted
15	Dual	47	Medium corporate	Purpose built

Five hundred and forty-eight residents were referred by their general practitioners between 1st November 2015 and 31st December 2017. Three hundred and fifty-eight residents (70.5%) were female and 150 (29.5%) were male.

Five hundred and twenty-nine (96.5%) residents underwent CGA between 1st December 2015 and 31st January 2018. Six residents died before an ACP could be drawn up; 14 residents left the care home, either to go home or to a care home uninvolved in the project; these residents were excluded from the evaluation. The records of one resident could not be traced. The mean age of the residents at CGA was 85.5, SD 7.7 years, with the mean age for males being 83.5, SD 8.5 years and females 86.4, SD 7.2 years. The mean age at CGA of residents who died was three years greater than the mean age of surviving residents ($p=0.015$).

The demographic characteristics of those who died and those who were alive at the end of the follow up period, 31.1.2019, are illustrated in Table 5.2. By the end of the follow up period 300/508 residents had died. Of these residents, 101 (33.7%) were men and 199 (66.3%) women. For the surviving 208 residents, 49 (23.6%) were men and 159 (76.4%) women.

Table 5.2 Demographics of care home residents included in service evaluation

	Alive on 31.1.2019			Dead		
	All Residents	Male	Female	All Residents	Male	Female
Mean Age at CGA (years) +SD	84.0 +8.2	79.5 +9.3	85.3 +7.3	87.0 +7.2	85.5 +7.4	87.2 +7.1
Mean Age at Death (years) +SD				87.3 +7.3	86.2 +7.4	87.8 +7.1
Survival (%)	208 (40.9)	49	159	300 (59.1)	101	199

The mean scores of the tools used for CGA were calculated. The results are illustrated in Table 5.3 and showed that the overall population had severe frailty, impaired function, severe cognitive impairment and 29.5% had BMI measurements of <20.

Table 5.3 Clinical characteristics of residents recruited to project

Tools used for Comprehensive Geriatric Assessment	Mean score \pm SD	Category		
		severe	moderate	mild
Edmonton Frail Scale	12.4 \pm 2.9	71%	15.5%	9.5%
Barthel Index	8.1 \pm 6.3			
Montreal Cognitive Assessment	7.2 \pm 7.9	63.5%	25.5%	7.4%
Malnutrition Universal Tool	1.0 \pm 1.4			
Body Mass Index	22.8 \pm 5.0			

Gold Standard Framework prognostic indicator guidance (Thomas and Free 2011) was used to assess residents who underwent CGA. These prognostic indicators were described in section 3.2, Table 3.2. They identify three triggers: the “Surprise Question”, general indicators of decline and condition-specific indicators.

More care home residents with ACPs (91%) were GSF positive than those without ACPs (9%) ($p < 0.0001$).

Table 5.4 Relationship between GSF and ACP

	ACP	No ACP	Pearson Chi squared test
GSF positive (%)	203 (91)	21 (9)	p<0.0001
GSF negative (%)	191 (69)	87 (31)	

5.2 Outcomes relating to research question

5.2.1 Characteristics of participating care homes

The outcome of the care home recruitment process is shown in Figure 5.1. The majority (72%) of the 25 care homes originally identified, agreed to participate in the project, supporting the first of the objectives of my research question. Of these, one care home was used as the pilot; the service could not be offered to one because of funding and the service was withdrawn from another because of a CQC inspection.

5.2.2 Recruitment of care home residents

Five hundred and eight residents were offered ACPs. Four hundred and four (79.5%) residents agreed to an ACP and 104 (20.5%) declined. These results demonstrated that, when implemented in routine practice, ACPs are acceptable to most care home residents, thus supporting the second research objective for my research question. Figure 5.2 illustrates the recruitment of care home residents into the service. These residents were followed up until death or until 31st January 2019.

Figure 5.2 Overall flow chart for residents recruited to and participating in project and their outcomes



5.2.3 Results of healthcare use

Healthcare use was the third objective of my research question. The results of hospital admissions of care home residents using the step wedge randomised cluster model are illustrated in Figure 5.3.

The results of the step wedge analysis showed a non-significant increase in admission rates and hospital length of stay following the intervention (see Table 5.5).

Two analyses were conducted to assess the effect of the intervention. The immediate effect was calculated by looking at the three-month admission data after the intervention was implemented in the last care home. The sustained effect was assessed by including ten months outcome data after the intervention was implemented in the last care home. Both analyses showed the same pattern.

Figure 5.3 Monthly hospital admissions by care home

Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1	2	1	1	2	1	2	1	0	1	1	4	0	1	0	1	1	1	3	0	2	0	0	1	4
2	0	2	4	4	1	6	4	3	3	6	3	1	1	6	2	4	3	7	4	1	2	1	5	5
3	1	1	1	1	0	1	3	2	2	2	3	1	0	5	1	4	0	1	3	0	0	0	0	2
4	0	0	0	1	0	0	1	1	0	1	2	1	0	0	0	0	2	0	0	0	1	0	0	1
5	2	0	1	3	1	5	3	4	3	5	5	5	3	7	7	2	2	4	1	5	3	7	3	4
6	0	5	2	0	3	2	4	3	6	2	3	2	2	0	2	6	2	3	2	8	7	2	5	3
7	1	0	1	3	2	2	2	0	0	0	1	5	2	0	1	2	2	3	0	1	4	4	1	3
8	3	2	4	1	1	4	1	3	3	5	1	4	4	0	3	1	3	3	1	2	2	2	4	2
9	1	0	2	4	2	3	1	1	1	0	1	1	1	1	0	3	2	0	3	1	1	0	2	1
10	5	3	4	2	2	4	5	4	2	3	5	3	2	3	4	5	3	3	4	6	2	3	3	4
11	6	4	2	1	1	5	4	3	2	2	1	2	1	2	3	3	0	1	0	5	0	0	1	3
12	8	9	5	9	3	6	7	5	7	6	5	9	15	3	5	6	6	9	3	10	4	2	4	6
13	6	7	5	5	5	3	4	2	4	2	4	5	6	4	2	3	1	4	3	0	3	3	1	3
14	4	2	4	3	1	0	2	2	4	1	1	2	3	3	2	4	2	0	3	0	2	1	5	4
15	1	0	3	0	1	1	5	2	2	1	3	0	1	0	2	0	1	2	1	3	0	1	2	2

Legend: coloured rectangles represent care homes. Start: month project started in care home. Finish date: month first tranche of CGAs completed

Care Home 1	Care Home 2	Care Home 3	Care Home 4	Care Home 5	Care Home 6	Care Home 7	Care Home 8	Care Home 9	Care Home 10	Care Home 11	Care Home 12	Care Home 13	Care Home 14	Care Home 15
• start 12/15 • finish 1/16	• start 1/16 • finish 3/16	• start 3/16 • finish 4/16	• start 5/16 • finish 7/16	• start 7/16 • finish 9/16	• start 9/16 • finish 11/16	• start 11/16 • finish 12/16	• start 12/16 • finish 01/17	• start 1/17 • finish 2/7	• start 3/17 • finish 5/17	• start 5/17 • finish 6/17	• start 6/17 • finish 7/17	• start 8/17 • finish 8/17	• start 9/17 • finish 9/17	• start 10/17 • finish 10/17

Table 5.5 Rates/odd of outcome by exposure status with effect of the intervention adjusted for time

	Control period incident rate/odds (95% confidence interval)	Intervention period incident rate/odds (95% confidence interval)	Effect size incident rate ratio/odds ratio (95% confidence interval)	p-value
IMMEDIATE EFFECT AFTER THREE MONTHS OF FOLLOW-UP				
Hospital admissions	1.87 (1.33-2.61)	2.18 (1.63-2.92)	1.15 (0.93 -1.42)	0.19
Hospital length of stay (days)	2.95 (1.38-6.28)	7.23 (2.84-18.42)	2.04 (0.83-5.02)	0.12
SUSTAINED EFFECT AFTER TEN MONTHS OF FOLLOW UP				
Hospital admissions	1.87 (1.38-6.28)	2.11 (1.55-2.87)	1.10 (0.91-1.35)	0.32
Hospital length of stay (days)	2.95 (1.38-6.28)	5.25 (2.46-11.22)	1.54 (0.69-3.43)	0.29

Following receipt of the analysis, I considered the possible reasons for this outcome. I re-examined all the admission data and found no discrepancies. Since the results of the step wedge randomised cluster study design had been implemented correctly, a sensitivity analysis was conducted to examine the periods 12 months pre-and post-intervention to see whether the implementation of advance care planning was associated with an increase in shorter admissions (Table 5.6). Neither the results of the step wedge randomised cluster analysis, nor the before/after analysis of admissions, supported a reduction in health care use associated with advance care planning as an intervention. These results confirmed that implementation of advance care planning by the Lincoln care home project was not associated with a reduction in admissions, and there was a trend towards an increase.

Table 5.6 Admissions before and after the intervention was introduced

Admissions	All admissions	>1 day	>2 days
12 months pre-intervention	362	340	268
12 months post-intervention	459	410	347
Increase in admissions	+97	+70	+79

5.2.4 Place of death

The care home was both the preferred and actual place of death for 219/248 (88.3%) residents with ACPs. One resident with an ACP wished to die in hospital and did so. For 49 care home residents without ACPs who died, 33 (67.3%) died in the care home, whereas 16 (32.7%) died in hospital (see Table 5.7). This result shows that having an ACP was associated with a significantly increased chance of dying in the care home, that is, in their preferred place of care, thus supporting the fourth objective of my research question.

Table 5.7 Deaths in care home according to ACP

	Deaths in care home	Deaths in Hospital	Pearson Chi squared test
ACP	219	29	P<0.01
No ACP	33	16	

5.3 Summary and conclusions

The key quantitative findings from this project were:

- The majority (72%) of the 25 care homes originally identified, agreed to participate in the project. However, one was used as a pilot care home, the service was withdrawn from one, and another did not participate because of lack of funding. Seven care homes (28%) declined to engage.

- Most residents (79.5%) agreed to have an ACP. These residents tended to be older and frailer, and were more likely to fulfil GSF prognostic indicator guidance
- The overall rate of hospital admissions for homes after the intervention did not decline. The trend was an increase in hospital admissions
- Of those residents who died, 33 (67%) of those without an ACP did so in the care home, compared to 219 (88%) of those with an ACP

Implementation of this service, delivering advance care planning to care home residents in routine practice, resulted in three of my four research objectives being met. However, this study failed to replicate one of the key findings of previous research, in that healthcare use was not reduced by the intervention. This finding clearly requires further investigation using implementation science models, which address implementation of the project within the wider system in which it was embedded.

This analysis will be discussed in the next chapter.

Chapter 6 Application of implementation science

6.1 Introduction

Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care home residents as part of Comprehensive Geriatric Assessment (CGA)?

The objective of this project was to establish whether the findings from randomised controlled trials of advance care planning for care home residents could be replicated when implemented in routine clinical practice, and to identify what issues arise in implementation. This chapter addresses the following:

1. Application of Soft Systems Methodology to the outcomes of the project
2. Application of the Consolidated Framework for Implementation Research (CFIR) to the outcomes of the project

6.2 Application of Soft Systems Methodology and implementation science

Soft Systems Methodology, as described in Section 4.1.1, helps to understand better how the different individuals and stakeholders involved in a project or system influence outcomes. The mnemonic CATWOE (Checkland and Scholes 1990) is often used to describe the root definition of the service.

