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Running Side by Side:
An Ethnography of Multi-Professional Involvement in the Advance Care Planning Process in Two Nursing Homes

by

Nicola Marie Andrews

ORCID ID 0000-0003-2595-1825

Thesis for the degree of Doctor of Philosophy

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Abstract

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This thesis explores the involvement of health and social care professionals in advance care planning (ACP), as an exemplar of end-of-life care practice, and the impact of this involvement in two purposively selected nursing homes. Nursing homes are significant providers of end-of-life care and their role in this area of care is likely to increase given the ageing population. Multi-professional working is a key component of the espoused model of palliative care delivery. Yet, there has been limited research into multi-professional working in nursing homes. Ethnography was used for the study, with between six and seven months spent in each home. Data collection methods were observation; formal and informal interviews; and document review. Participants included nineteen nursing home staff, seven health and social care professionals, six residents and four relatives. Thematic analysis was integrated with documentary analysis, mapping of resident ACP trajectories and comparative analysis of data from the two nursing homes.

Three key findings were identified: the structure and organisation of professional practice was disjointed and disrupted the continuity and coordination required to enact ACP; challenges were encountered in the enactment of ACP which impact multi-professional involvement; and the dominance of a biomedical approach to ACP constrained the breadth of both ACP and multi-professional working. Multi-professional working was not integrated with ACP in either nursing home and a conceptual framework has been developed which represents ACP and multi-professional working as 'Running Side by Side'. The conceptualisation of ACP, with a lack of collective understanding, and its construction as a professional process, defined in biomedical terms and controlled by professionals, meant there could be different professional ACP processes running side by side. Professional-led ACP frequently ran side by side with resident priorities for future planning. The involvement of relatives and a wider multi-professional team, beyond nurses and GPs, was not always recognised, so ACP they undertook could also run side by side with other strands of ACP. The conceptual framework provides one way to better understand this complex and under-researched area of practice. It highlights a reciprocal impact between ACP and multi-professional working which, to my knowledge, has not been identified in previous research. The conceptual framework could also be applied to end-of-life care more broadly and suggests greater inter-agency and inter-professional working is required to ensure nursing home residents' future wishes are both known and honoured.

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Academic Thesis: Declaration of Authorship

I, Nicola Marie Andrews, declare that this thesis entitled:

Running side by side: an ethnography of multi-professional involvement in the advance care planning process in two nursing homes

and the work presented in it is my own and has been generated by me as the result of my own original research.

I confirm that:

- This work was done wholly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission.

Signed:

Date: 14 May 2021

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This thesis is dedicated to my dad, my inspiration: Ian Victor Andrews, 1935-2020.

Definitions and Abbreviations

Definitions

Advance Care Planning (ACP)

For the purposes of this study ACP encompasses:

- "A voluntary process of discussion and review to help an individual with capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses" (National End of Life Care Programme 2011, p. 6).
- The processes, including end-of-life care decision-making, through which an individual's expressed wishes and preferences are implemented.

Multi-professional, multi-disciplinary and inter-professional working

From multi-professional to multi-disciplinary and inter-professional to trans-disciplinary, there is a confusing array of terminology used to describe healthcare teams, with each term understood differently by different people (Leathard 2003; Reeves et al. 2010). For the purposes of this study, the literal translation of the prefix 'multi' meaning many and 'inter' meaning a connection between two or more people is used (Collins Dictionary 2021). Multi-professional is understood as involvement of more than one professional and inter-professional as shared work between professionals. Multi-disciplinary is understood as more than one professional discipline, such as nursing or social work, rather than more than one individual professional from the same discipline.

Abbreviations

ACP	Advance Care Planning
AMED	Allied and Complementary Medicine Database

Definitions and Abbreviations

BNI	British Nursing Index
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CCG	Clinical Commissioning Group
CNS	Clinical Nurse Specialist
CPN	Community Psychiatric Nurse
CQC	Care Quality Commission
DH	Department of Health
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
EPaCCS	Electronic Palliative Care Coordination System
EMBASE	Excerpta Medica Database
GP	General Practitioner
GSF	Gold Standards Framework
GSFCH	Gold Standards Framework Care Homes
IBSS	International Bibliography of the Social Sciences
LPA	Lasting Power of Attorney
NEOLCP	National End of Life Care Programme
NHS	National Health Service
OOHs	Out of Hours
OT	Occupational Therapist

PHE	Public Health England
REC	Research Ethics Committee
RN	Registered Nurse
UK	United Kingdom
US	United States of America

Chapter 1 Introduction and Rationale for the Study

1.1 Introduction

The focus for this PhD thesis originated from my experiences working as a Palliative Care Nurse Specialist providing education and support to nursing homes. From my work with the nursing home sector, my perception at the outset of this research was that nursing homes frequently worked in isolation from the wider healthcare system. This led me to want to explore multi-professional working in end-of-life care within nursing homes to better understand the involvement of visiting professionals in the nursing home setting and how this impacts on end-of-life care provision.

The study setting of the thesis is United Kingdom (UK) nursing homes, which are long term residential care settings with on-site nursing. The term nursing home is therefore used in this thesis wherever possible, although different terms are used in different countries, such as Residential Aged Care Facilities in Australia. In the UK, nursing homes are also referred to as care homes with nursing. The Care Quality Commission (CQC), the independent regulator of health and social care in England, uses the term 'care home' as an umbrella term, using the term to refer to both care homes with nursing and care homes without nursing. Therefore, where reference is made to statistics, reports or literature that do not differentiate between those care homes with nursing and those homes without nursing, the term care home is used in the thesis.

This first chapter sets the study and this thesis in context. It outlines the role nursing homes increasingly have in providing end-of-life care and provides an overview of what advance care planning (ACP) is and its role in end-of-life care. It considers the part multi-professional working plays in palliative and end-of-life care provision and the current levels of multi-professional involvement in UK nursing homes. The research questions and aim and objectives of the study are then stated, and the contents of this thesis explained.

1.2 Palliative and end-of-life care in nursing homes

There are more than four thousand nursing homes registered to provide care to older people in England (CQC 2021). These homes are recognised as key providers of palliative and end-of-life care in the national End of Life Care Strategy (Department of Health [DH] 2008). In 2019 22.5% of all deaths in England occurred in care homes, an increase over the previous decade from 17.5% in

2009; 37.5% of deaths in people aged eighty-five or older in 2019 were from those residing in care homes (Public Health England [PHE] 2021). Forder and Fernadez (2011) estimated the median length of stay for nursing home residents to be 1.2 years, based on a sample of over eleven thousand residents who died in care homes run by BUPA, a large private healthcare company, over a two-year period. Collectively these figures indicate that at any one time most nursing home residents fit the criteria for palliative and end-of-life care. This is based on the definition used by the Leadership Alliance for the Care of Dying People which states that "patients are 'approaching the end of life' when they are likely to die within the next 12 months" (Leadership Alliance for the Care of Dying People 2014, p. 106).

The nursing home population is characterised by the most frail and vulnerable members of society, nursing home residents having multiple medical conditions and profound physical dependency (Bowman et al. 2004; Gordon et al. 2014; Gordon 2015). A longitudinal study of the health status of a representative sample of 227 care home residents found multiple morbidity and polypharmacy to be prevalent, with the average resident having six medical diagnoses and taking eight medications (Gordon et al. 2014). Seventy-five per cent of residents had cognitive impairment