Figure 6.1 The CATWOE Mnemonic (Checkland and Scholes 1990)

C	customers: the victims or beneficiaries of the transformation process
A	actors: those who do the transformation
T	transformation process: the conversion of input to output
W	Weltanschauung: the worldview which makes this transformation meaningful
O	owners: those who could stop the transformation
E	environmental constraints: elements outside the system which it takes as given

The importance of conducting studies in routine practice has already been stressed. To interpret the findings from this project the CFIR was used to analyse the results. As described in Section 4.1.3 and depicted in Figure 4.1, the CFIR consists of five domains:

1. the intervention
2. the inner setting
3. the outer setting
4. the individuals
5. the implementation

In developing the CFIR, Damschroder et al (2009) distilled constructs from 19 implementation theories. Application of the CFIR and these domains to this study is illustrated in Figure 6.2. It would be cumbersome and illogical to analyse separately the application of Soft Systems Methodology and the CFIR to the outcomes of the project, and therefore I have integrated the soft systems, where relevant, into each CFIR domain. The next sections describe this analysis of the project.

6.3. First domain: the intervention

6.3.1. The unadapted periphery

The reader will recall from Chapter 4 that the first domain of the CFIR describes how the intervention is implemented into an organisation. Without adaptation, the intervention is termed the unadapted periphery, which usually fits poorly into a setting. The nature of the intervention can

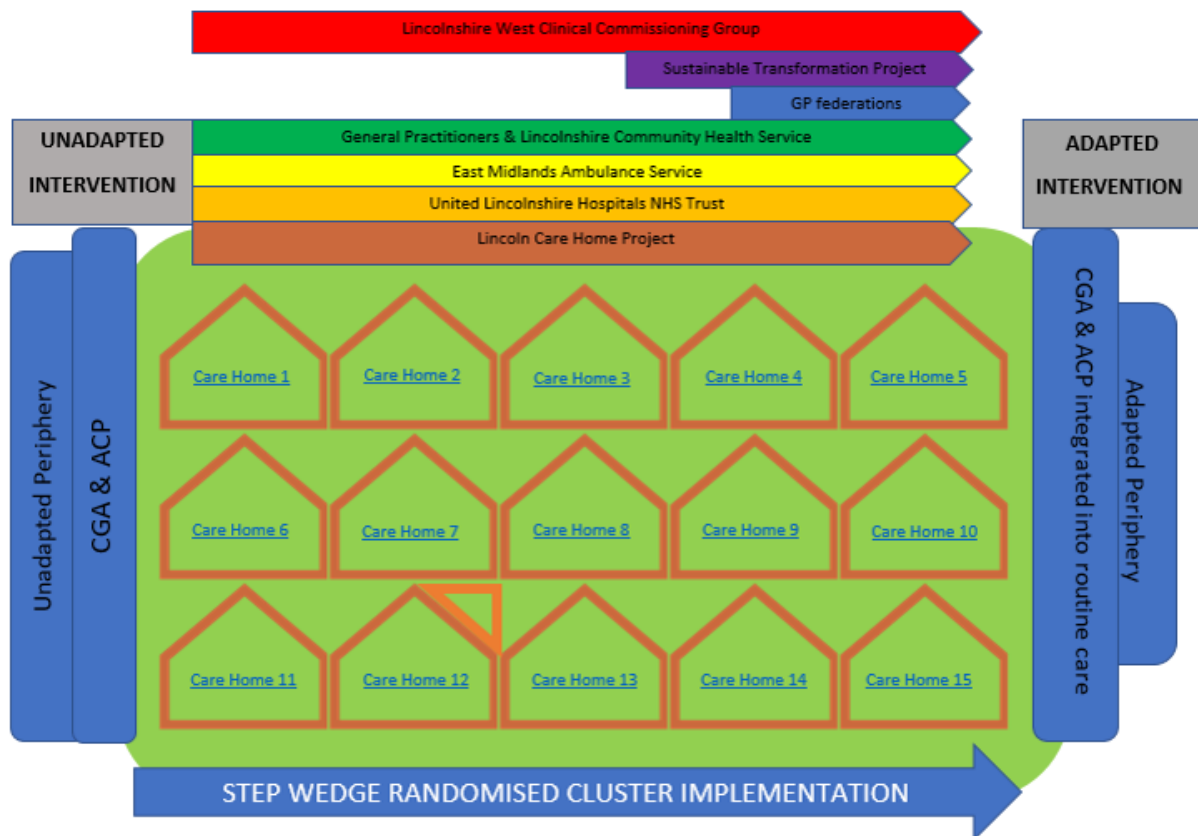
be shown with core components representing the essential and indispensable elements. The essential and indispensable core component of the intervention, representing the unadapted periphery in this project, was advance care planning embedded in Comprehensive Geriatric Assessment. The project was able to implement this core component in care homes, which agreed to participate in the project, without adaptation of the process of advance care planning or CGA.

6.3.2 The adapted periphery

6.3.2.1 Integration of intervention in care homes

By use of an active process to engage individuals affected by the intervention, it becomes the adapted periphery. The latter represents adaptable elements, structures and systems which can be modified according to the circumstances of the project. Thus, the adapted periphery represents how advance care planning, as part of CGA, was integrated into routine practice in the care homes. The plan from the outset of the project, was to store the results of the ACPs, the CGA, and the completed DNACPR forms as part of the residents' care records, so that they were available to both care home staff, and visiting healthcare workers. Only Care Home 2 declined to include ACPs and DNACPR forms in the body of their residents' care records; the possible reasons for this decision are discussed in section 6.6.3.

Figure 6.2 Application of the CFIR to the care home project



6.3.2.2 Integration of intervention into general practice

It was my experience that access to the health records of residents was routinely denied by many general practices, without written permission from their patients, because of data protection regulations. As data owners, the general practices were protecting their patients’ confidentiality, but gaining consent from the care home residents, who participated in the project, posed a challenge. The outcomes of Montreal Cognitive Assessment for care home residents in the project indicated significant cognitive impairment, with a mean score of 7.2. Of the residents undergoing advance care planning, only 96 (23.8%) had mental capacity to discuss their health care and future health plans. It is likely that their capacity to consent to sharing of their medical records might also have been impaired. Without permission to access the care records, the care home project team was dependent upon administrative staff in general practices to upload the documents, and so CGA assessments, DNACPR forms and content of ACPs were not consistently visible to healthcare professionals. To overcome this obstacle, the care home assessment team worked with each general

practice Caldicott guardian to help them understand the project, to establish their preferred process to share medical records on a best interest basis and thus to become actors in the project.

6.3.2.3 Integration of intervention into the electronic care record

Although inclusion of ACP, CGA and DNACPR forms in the care home records was decided by the individual care home, their inclusion in the electronic care record, SystemOne, was not. This process ensured consistency in availability of information about the residents to other healthcare professionals and helped to circumvent the issue with Care Home 2. The community health services trust, Lincolnshire Community Health Services NHS Trust (LCHS), was the owner of access to SystemOne. As with the general practice Caldicott guardians, after negotiation with Lincolnshire Community Health Services NHS Trust, its information technology department became an additional actor, which gave project team members full editing rights, and enabled them to upload ACP, CGA and DNACPR forms, complete the GSF record and add high priority notifications, which were visible to routine primary care, out of hours services, ambulance crews and the hospital emergency department.

6.3.2.4 Analysis of constructs relevant to the intervention

Constructs identified as relevant to the intervention were the source, evidence strength and quality, advantage, adaptability, trialability and complexity of the intervention, peer pressure and external policies and incentives. Each of these constructs will be applied in turn.

The intervention in this project, advance care planning for care home residents, was not part of the routine practice of the provider organisations in the outer setting organisations. The source of this project was a service developed in Boston, Lincolnshire in 2011 (Garden et al 2016), which Lincolnshire West Clinical Commissioning Group (LWCCG) wished to replicate in Lincoln.

The evidence for the intervention came from the two controlled research studies by Molloy et al (2000) and Caplan et al (2006), and the preliminary results of the small service evaluation in Boston (Garden et al, 2016). Although the quality of the research interventions was good, both published trials had been implemented in countries with very different healthcare systems. In contrast,

although the service intervention in Boston was not a randomised control trial and used a before/after design, it had been implemented in a local health care setting, had demonstrated a reduction of admissions from care homes in Boston, and thus was a source of interest to the wider Lincolnshire health community.

LWCCG, as a stakeholder, wished to implement an intervention which had been reported to be successful in another Clinical Commissioning Group in the county. It was my impression from discussions with leaders of LWCCG that their motivation was not just to reduce admissions from care homes, but also to introduce an intervention which benefited the care home population. This aspiration may also have been influenced by the chief operating officer, who hitherto had been Chief Executive of St Barnabas Hospice. Therefore, her worldview about the relevance of ACPs for care home residents was an important factor in choosing this intervention.

The project was considered attractive to LWCCG because it was readily adaptable to the Lincoln setting, and United Lincolnshire Hospitals Trust (ULHT) was willing to host the service.

Trialability was enabled by introduction of the intervention as a pilot in one of the Lincoln care homes which allowed the care home project team to develop expertise in CGA and advance care planning before implementation of the project in the randomised care homes. The pilot enabled the team to become familiar with SystmOne, to establish the best methods of documenting CGA and advance care planning outcomes and to alerting all health care professionals as to the presence of these plans and thus increased the chance of successful implementation.

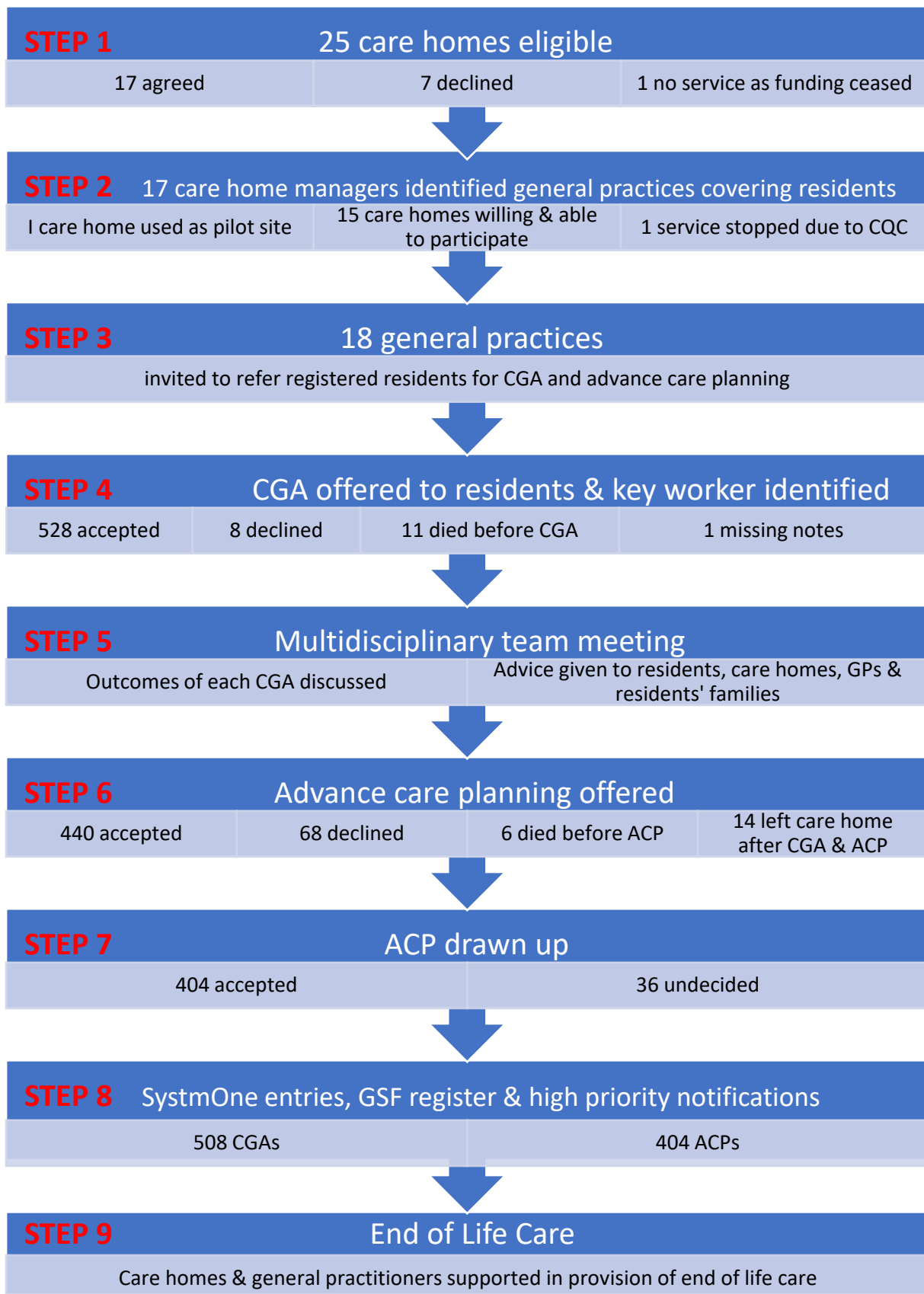
Complexity was the sixth construct to be considered for the intervention. Introduction of advance care planning as part of CGA to care homes in Lincoln was a highly complex process. There were nine steps in the implementation of this intervention with choice to participate at different steps of the intervention. Figure 6.3 illustrates the uptake of the intervention at each step. To implement the project successfully, the project team had to deliver each step as consistently as possible, whilst

negotiating the social characteristics of each home and individuals with different attitudes to the project.

The quality of the project design and packaging took account of the views of my PhD supervisors, stakeholder representatives from LWCCG, care homes and general practices. Packaging the intervention required development of leaflets explaining the project for stakeholders as well as preparation of templates for the assessments and advance care plans. The quality of information leaflets was improved with feedback from the ULHT readers' panel. Referral letter, CGA and ACP templates were designed to be comprehensive but sufficiently concise to attach to the electronic primary care record and to enable key facts to be readily visible to other healthcare workers. Use of these documents in the pilot home enabled further refinement before the project was implemented in the randomised care homes.

The overall cost of the service needed several factors to be considered. Money received from the Bromhead Medical Charity totalled £418,000 which included start-up costs for laptops, SystemOne licences, uniforms, the salaries of the project team, travel and training costs. Although the outcomes for 508 residents from the randomised care homes were analysed for the project, the overall cost of the project also included assessment of 129 residents in the pilot care home, 20 residents in the care home which withdrew from the project and 20 residents excluded from the evaluation, a total of 677 care home residents.

Figure 6.3 Figure illustrating steps/complexity of service



6.4 Second domain: the inner setting

The care homes in this project represent the inner setting for the intervention. The way in which constructs relevant to care homes interacted and influenced the project was complex and applied to differing degrees in individual care homes. The constructs which will be considered are the structural characteristics and the implementation climate.

6.4.1 Structural characteristics

Structural characteristics are the social architecture, age, maturity and size of an organisation. Each care home was an organisation, with different structural characteristics which influenced implementation of the intervention. The care homes which participated in the project were diverse, not only in registration, ownership and size as described, but also in nature.

During the project, four care homes were taken over by larger corporate organisations with associated changes in managers. Another manager retired. However, in most homes there was little turnover of nursing and care staff; the senior nurse and manager of Care Home 15 had been in post for 20 years. I observed that, in some instances, change in ownership led to improved governance and enrolling new care home managers as actors was key to continued successful implementation of the project.

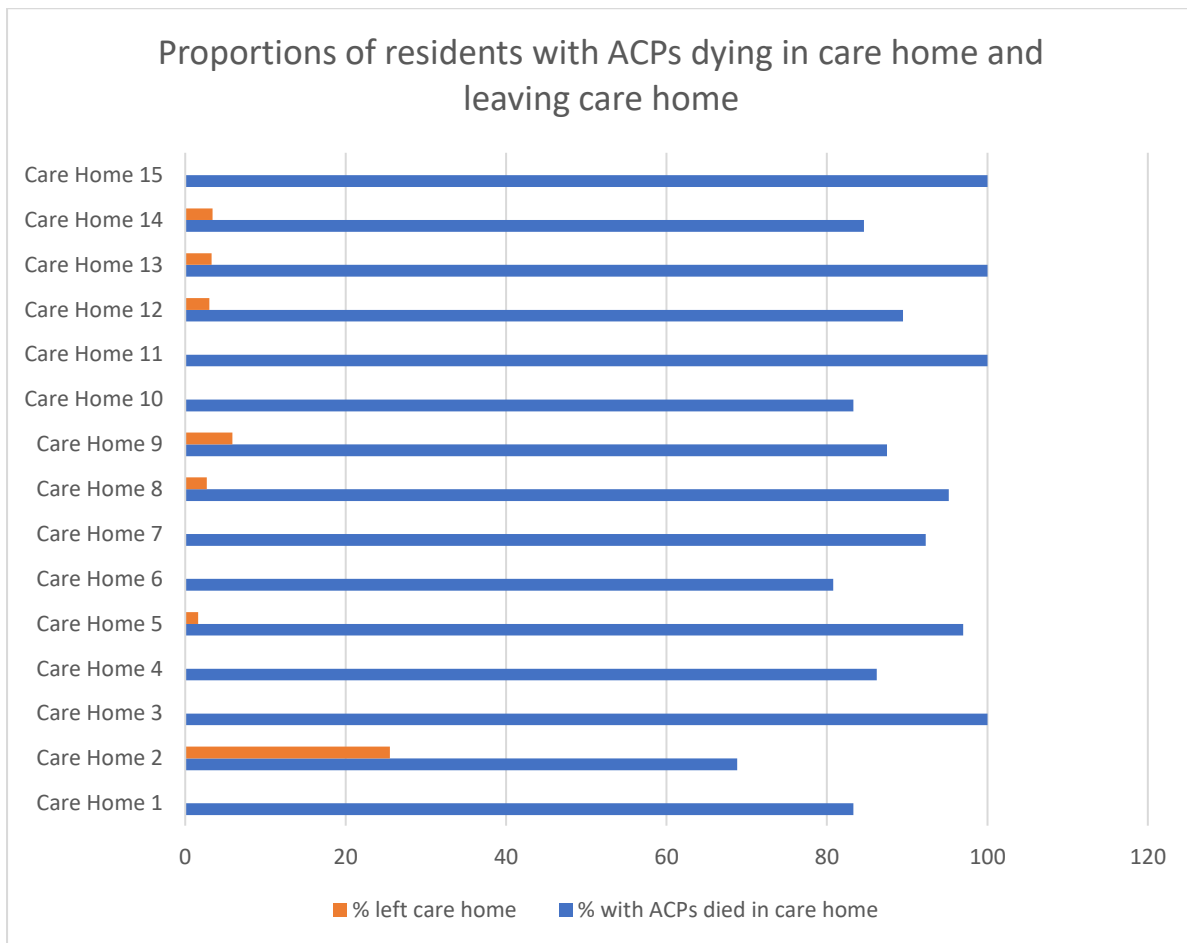
The *de facto* leadership, as opposed to the official leadership, in a care home appeared important in the project implementing advance care planning. In Care Homes 4, 11 and 15, there was stable, respected leadership, coupled with an understanding that their frail residents were coming to the end of life, which permeated to the staff. Therefore, the care home manager and the staff in these homes quickly became actors because they already shared the project's worldview and so advance care planning could be implemented. The proportion of residents with ACPs, who died in the care home, is illustrated in Figure 6.4. However, there was a different social architecture in Care Home 7. When the project was introduced, it was observed that care home staff, and local general practitioners took their lead from the senior carer, who appeared to be more influential than the

manager. However, with support from the team, the manager became more assertive, took on ownership of the project, became an actor in the transformation and persuaded her staff of the merits of advance care planning.

The social architecture in care homes did not only apply to leadership; it also was relevant to the facilities and activities offered by the participating care homes. In some homes, the environment appeared very clinical, whereas others were more like social centres. Care Home 2, for example, had beautiful décor, furnishings and facilities, and operated rather like a cruise ship with a routine and activities, in which all residents were expected to participate. It is relevant that it had the highest proportion of care home residents leaving the home; 12 (25.5%) of the residents assessed by the project team left during the project or follow up period, in contrast to 0% and 1.6% respectively in Care Homes 4 and 5 and less than 5% in all the other homes (see Figure 6.4). The project was unable to make the intended transformation in this home, because residents moved as their frailty increased, and the outcomes reflected this difference.

Interestingly, four care homes which declined to participate in the project, were long-established care homes owned by large charitable organisations. One had a corporate policy to admit sick residents to hospital; three, owned by the same organisation, declined to take part because of fears of upsetting families by talking about death. Discussion of advance directives on entering a care home in USA is mandated by law but remains optional in the UK. These care homes, although mature and well-meaning, as owners, effectively denied their residents and families choice to determine their care or become actors in the intervention. Although this group represented a minority (16%) of the care homes eligible for the intervention in Lincoln, these two organisations own 158 care homes across the UK, and would be an important consideration, as their attitudes might be a significant barrier to achieving more widespread implementation of advance care planning in the future.

Figure 6.4 Proportions of residents with ACPs dying in the care home and leaving the care home



6.4.2 Implementation climate

There has been increasing evidence for people’s preferences to die in their own home rather than hospital (National End of Life Intelligence Network, 2012). Advance care planning has been promoted by organisations such as the Gold Standards Framework as a means of enabling these preferences, and so there has been a changing worldview about ACPs. However, implementation is costly; care homes must pay for GSF training and trained staff need time to deliver ACPs, so advance care planning has remained an aspiration for many care homes. Therefore, we were implementing the project at a time when many care home managers wanted to become actors and welcomed implementation of advance care planning free of charge. Twenty-five (86.2%) of the residents who had ACPs died at Care Home 4, despite it being a residential home and 32 (97%) of residents with ACPs died in Care Home 5, a nursing home, suggesting that both care homes had receptive implementation climates. Once the project was instituted in these homes, they needed relatively

little support to follow ACPs, and to initiate end of life care when required. The implementation climate in Care Homes 6 and 12 was also supportive of advance care planning, but these care homes did need regular advice about implementation and help to organise end of life care.

6.5 Third domain: the outer setting

The outer setting comprised the following constructs: patient needs and resources, cosmopolitanism, networks and communication, culture, peer pressure, external policies and incentives. The different organisations or owners included:

- Individual general practices
- Lincolnshire Community Health Services NHS Trust (LCHS)
- NHS Lincolnshire West Clinical Commissioning Group (LWCCG)
- East Midlands Ambulance Service NHS Trust
- United Lincolnshire Hospitals NHS Trust (ULHT)
- Lincolnshire Sustainability and Transformation Partnership (LSTP)
- Two GP federations: Lincolnshire Imp Healthcare Limited (North Lincoln) and South Lincoln Healthcare Federation

The outer setting proved the most complex to negotiate, in part because of the large number of organisations, but also because of turnover of leadership, worsening financial positions, and changes in structure and influence of health and social care organisations during the project period.

Understanding how all the constructs of the outer setting of the CFIR applied to each organisation was challenging, in part because they were evolving during the project period, and in part because I was a minor service provider, rather than a leader in any of these organisations.

6.5.1 Patient needs and resources

It was my experience that all the organisations were aware of their patients' needs. However, the composition of the patient groups served by the acute, community and ambulance trusts and general practices differed, albeit with overlap. Therefore, for the ambulance trust, the core patient

group was people with acute illness. For LCHS, the community trust, many of their patients were frail older people and people with long term conditions, and for ULHT, the acute trust, patient groups were the acutely ill, outpatients and patients admitted for elective procedures. LWCCG had responsibility to purchase care for all these groups, whilst general practitioners were contracted to provide services for patients from all groups, but also for a substantial patient group with minor medical problems. These differences meant that each organisation's patient priorities varied.

The care home project's host organisation, United Lincolnshire Hospitals NHS Trust, whilst benefiting from income from acute admissions, had emergency, outpatient and treatment waiting time targets, and so had to prioritise these activities. Conversely, its clinicians, under whom care home residents were admitted, were strong advocates for the benefit of advance care planning; their clinical observation being that admission for care home residents with severe frailty often conferred little benefit, and indeed could sometimes cause harm. Despite this clinical view, unless the acute trust received future resources to deliver the care home project, it had no financial incentive to deliver an intervention which would reduce its income from acute admissions, and thus would never become an owner of the transformation.

Care of older people with frailty in the community comprised a substantial proportion of Lincolnshire Community Health Services workload, but the resources to deliver basic care were severely constrained; staff had large caseloads and were overstretched. Although the community trust had no specialist expertise in frailty, CGA or advance care planning, and no resources to develop these services, its staff were sometimes hostile to the project because they perceived care home residents as their territory. These perceptions undoubtedly deterred its staff from becoming actors, and despite attempts to discuss establishment of the care home project team in the community trust, there was little managerial engagement. Ultimately, LCHS was commissioned by South Lincoln General Practice Federation to provide a service to relieve its general practitioners of some of the care home responsibilities in the south of Lincoln. Thus, the organisation which might have been the

main owner in the project, with its staff among the leading actors, developed a parallel, but not comparable service, making acute assessments of deteriorating residents, but not undertaking proactive assessment and advance care planning.

The ambulance trust, East Midlands Ambulance Service, received payment for conveyance of patients. At the outset of the project, ambulance crews, often highly trained in emergency care procedures, tended to disregard ACPs, their worldview being to save lives. However, in response to increasing pressure from acute admissions, the health community collaborated to address the challenges, and the ambulance trust was asked to reduce the numbers of patients conveyed to hospital. Hitherto, its practitioners had adhered to the notion of duty of care, which in emergencies had been to apply life extending procedures without asking for consent, and in fact assuming it. I was invited to collaborate to deliver this objective, and East Midlands Ambulance Service became another owner of the transformation. Its staff received training about the management of frail older people and ACPs and they started to appreciate that their role in the care of this group might be to provide supportive intervention and not always to prolong life. We developed a scheme comprising a simple sticker on the care home entrance doors notifying crews that residents might have ACPs. This work helped to change the ambulance crews' perspectives so that they too became actors in the transformation. On occasions when ACPs were ignored, East Midlands Ambulance Service management was informed so that such cases could be managed internally, with a consequent reduction in these events.

The Lincolnshire Sustainability and Transformation Partnership and general practice federations were introduced by NHS England during the project. Introduction of the Lincolnshire Sustainability and Transformation Partnership led to a countywide review of services and at the same times the Clinical Commissioning Groups' commissioning role altered. Two general practice federations, Lincolnshire Imp Healthcare Limited and South Lincoln Healthcare Federation, were set up in the Lincolnshire West catchment area, each in competition for resources for service development. The

perception of leaders of the South Lincoln Healthcare Federation was that care home residents consumed a significant amount of general practitioners' time. It was successful in securing a large proportion of the available funding to set up an acute community response team. In contrast, Lincolnshire Imp Healthcare Limited received nothing; thus, care home residents in the south of the city were visited by specialist nurses whereas, in the north, visits remained the responsibility of the general practitioners. The changing roles of the existing organisations and evolution of new organisations with different perceptions of patient needs during the project not only impacted on care of residents in the south of Lincoln, but ultimately on long-term survival of the service provided by the care home project.

6.5.2 Cosmopolitanism, networks and communication, peer pressure

The stakeholders in Lincolnshire interacted with each other at senior level but networking further down the hierarchy, across the county and further afield, was inconsistent, in part because of geography and poor staffing levels. ULHT was in special measures due to a series of adverse Care Quality Commission reports and had a severe financial deficit which meant that there was persistent pressure to reduce the deficit and meet Care Quality Commission and A&E targets. It was my impression that the acute trust was under pressure to make existing systems work better, and to contain costs, rather than to develop new services. This firefighting culture reduced the social capital of the organisation and sapped the energy of its staff to work collaboratively, to explore innovations from outside Lincolnshire, or to implement them. In contrast, the Clinical Commissioning Groups appeared to have more time to network with each other, and further afield, and were more open to innovation. It is likely that LWCCG wanted the care home project to be implemented in Lincoln, in part because LECCG were proud of the outcomes of the Boston service, and the publicity generated by its shortlisting for two Health Service Journal awards. Thus, LECCG, as an owner, had become a customer and actor in the transformation, and by mimicking the service, LWCCG wanted to become a customer and actor too.

6.5.3 External policies and incentives

External policies and incentives are the final construct relevant to the outer setting. At the inception of the project there were no government mandates, recommendations or incentives to offer a care home intervention delivering advance care planning in Lincolnshire.

During the project, an external policy in the form of the Sepsis bundle was introduced. This bundle was developed in the UK and describes the six interventions intended to detect and treat sepsis in order to reduce mortality and morbidity (Daniels et al 2006). Introduction was associated with a national health campaign for universal delivery, irrespective of the patient group and prognosis. Although the term “infection” had been used in the early ACPs, healthcare and care home staff ignored these because they did not contain the term, sepsis. In this instance instigation of ACPs and the sepsis bundle did not anticipate the consequences of each other.

6.6 Fourth domain: the individuals involved

The individuals involved included: the project team members; residents and their families; care home managers and staff; general practitioners and community service staff. Engagement with these individuals was of paramount importance for successful project implementation but was also a challenging aspect of the project. At the outset, as they were recruited, the other members of the care home project team had a role as customers of the project. However, once the team had formed, we all became the actors delivering the transformation of advance care planning for care home residents in Lincoln. This transformation required the recruitment of other customers: care home residents and their families, care home staff, general practitioners and community health service staff. Each of these groups of individuals had different perspectives and depending upon those perspectives, participated to varying extents to deliver the transformation or declined to be involved. The varying attitudes to optimal care of frail older people in care homes, represented their worldview, which impacted upon delivery of the transformation, as did the stakeholders or owners, and the care home setting, the environment.

In the following sections I will address each group of customers and actors, and their role in the intended transformation.

6.6.1 Project team staff

The project team comprised two Registered General Nurses, a physiotherapist, an occupational therapist and me. The original members of the team had experience in the health care of older people, three at ULHT and two at LCHS. The latter had also worked for St Barnabas Hospice in the past. Although all members of the team worked in NHS posts prior to the project, their willingness to sacrifice the security of a permanent post for a two-year contract demonstrated, not only their commitment to the ethos of the project, but also their willingness to take a risk. The posts required ability to manage uncertainty and to have uncomfortable conversations with residents, their families and care home staff, as well as the practical skills for CGA.

The nurse who left was experienced in CGA, but I observed that managing uncertainty was challenging for her, and she preferred the structure of a hospital setting. Therefore, although she shared the team's worldview, she found she was unable to become an actor in the implementation. Her post was filled by a Registered General Nurse, who worked for the mental health trust's addiction services. My observation was that her practical expertise in CGA, together with her ability to manage uncertainty, difficult conversations, and to allow residents and their families time to make decisions, was an effective combination. Although her pace was slower, her ability to implement advance care planning effectively was excellent, and no complaints arose from her work. In retrospect, I think what made her effective was her ability to reconcile her worldview with her respect for the choices made by residents and their families. I observed that the other staff found uncompleted tasks unsettling. Hitherto, they worked for organisations with rapid patient turnover, performance measured by task completion, and little patient dissent about clinical tasks, so leaving an ACP incomplete was an anathema to them. Thus, their occupational culture, motivation for the success of the project, and belief in the value of advance care planning could lead to rushing

inadvertently to complete ACPs. The analogy with the fable of the hare and the tortoise was, and remains, important in successful transformation.

These observations lead me to examine my own contribution to the project and its implementation, and the lessons learned for successful future implementation. I have already described my role in the funding, the design, development and clinical delivery of the project. How much did my professional background, experience and personality contribute to the project outcomes? On reflection, my background in mental health and physical medicine was a valuable combination. Ability to undertake CGAs and formulate escalation plans, experience in leading multidisciplinary teams and management of people with challenging mental health disorders, in whom improvement is variable, and uncertainty frequent, were all skills acquired during my career. These were readily applicable to the project, as healthcare of care home residents is complex and nuanced. All are in the last few years of life, and many have multiple comorbidities associated with frailty, for which clinical guidelines and associated investigations and treatment need to be used cautiously and communicated sensitively. Remarkably, many of the families of care home residents in this project told me that no one had discussed their loved one's condition with them before. News of poor prognoses were often met with tears, but sometimes with anger or denial. In consequence, the project team had to support families in adjusting to this information, and in turn needed my support and guidance to do so. My role was particularly important in developing pragmatic and incremental management plans, helping the team to respect choice, irrespective of whether, in their view, it was not in the best interests of the residents. For future successful implementation, practitioners with these skills will be important. I would argue that specialist training in healthcare of older people should deliver many of the attributes required, especially as the principle of advance care planning becomes more widely appreciated.

6.6.2 Care home residents and their families

Care home residents and their families responded in different ways to advance care planning, as described in Chapter 5. Altogether, 404 (79.5%) residents, or their families, welcomed advance care

planning and wished to participate in discussions which proceeded to development of individual ACPs. Using the CATWOE model, they could be considered as additional customers who shared the worldview of escalation planning for deterioration in health, and by participating in advance care planning, they became actors in the transformation. Thirty-seven (7.3%) participated in advance care planning discussions but were unable to agree to a formal ACP. These people did not object overtly to advance care planning, but appeared to have difficulty in managing uncertainty, or could not achieve consensus within the family. Although they were customers, they did not become actors and were unable to embrace the transformation. The remaining 68 residents (13.4%), or their families were hostile to the concept of an ACP; they too were customers, but had a different worldview, and declined to participate in discussions. However, attitudes could change depending upon circumstances. For example, following experience of a hospital admission, some members of the latter two groups approached the project team for ACPs, and they too became actors in the transformation. Appreciating the views of different factions within the group of care home residents and their families was important, not only to respect their choices, but also to appreciate that choices can change, and the door should always be left open.

6.6.3 Care home staff

There was a difference in philosophy about advance care planning amongst staff in the care homes in which the project was implemented. In some care homes staff shared the worldview of the benefits of advance care planning, whilst in others, staff were more ambivalent, or frankly hostile.

In Care Home 7, 21 (92.3%) residents with ACPs died in the care home. However, the overall numbers belied a more complex pattern of admissions. There was an increase in admissions from three in the six months before the project started, to seven in the six months after implementation. These results demonstrated the pivotal role of care home staff in implementation of ACPs. In this care home, the senior carer did not agree with the concept of ACPs and resisted their implementation. These objections were shared by the other carers and passed on to families of residents. I learned soon after we arrived that members of the project team were called “Angels of

Death". Initially, the carers were also resistant to medication changes, especially reduction of antipsychotics. SystemOne review showed that the senior carer frequently contacted the general practice to request a reinstatement of any medication stopped, or reduced, by the care home project team. These carers also believed the best care for their residents, when ill, could only be provided in hospital, and as such they were acting as their residents' owners.

In this care home, sensitive support from the project team, together with education sessions about frailty, ACPs and end of life care, led to changed attitudes to ACPs. The staff began to appreciate the benefits of good palliative care, not only for their residents, but also for families, and for their own professional satisfaction. Thus, they became actors in the transformation, and started to take pride in being able to look after their residents, even when dying. This transformation was reflected in a decline in admissions to hospital: six in the subsequent 15 months; an increase in the uptake of ACPs and increasing numbers of residents dying in their preferred place of care. At my final interview with the manager of Care Home 7, she described, weeping, the positive impact of this philosophical transition, and the pride it had instilled in her staff.

I witnessed different degrees of paternalism in many care homes. Improving respect for autonomy, expert opinion, and notion of shared decision making in the public sector, is not always mirrored in care homes, and their residents, especially those with cognitive impairment and severe frailty, are highly vulnerable to paternalism. However, whilst in Care Home 7, education and support changed attitudes to ACPs; in another care homes paternalism continued, despite the intervention. Care Home 2 had the lowest proportion of residents with ACPs, and just 11 residents (68.8%) died in their preferred place of care. These outcomes reflected the care home leadership. It was my observation that the manager acted as though she was the owner of her residents' care and had strong opinions about diagnosis, medication and medication, despite lack of clinical background. She never embraced the concept of ACPs, declined to include them in care records, and appeared to disregard them if, in her opinion, the resident should be admitted to hospital. Despite our efforts, she never

participated as an actor, instead asserting her ownership over all aspects of the home, and those who visited.

In summary, the Weltanschauung, or worldview, of key staff within each care home impacted upon their ability to become actors in the implementation of advance care planning. Some staff were actors from the outset, others took time to enrol, and some retained their disapproval. Thus, care home staff had a crucial role in the success of the intervention in each home.

6.6.4 General practitioners

General practitioner engagement in the project varied greatly, and as such their role as customers and actors varied too. To understand the reasons better, issues such as care home cover, consultation styles and attitudes require description.

General practitioners' attitudes to provision of cover for care homes residents varied greatly and were influenced by their worldview, which in turn reflected professional speciality preferences, targets determined centrally by NHS England, care home cover arrangements, and preferences for individual care homes or environments. Many general practitioners regarded care home residents as an onerous responsibility, for which they received no additional remuneration, and which they had to fit in around their surgeries and home visits. At the outset, we that found most were resistant to prescribing pre-emptive drugs (drugs for pain, sickness, agitation, delirium and respiratory secretions), possibly because of the aftermath of the Shipman case, but also because of their own misconceptions. One general practitioner told us "people with dementia don't feel pain"; another when requested to prescribe pre-emptive medication said "I thought those drugs were just for people with cancer"; another, married to a pharmacist, objected to the expense of too many "just in case" drugs being made available. I took every opportunity to participate in general practice educational meetings, and once the project became established, and trust in the care home project team developed, we found that attitudes changed. Most general practitioners became comfortable and confident in prescribing pre-emptive medication, and would initiate these drugs themselves, thus aiding the transformation.

Some general practitioners also welcomed the project because it provided a thorough baseline assessment of each resident; delivered an escalation plan; reduced the need for them to have lengthy conversations with relatives, and fulfilled statutory obligations, such as medicines review. They became willing customers and actors, who contributed to transformation, and were powerful advocates of the project. Some appeared to dislike delivery of care for this group, managing routine care by delegating to practice nurses, and sending care home residents with deteriorating health to emergency services. Although this group of general practitioners were customers, the proactive nature of the care home project was insufficient, and they never engaged as permanent actors. Ultimately, as the South Lincoln Healthcare Federation, this group developed a reactive nurse-led service.

Seven of the care homes in the project were covered by multiple general practices and eight were covered by just one practice. The former arrangement caused considerable discontent, because the general practitioners viewed it as inefficient; they would be called out on successive days to the same care home, often meeting colleagues from other general practices visiting simultaneously. The rationale for multiple general practice cover was given as patient choice, but as mentioned previously, most residents lacked mental capacity to discuss their healthcare. Many had moved out of their former general practice area; they rarely visited surgeries and many of their former general practitioners had retired or moved, and replacements appointed. It was clear that patient choice did not explain why some care homes were covered by one practice, and others by multiple practices. It was my perception that some care homes were unpopular with general practitioners, and at these care homes new residents were allocated to general practices by the Clinical Commissioning Group. Conversely, some general practices were unpopular with care homes, and perceived as uninterested, always being in a hurry or advising contacting 999 in the event of a medical emergency rather than visiting. These local factors appeared to impact upon healthcare use in complex ways; for example, in the same care home, residents covered by one general practice might always be visited by a general practitioner, whereas residents covered by another general practice might be sent into

hospital via a 999 call. Even for care homes covered by just one general practice, responses to a deteriorating resident differed; some general practitioners prescribed antibiotics on being telephoned by care home staff; one general practitioner always delegated visits to practice nurses; another would visit, but admission to hospital would usually ensue.

6.6.5 The community healthcare services staff

The community health care services in Lincoln were delivered by Lincolnshire Community Health Services (LCHS). Within Lincoln, services were organised geographically into north and south neighbourhood teams led by different managers. Prior to starting the project, I attended neighbourhood team meetings to introduce the project.

The care home project was introduced at a time when LCHS staff had large caseloads. It was my observation that morale was poor, and although staff had considerable experience in caring for older people, much was task-orientated tissue viability visits, for which they were required to make detailed records about the task and time spent on SystmOne. There had also been a shift in base from general practice to community hot desks, so liaison with general practices was curtailed, and with that, a sense of belonging, and less access to medical expertise. It was into this climate that the care home project, replete with its own doctor, multidisciplinary team, smaller caseload and single purpose, was launched. The community staff knew nothing of overtures made to their leaders about setting up the project in their Trust, and in retrospect, the hostility the project team encountered was, perhaps, understandable, as the community staff perceived care home residents as their territory. Added to this intrusion, invariably contact from the project team was to ask community staff to do more, such as order equipment, which added to their workload. Given these circumstances, it is hardly surprising that community staff were deterred from becoming actors.

6.7 Fifth domain: the implementation process

The implementation process was the introduction of the care home project. Its successful introduction required several factors to be addressed:

- Choice of a service model which would offer the best way of evaluating the project. For reasons discussed in Section 4.2, the step wedge randomised cluster intervention was thought to be the best method for evaluating the project
- The cooperation of the stakeholders in the outer setting
- The cooperation of the care homes in the inner setting

Execution of the step wedge randomised cluster implementation was complex.

- The care homes were of different size and had different resident profiles. It would not have been acceptable to alter the initial service introduction period to ensure all the steps were of identical length, because that would have meant that members of the care home project team were either underemployed, or working under too much pressure. Therefore, the steps were of variable length.
- The capacity of the care home project team varied due to staff illness, vacancy and experience. Two members had lengthy periods of sickness. Two members left during the project and a third member returned to hospital work after three months, which led to prolonged vacancies because of human resource issues. One replacement member appointed left after a year, by which time it was felt that it would be difficult to recruit another person just for a six-month period. At the outset of the project, the team was inexperienced, whereas towards the end of the project processes were familiar, and so introduction of the service to care homes, and the ensuing assessments of residents required less time. As care homes had differing number of residents, the team spent varying periods of time in each care home during the step-wedge implementation.

6.8 Conclusion

This chapter has provided an analysis of the project outcomes using Soft Systems Methodology and the Consolidated Framework for Implementation Research. Analysis of the outcomes of the project implemented in routine care using theoretical frameworks illustrated not only the complexity of the

healthcare system, but also its dynamic nature. It is acknowledged that my own worldview may have influenced my interpretation of the outcomes of the project. Objectivity might be improved by involvement of independent researchers in the analysis. The next chapter brings together the findings from both quantitative data and implementation methods and seeks to place the significance of this work in the overall context of research, practice, and policy of advance care planning.

Chapter 7 Discussion

7.1 Summary of the core results that address the research questions

Are the benefits of advance care planning for care home residents, as demonstrated by research studies, seen when implemented in a large-scale clinical service offering advance care planning for care residents as part of Comprehensive Geriatric Assessment (CGA)?

The benefits demonstrated by the research studies were:

- a reduction in hospital admissions of 42% (Molloy et al 2000); Morrison et al 2005; Caplan et al 2007)
- increases in numbers of residents dying in the care home of 29% (Livingston et al 2013), 39.3% (Levy et al 2008) and 100% (Caplan et al 2006)
- a reduction in health care costs of 48% (Molloy et al 2000)

The implementation objectives were:

1. Were we able to implement a service delivering advance care planning as part of CGA as a large-scale clinical service in an unselected group of care homes?
2. Was advance care planning acceptable to care home residents in these care homes?
3. Did possession of an ACP for care home residents affect their healthcare use?
4. Did possession of an ACP for care home residents affect the place where they died?

In answer to the objectives of the research in this thesis:

1. Advance care planning embedded in CGA for care home residents was implemented as a large-scale service in unselected care homes. Of the care homes identified and offered the service during the project period, 68% were willing and able to participate
2. Advance care planning was acceptable to 79.5% of care home residents. Those residents who accepted ACP were significantly older, had significantly greater levels of frailty, poorer function, cognition, and nutritional status than residents who did not have ACPs.

Unsurprisingly therefore, a greater number of the group with ACPs who died were GSF positive (63%) compared to the group without ACPs (35.4%).

3. With respect to healthcare use, advance care planning was not associated with a reduction in admissions, as demonstrated by earlier research studies. In fact, there was a trend towards increased admissions.
4. Sixty percent of the residents; 249 (62.7%) of those with an ACP and 50 (44.5%) of those without an ACP died, enabling place of death to be ascertained. Residents with ACPs were significantly more likely than those without ACPs to die in the care home, which for 98%, was the preferred place of death.

Thus, implementation of this service, delivering advance care planning to care home residents in routine practice, resulted in three of my four research objectives being met. However, this study failed to replicate one of the key findings of previous research, in that healthcare use was not reduced by the intervention.

7.2 Limitations and strengths of the study

With respect to hospital admissions, the results of this study do not reflect the findings of the research studies, and so errors in implementation, data collection or data analysis need consideration.

7.2.1 Data collection and analysis

The hospital admission data were collected electronically by the hospital informatics department.

The same information officer was responsible throughout the project and used a consistent data collection system. The admission data were double checked, and therefore, there is no evidence to suggest the admission data were inaccurate.

The demographic data, results of the CGA, and ACP status of individual residents were entered by project team members, and double checked by reference to the original case notes. In the case of

the residents who died, a further check of the data occurred with completion of a Client Service Receipt Inventory. Therefore, all reasonable steps were taken to ensure the data were accurate.

Analysis of the results of step-wedge admission data was conducted by a medical statistician, with experience of step-wedge analysis. The contradiction of the results of this study with those of research studies led me to do an analysis of admissions 12 months before and after implementation of the project. This secondary analysis supported the results of the step-wedge analysis, and thus there is no reason to support the latter being invalid.

7.2.2 Uptake of ACPs and fidelity

This project was implemented in a whole health system in an unselected group of care homes, supported by more than 18 different general practices and 90 general practitioners. I tried to mitigate inconsistency by visiting all care homes and general practices before and during the project, but the degree of motivation, participation and support was variable.

Seven (28%) of the care homes chose not to participate in a quality improvement exercise. These homes did not have ACPs in place, and so they denied their residents opportunity to undergo CGA, to have an ACP and to be able to express choice in their future care, in accordance with best ethical practice.

One of the strengths of this study was the choice of a step wedge randomised cluster design, and its successful execution. Although the step wedge randomised cluster design did not have the same degree of control as a randomised controlled trial might have done, its use for a service evaluation had many advantages. The order of implementation was randomised, and the design allowed for each care home to have a control period before the service was implemented. Additionally, the fact that the plan was to offer all identified care homes the service made the study design more acceptable to the funding charity, care homes, general practitioners, and other stakeholders than a RCT. The plan for universal implementation and use of an open cohort meant that ethics committee approval was not required and allowed residents admitted after the initial step to be offered

advance care planning for as long as the service was in operation. Furthermore, for a service with cost constraints, it was highly pragmatic. The whole multidisciplinary team could be deployed in each care home for the initial step, which enabled holistic assessments and made most efficient use of the available resources. Designation of a key worker to liaise subsequently with each care home enhanced relationships, and ensured new residents and deaths were identified.

However, there were limitations in using a step wedge randomised cluster design for this project. These limitations included accurate determination of step length; synchronicity of step start and finish and admission data; unequal step length; differences in care home cultures and longitudinal changes in ownership, leadership and staffing of care homes, community resources and acute hospital targets.

- Completion of each step of the intervention, particularly using an open cohort model as in this study was difficult to define. Whilst the dates CGAs were completed, the time when all the residents' ACPs in a specific care home were documented in the care records and the primary care electronic records were much less precise, and could lag weeks beyond the CGA date, particularly if communication with families was challenging.
- Hospital admission data corresponded to calendar months, whereas the start and finish of each step might occur at different times of the month.

The care homes differed in size, so steps could not be uniform which made analysis more complex. However, analysis of the results of step-wedge admission data was conducted by a medical statistician, with experience of step-wedge analysis so this limitation was overcome. Furthermore, the results of the step-wedge analysis were supported by the secondary analysis of admissions 12 months before and after implementation of the project.

- The step wedge randomised cluster design could not control for differences between care homes in uptake and acceptance of ACPs. In some care home ACPs were embraced and

implemented immediately. In others, acceptance might take several months, whilst in a minority there might be no acceptance at all.

- Step wedge randomised cluster designs are vulnerable to longitudinal change. The project was conducted over a twenty-five-month period, during which there were changes in care home ownership, managers, care registration, staff turnover and ease of recruitment. Thus, a care home might have had more nursing beds, less staff turnover and fewer recruitment challenges in the control period than in the intervention period when nursing beds were deregistered, and staff shortages were common. Unlike a parallel controlled study, the impact of such factors on admission rates could not be assessed.

Lack of a control group might have been mitigated by monitoring admissions to Lincoln County Hospital from other care homes in the area. A secondary analysis of admissions from the care homes which declined to participate would be possible, but their refusal to participate may have reflected that they were different in some way from the participating homes. If a secondary analysis were undertaken, it would be preferable to compare with care homes, which would have participated in the project, had they had opportunity to do so.

The previously published RCTs had follow up periods of 18 months or longer (Molloy et al 2000; Caplan et al 2006). Use of the step-wedge project design in this project meant that the care homes had different lengths of follow-up of between 22 months and one month (mean 10.7 months) whilst the project team was in place and between 33 and 12 months (mean 23 months) overall. Therefore, a possible limitation of the project, was that there was insufficient follow up with the team supporting implementation of the ACPs. However, the care homes with follow up periods of 17 months or longer, when the project team was in place, had a four-fold increase in admissions, as opposed to no increase in admissions for the care homes which had follow up periods of six months or shorter. Thus, insufficient follow up would not appear to have been a limitation and reason for failure to replicate the results of the research studies.

Insufficient uptake of ACPs does not appear to have been a limitation. ACPs were put in place for 79.5% of care home residents participating in the project, in comparison to ACPs in place for 89% of residents in the Canadian study (Molloy et al 2000) and 31% in the Australian study (Caplan et al 2006), so insufficient uptake of ACPs does not explain the project's findings.

7.2.3 Systemic factors

Systemic factors should be considered. Chapter 6 has described the application of implementation science to the project outcomes. Implementation of this project was at a time of increasing pressures on the health and social care system. Failure to use an implementation science model, such as the CFIR, which prospectively addressed the integration of the project into the whole system was a limitation, as its use might have anticipated some of the challenges encountered. In the event, retrospective application of the domains of the CFIR to the project offered insight into the system dynamics.

There are three main research paradigms: positivism, constructivism, and pragmatism. At the outset, my intention was to take a deductive approach in that there was already a body of knowledge in existence which I wished to test using quantitative methods to answer my research question. This was a positivist approach. Constructivists, on the other hand, do not believe in a set reality and use interpretation to analyse results. The failure of the project to replicate the quantitative reduction in healthcare use reported by the research studies required additional explanation. The third paradigm, pragmatism suggests that reality is constantly renegotiated and interpreted and both quantitative and qualitative methods can be used to explain findings. Thus, having set out with a positivist approach, the study outcomes led me to adopt a pragmatist research paradigm. The challenge was retrospective application of qualitative methods to my study findings. On reflection, it would have been wise to have anticipated issues would arise when trying to implement research findings in routine practice and to have incorporated a qualitative study. Action research or ethnography would have been two possible methodologies.

Prospective use of action research could have been used because it is often associated with hands-on small scale projects in which research is done at the same time a service is implemented, knowledge gained about the setting and the process of research (Moule and Goodwin 2014). However, it is questionable as to whether it would have been suitable for a step wedge randomised cluster study design, because of the emphasis on continued reflection and consequent revision and action would have introduced more confounding variables.

Ethnography derives from social anthropology (Gilham 2008), a subject made famous by Margaret Mead in her study of Samoan culture (Mead 1928), and literally translated is a “portrait of people”. It investigates culture through in-depth study of certain groups (Spradley and McCurdy 1972) through immersion in the setting and attempts to understand how certain policies and practices shape human experience (Denzin 2003). It is highly relevant to health care settings and making improvement in the NHS (Morse and Field 1995) and thus to interpretation of the findings of this project. Three types of ethnography have been described: descriptive, critical and autoethnography.

By describing the organisations, groups and individuals in the health and social care system in which this project was embedded, patterns, power, hidden agendas, and categories could be identified analysed and thus ethnographic methods could be applied to the project. By using the domains of the CFIR, a detailed and systematic picture evolved.

When using the CFIR as a framework to examine the health and social care setting into which the project was introduced, the retrospective application required use of data collected from the sources described in 4.1.4. This problem was addressed by use of trustworthiness (Lincoln and Guba 1985) described in the following section.

7.2.3.1 Trustworthiness

The validity, reliability and generalisability of retrospective application of qualitative data drawn from field notes, diaries, MDT and healthcare records to the CFIR is an important consideration. Use of a

respected systematic model is especially important when using content from such raw data without a theory-based categorisation matrix (Elo et al 2014). Trustworthiness, originally described by Lincoln and Guba (1985), provides criteria which allow the analysis to be reported accurately, thus supporting the argument that that the findings “are worth paying attention to” (Lincoln and Guba 1985). They proposed four alternatives to assess the trustworthiness of qualitative research: credibility, dependability, conformability, and transferability. Since their original proposal, authenticity has been added as an additional criterion (Guba and Lincoln 1994), and there has been further operationalisation (Elo et al 2014).

The strategies I used to ensure trustworthiness as described by Lincoln and Guba’s model when applying the findings from this project to the CFIR are described in Figure 7.1.

Figure 7.1 Strategies I used to ensure Trustworthiness when applying findings from this project to the CFIR

Criteria	Strategies
<p>Credibility: the degree to which the data makes sense (Finlay 2006)</p>	<ol style="list-style-type: none"> 1. Extensive experience in advance care planning acquired as part of my clinical work as a liaison psychiatrist in running outpatient clinics for people with dementia and an earlier care home project (Garden et al 2016) 2. Prolonged engagement with representatives of the outer setting (WLCCG, LCHS, ULHT, LSTP and general practitioners) and individuals in the inner setting (care home staff) for six months prior to the project starting, throughout the implementation and the follow up period, which totalled 44 months. Prolonged engagement with care home staff, residents, family, and the project team during the implementation period. This engagement allowed me to learn about the culture in which the project was implemented, build trust, reflect upon how the project itself, my own and the project team’s attitudes to advance care planning and CGA might influence outcomes 3. Triangulation <ol style="list-style-type: none"> a. Data triangulation by combining project outcomes for individual care homes or general practices with persistent observation, interviews, field notes, multidisciplinary team meeting and diary records and information from the electronic care record. b. Theoretical triangulation by combining multiple perspectives from the sources described above applied to the CFIR to explain the overall project outcomes 4. Member checking by returning data and their interpretations to organisations in the outer setting, specifically LWCCG, ULHT and general practitioners, and care home managers in the inner setting

	<p>This process allowed access to data derived from the project and their interpretations to be supported or challenged</p> <p>5. Peer debriefing through regular discussion with my academic supervisors</p>
<p>Dependability: the stability of data over time and under different conditions</p>	<ol style="list-style-type: none"> 1. Detailed description of project implementation over 26 months and follow up over 12 months and changes, if any, over time and in different settings 2. Regular discussions with my academic supervisors
<p>Confirmability: objectivity about the data's accuracy, relevance and meaning</p>	<ol style="list-style-type: none"> 1. Reflexivity: by describing my position as a researcher at the outset and end of the project, how that influenced implementation of the project and expectations of organisations and individuals in the outer and inner setting, and how my position was influenced by the project process 2. Triangulation: my observations, interviews, field notes, multidisciplinary team meetings, diary records and information from the electronic care record; this diverse data contained varied perspective, thus increasing the credibility of my synthesis using the CFIR 3. Detailed description of project implementation over 26 months and follow up over 12 months and changes, if any, over time and in different settings
<p>Transferability: potential for extrapolation relying on the reasoning that findings can be generalised or transferred to other settings or groups</p>	<ol style="list-style-type: none"> 1. Thick contextual description of the context of the project with information about the responsibilities and constraints of the organisations in the outer and inner settings and the background, experience, and roles of individuals in the inner setting illuminated the social interactions impacting the project

<p>Authenticity: extent to which researchers, fairly and faithfully, show a range of realities</p>	<ol style="list-style-type: none"> 1. Fairness: <ol style="list-style-type: none"> a. the project was implemented in an unselected group of care homes b. the same process (CGA and advance care planning) was implemented in all the care homes and the outcomes communicated in the same format by use of SystemOne c. By selection and description of material from my data sources, and discussion of meaningful interpretations I have added my voice to the discourse system 2. Ontological authenticity: inherent to CGA is placement of the person and their carers at the heart of the process. Relationships with care home staff, residents, family and general practitioners were fostered to raise consciousness, improve understanding, and sophistication in relation to CGA and advance care planning, ACPs and their implementation 3. Educative authenticity: By including education as part of the implementation the project team enhanced general practitioner and care home staff understanding of CGA and advance care planning 4. Catalytic authenticity: sharing and developing the project plans with stakeholders prior to and during implementation and the follow up period, maintained awareness of the project, improved understanding of frailty CGA and advance care planning in the health and social care community
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7.2.3.2 The first domain: advance care planning

The first domain was the intervention, advance care planning. The nature of this process, including insufficient specificity or the content may have influenced the study outcomes.

There was no evidence the ACPs were insufficiently specific, except for using the word sepsis instead of infection, when the Sepsis bundle was introduced. There has been a tendency to conflate possession of an ACP with a wish for palliative care and avoidance of hospital admission. Although care home residents are in the last years of life, their levels of day to day function vary considerably. During this study, it was evident that care home residents and families often wanted hospital admission for non-fatal changes in health, whilst function and quality of life were perceived as good, whereas when GSF prognostic indicators were fulfilled, palliative care was usually the preferred option. Thus, it is possible, by enabling care home residents to have comprehensive ACPs, residents' wishes as to how care home and healthcare staff should proceed, in the event of an emergency, were articulated clearly, and if hospital admission were the preferred option, that would be enacted. Although such an outcome might not replicate the findings of the research studies, arguably it was a victory for ACPs, as a means of delivering choice for care home residents.

7.2.3.3 The second domain: the care homes

During this project the care home sector, the inner setting, was experiencing serious financial challenges. Local authority reimbursement did not cover the cost of care and fees from self-funding residents helped to bridge the financial gap (LaingBuisson 2017). Therefore, periods without residents to look after due to hospital admission, and uplifts in funding following admission might have been a means of increasing profitability and, in some instances, maintaining financial viability. There was direct evidence from the electronic record of this strategy being employed in Care Home 2, which had one of the highest admission rates, and the greatest number of residents dying in hospital in this project.

I observed increasing shortfalls in care home staffing during the project. The appointment of registered mental health nurses with minimal experience of physical illness in the pilot home and

one of the project homes was associated with increased admission for health crises or deteriorating health. In addition, I observed that use of new or agency staff, unfamiliar with residents and ACPs was associated with increased admissions. Changes in registration of beds from nursing to personal care, even though the residents remained the same, may also have had an impact upon admissions. The Health Foundation's report in 2019, showed that A&E attendance and emergency admission rates, are greater for residential homes than nursing homes (The Health Foundation 2019). Thus, the financial and staffing challenges faced by the care home sector during the project may have reduced their resilience to look after ill residents at home.

7.2.3.4 The third domain or outer setting

7.2.3.4.1 ULHT, the acute trust

The conversion of A&E attendance to hospital admission for people over 65 is higher than for other age groups, and this risk increases further if there is associated frailty (National Audit Office 2018).

The National Audit Office has shown that a quarter of admissions from A&E departments occur in the last ten minutes of the four-hour period (National Audit Office 2013) which suggests admissions are a means to reduce financial penalties incurred by breaching waiting time targets. During the project, waiting times in A&E departments in the UK increased; ULHT reported high numbers of breaches of the waiting target. The incentive to admit were compounded by additional factors delaying discharge, including the mandatory requirement for a further health care checklist to be completed after 48 hours; the requirement of a care home to reassess residents prior to accepting their return, and more recently, a negative Covid-19 test.

7.2.3.4.2 General practitioners

General practitioners saw unprecedented increases in surgery attendances during the project, leaving less time to devote to community visits. In addition, although they are regarded as "Jacks of all Trades", the reality is that few general practitioners have extensive training in the healthcare of older people, and if they have, this training may have been very brief, undertaken at a junior level and many years previously. High workload, lack of expertise, confidence and community resources may have explained the wide variations in attitude to care home residents that I observed. In such

circumstances, at the present time in the UK, hospital may be the only way of delivering adequate care for a resident whose health deteriorates.

7.2.3.4.3 The advent of LSTP and general practice federations

At the inception of the project, the financial position of LWCCG was good but worsened considerably during the implementation period. In a climate of austerity, CCGs may not have the funding to invest in new services. Furthermore, with development of LSTP and the two general practice federations, the influence of LWCCG, and hence its control of spending, diminished. Despite health commissioners acknowledging the merits of advance care planning, in a climate of economic austerity, if admissions were not reduced by the intervention, the project was unlikely to be sustainable or to be supported, as evidenced by it coming to an end.

7.2.3.5 The fourth domain: the individuals involved

Evidence from the electronic care record, MDT meetings and care home staff showed that there was frequently a lack of respect for ACPs, which may have been important. ACPs were a novel concept in Lincolnshire, and none was in place at the start of the project. Some care home, ambulance and general practice staff misconstrued ACPs as a means of reducing access to healthcare.

The results of the systematic literature review, including the SWiM may offer some insight into these observations. Whereas the overall systematic review of research studies implementing advance care planning in care home residents showed evidence for reduced healthcare use, the results of the SWiM, which examined studies with the greatest directness to the research question failed to do so. The latter were like this project in that they implemented advance care planning using specialist teams, whereas the remaining seven studies implemented advance care planning using educational interventions. On reflection, it is possible that the educational interventions were more successful because care home staff and primary care physicians took ownership of the advance care planning process, in doing so had greater respect for the ACPs, and were more likely to implement them. By contrast specialist teams might be viewed as intruders and the resultant ACPs, imposition resented by staff.

Alternatively, only residents identified as being close to death might have been identified as needing advance care planning by the care home staff. The reduction in healthcare use reported by Garden's study may have reflected that care home staff were asked to identify residents with a poor prognosis for whom they thought advance care planning was appropriate (Garden et al 2016). This process may have led to the care home staff having greater influence over advance care planning and thus increased the chances of implementation. Further support for this theory is that in this project, the group with ACPs were frailer and more likely to fulfil GSF criteria than the group without ACPs. The finding of greater acceptability of ACPs for residents with greater frailty and poorer prognosis is important because it contradicts the practice of advance care planning early during conditions, such as dementia.

There may have been other reasons for lack of fidelity to ACPs, including care home staff ownership of the process and poor understanding of frailty and absence of community services to support care at home. All residents in this project, irrespective of prognosis, were referred for CGA by their general practitioners, rather than care home staff. Thus, amongst care home staff, there may have been less familiarity with, and less acceptance of, the resulting ACPs, and less responsibility for implementation. Additionally, irrespective of the presence of ACPs, care home staff's perception that it would be wrong to "do nothing" for a resident who fell ill, and whose quality of life was perceived as good, was an important consideration. Although trained in personal care, such staff may have perceived hospital as always being in the best interests of their residents and may have little understanding of the trajectory of frailty, diminishing response to treatment and potential risks of hospitalisation. Last, care home staff faced a very real challenge in caring for residents at home since there was no rapidly accessible service to support them in providing care, and transfer to hospital was, in some instances, the only option.

However, even if services had been available, adequate palliation in the care home setting was impossible for some conditions such as acute heart failure, exacerbation of chronic obstructive

pulmonary disease or major fracture. I observed that some residents with such conditions chose hospital as their preferred place of care and death for these reasons, and their ACPs reflected those choices.

7.2.3.6 The fifth domain: implementation of the step-wedge randomised cluster study

Regarding implementation, the project adhered to the randomisation order, and whilst the steps could not be uniform, because the care homes differed in size, the project was implemented in a step-wedge pattern as illustrated in Figure 5.3. Therefore, there is no evidence to suggest that the results from this study were due to a failure to implement the proposed study design.

The advent of Covid-19 did not directly affect this study as the data collection had been completed in January 2019. However, the pandemic has had major consequences for care home residents in the UK, and so a limitation of this study, is that it describes perceptions and uptake of ACPs before arrival of the virus.

It does not appear that any one of the systemic factors was solely responsible for why having an ACP did not reduce healthcare use. More properly, it is likely that a combination of these factors may have influenced the project outcomes.

7.3 Strengths of the project

This project demonstrated that a service can be implemented with a step-wedge design model in the majority (68.2%) of unselected care homes in a health and social care system in the UK. It also demonstrated that widescale implementation of advance care planning (79.5%), embedded in CGA (98.5%), for unselected care home residents is feasible. Furthermore, documentation of those processes and GSF status can be entered successfully in the electronic primary care record, enabling the residents' general practitioners, community staff and out of hours services to have access to these assessments and plans.

A further strength of the project was our recruitment strategy; because the project was a service evaluation, recruitment was much simpler than for a research project, and much higher than that

seen in RCTs. Therefore, the outcomes from this study reflected better the wider care home population than an RCT would have done.

Additionally, the project introduced the concept of advance care planning to health and social care staff in an area where there was little familiarity with this subject. The project was also able to develop better understanding of end of life issues in general practice and in care homes through face to face contact and formal education sessions.

Finally, although the project demonstrated that ACPs were acceptable to most residents, the frailer residents fulfilling GSF criteria were most likely to receive palliative care, and there seemed to be greater consensus with this option amongst those caring for them. There was much less agreement about the management of residents whose function remained good, and who did not fulfil GSF criteria.

7.4 What do these results add to the existing evidence?

These results show that the reduction in admissions, associated with ACP educational interventions, demonstrated by previously published controlled studies (Molloy et al 2000; Caplan et al 2006) may not be replicated when advance care planning is implemented by a specialist team in routine care for an unselected group of care home residents, and are more in keeping with studies also employing specialist teams to implement ACPs, which demonstrated no change in health care use. (Harvey et al 2014; Hickman et al 2019). However, for those residents who died, this project demonstrated that possession of an ACP was associated with a 90% chance of dying in the preferred place of care, which supported findings of earlier studies (Caplan et al 2006; Livingston et al 2013).

There has been a tendency to conflate ACPs with palliative care and reduced hospital use. This study not only demonstrated an association of frailty with uptake of ACPs, but also that the choices made by care home residents and their carers depended on their functional status, and their perception of healthcare available in a health crisis.

7.5 Implications for practice, research and policy

Issues around the most effective use and implementation of ACPs remain unresolved. These issues are important as there has been a drive for people with long-term conditions to draw up ACPs, while they still have mental capacity, so that the ACP reflects their wishes at that time. In the future, there may be merit in focussing on whether there is a specific group who benefit most from advance care planning, the optimal time for an ACP to be drawn up. Additionally, given the healthcare benefits shown by research studies using advance care planning educational interventions in controlled studies (Molloy et al 2000; Caplan et al 2006) or selective settings (Livingstone et al 2013; Finucane et al 2013), it would be important to examine whether educational interventions have the same impact when applied in routine practice. Comparison of findings from such studies with this study would help address whether resources for implementation of ACPs in ordinary healthcare settings should be in the form of education interventions for care home staff, specific service interventions delivering ACP or a blend of both.

Although familiarity with ACPs and frailty in the health and social care sector is increasing, that is not the case in the wider population. My observations suggested there is limited societal understanding that, for people with extreme frailty, life extension may be of diminishing value. Hospitals may be able to deliver life extending treatments, but such treatments may fail to add to the remaining life for frail older people (Dwyer et al 2014; Givens et al 2010). Better understanding of frailty, the impact of hospitalisation, life expectancy of care home residents and the potential benefits of ACPs, not only amongst health and social care staff, but also the general population is crucial.

We also need to appreciate and respect that choices of care home residents, and their families, will differ. Whilst only a minority might opt for life sustaining measures until death, and others might

want palliative care, irrespective of function, many choose ACPs tailored to their level of function. An important finding from this study was that, with appropriately presented information, the choices made by care home residents were not always binary, and more often they were considered and nuanced. This finding suggests further study is warranted of the choices made by care home residents and their families, and when implementation is most likely to be effective.

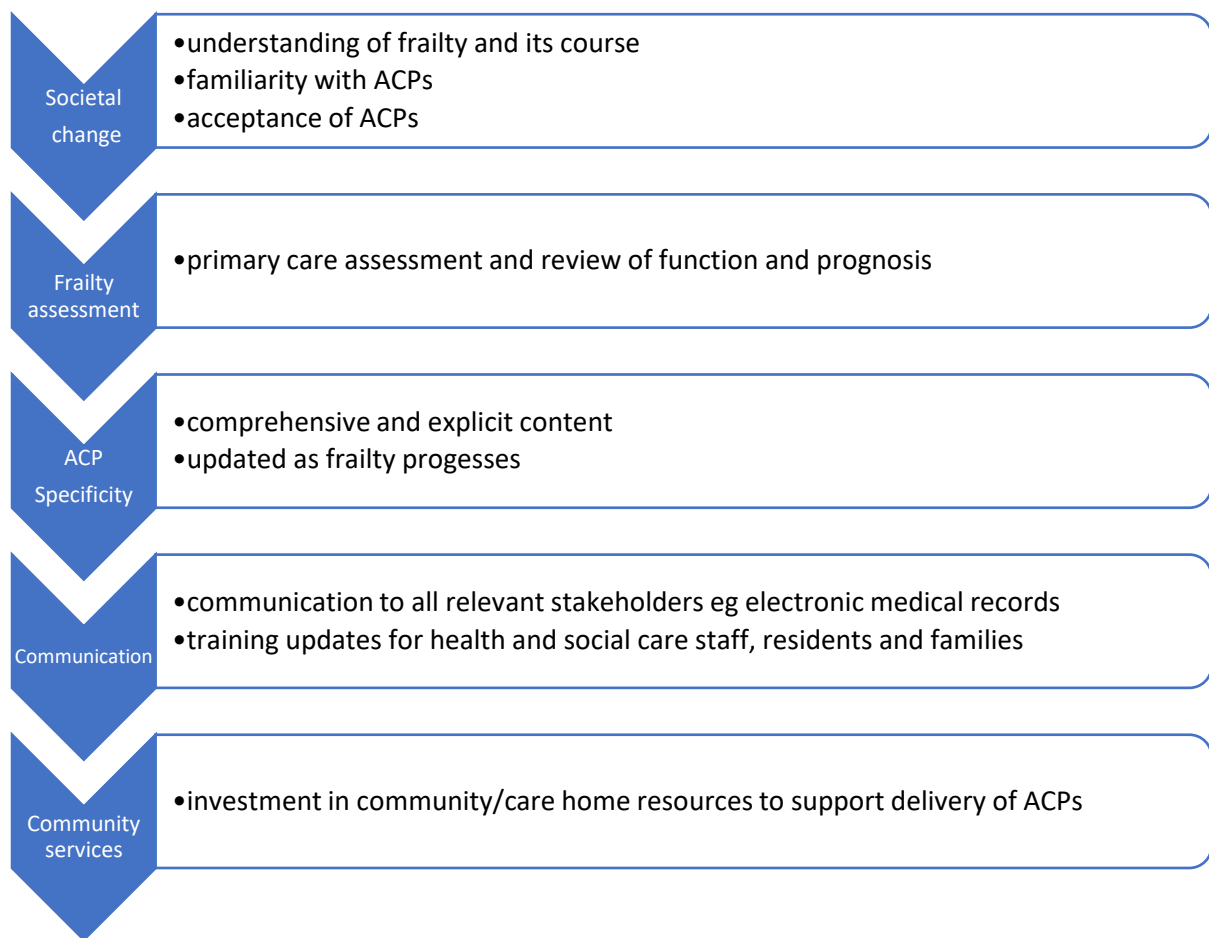
At the time of writing, in the UK, ACPs have been viewed as an optional extra, without any systems in place to promote, deliver or support them, and most of the hospice care and community palliative care is funded by charities. There is no national guidance on staffing levels, nurse: patient ratios and skill mix in care homes (Royal College of Nursing, 2020), which are regulated by the Care Quality Commission. Guidelines from the latter state that providers must deploy enough suitably qualified, competent, skilled, and experienced staff to meet the needs of the people using the service (Care Quality Commission, 2020). The RCTs which demonstrated the effectiveness of ACPs in reducing healthcare use of care home residents were in countries where care homes have healthcare embedded, thus allowing health crises or palliative care to be managed on site, without resort to hospital admission.

In recent years, the UK care home sector has been under enormous financial pressure, which is unlikely to abate (NHS Digital 2016). In the UK, spending on long-term care is approximately 0.6% of Gross Domestic Product, whereas in the Canada it is 1.3%, and 3.7% in the Netherlands (Robertson et al 2013). Whilst the social care system and community services in the UK remain poorly funded, there may be perverse incentives to admit residents to hospital, and insufficient resources to provide alternative good quality care for residents wishing to stay in their care home.

The findings of this study suggest that successful implementation of advance care planning requires a more sophisticated understanding of ACPs, and the conditions required for their enablement. Effects on healthcare use should not be the only measure of success; promotion of dignity, comfort and choice are of paramount importance. Greater value set on the correlation between preferred,

actual place of death, and comfort in the last days of life, would be markers of a society which respects its elderly population. If ACPs are to deliver residents' choices and to affect healthcare use, wholesale change in societal attitudes and health and social care systems must be in place, and the latter adequately funded. Figure 7.1 proposes a programme of measures that would enable ACPs to be delivered more effectively.

Figure 7.1 ACP programme



7.6 Personal reflection

In considering a subject as emotive as dying and death, it was perhaps naïve to suppose that the simple presence of an ACP would make a difference to healthcare use of care home residents in the UK. I thought that primary healthcare services and care homes would not only want to deliver choice

of care, but would be in a position to do so, and that, because care home residents were in the last years or months of life, they or their families would choose palliative care. That was an error; people with frailty do not see themselves as such (Nicholson et al 2012), and many are not ready to die.

Despite having worked in the community and in hospitals throughout my career, I think I underestimated the challenges in working across primary and secondary care health organisations in the UK, in which there are perverse incentives to admit, poor investment in community health services, and disinvestment in social care.

Amongst society, including the healthcare professions, value is attached to longevity, reinforced by the wonderful achievements of exceptional people like Captain Sir Tom Moore. At the age of 99, he walked hundreds of laps of his garden to raise money for the NHS during the Covid-19 lockdown, for which he was knighted. Although apparently frail, he appeared to relish life and to have no wish to relinquish it.

This project was a journey, which started from my role as a liaison psychiatrist in an acute hospital, in which there was a sudden surge in the admissions from care homes of older people with extreme frailty. Many of these people were in the last days of life, in an alien environment and separated from those who loved or knew them best. Irrespective of good care, the burden and distress of investigations and treatment were evident and outcomes poor. Most clinicians felt these patients might have had a more comfortable and dignified end of life in the care home, and ACPs were thought to be a suitable means to achieve this.

Unfortunately, in the UK at present, provision of good palliative care in care homes is arbitrary, depending not only on local resources, but also the attitudes of health and social care staff and the different policies of care homes. I witnessed good deaths in the care homes, but also deaths that were not, which echoes Pollock's analysis, challenging the current orthodoxy that home is always the best place of death (Pollock, 2015). What I have learned is, that, with support and training, care homes are capable of allowing many of their residents to die at home in peace and dignity should

they wish to do so, but even if resources improve, for some residents, dying in hospital is preferable, and may be a wise choice.

ACPs and choice are inextricably linked. It is ironic that I write this during the coronavirus pandemic, when residents have been protected so fiercely in care homes, that interaction with other residents and visits from families and friends have been prohibited in the interests of promoting longevity, but perversely visits from GPs have been curtailed too. The impact on residents' quality of life, and their right to choose, a fundamental human right, appeared to have been overlooked. The ACPs I drew up before the pandemic did not envisage the virtual imprisonment imposed upon this highly vulnerable population, and ACPs drawn up in the future will need to consider whether residents can make choices about whom they can see, in the event of further lockdowns, even if those risks endanger their health. I questioned the right of care homes to deny their residents advance care planning in section 6.4.1. Challenging the enforced isolation these residents have endured during the Covid-19 pandemic has brought the debate about quality of life versus longevity into the public eye. John's campaign was set up in 2014 to promote visiting rights for people with dementia in hospital (Gerrard 2019), but during the pandemic, this charity has sought a judicial review on care home visit guidance (BBC News 2020). This attention may help the importance of ACPs and the role they play in documenting choice to be appreciated more widely in the future.

7.7 Conclusions

In conclusion, advance care planning was implemented in most unselected care homes and was highly acceptable to care home residents and their families. However, although their implementation was associated with an increased chance of dying in the preferred place of care, implementation was not associated with reduced hospital admissions. The findings also reflected that the choices made by frail older people are not necessarily solely for palliation. The primary purpose of ACPs should be to achieve a fair and widely available system that allows people to express clear choices about their future care. To achieve this in the UK will require development of

resources to support those who choose to stay at home, widespread societal understanding of frailty and its trajectory, and above all, respect for the individual choices made by this venerable group.

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Appendix One: Anticipatory Care Plan

Name:		Dob:		
NHS number:		GP:		
Address:		GP's Telephone Number		
Telephone Number:		Lasting Power of Attorney for Health:		
Place of Care:				
Mental Capacity with regard to Anticipatory Care Planning				
The Patient is able to:		Yes	No	
Understand the relevant information				
Retain that Information				
Use or weigh up that information as part of the process				
Communicate their decision				
Discussions held on Best Interests Basis				
Date of Advance Care Planning Discussions				
Family/Informal Carers involved in Advance Care Planning Discussions				
Name:		Relationship:		
Health Professionals involved in Advance Care Planning Discussions				
Name: Dr Gill Garden		Registration: 2808884	Role: Consultant Older People's Services	
GSF Status	years	months	weeks	days
Information about resident including personal, social and medical history, summary of CGA and GSF findings				
Summary of interventions:				
Interventions not wanted under any circumstances				
Interventions wanted in all circumstances				
Interventions dependent upon GSF status				
Is there another Advance Care Planning document? No				
Spokesperson:		Telephone Number:	Address:	
Preferred Place of Care:				
Health Professional: Dr Gill Garden		Signature		Date:
Once completed, the ACP should be kept at Care Home with copies in General Practice and Hospital records				
GP	Neighbourhood Team	Family/Carer	Care Home	Hospital
Date:	Date:	Date:	Date:	Date:
To be reviewed if views, preferences or circumstances change				

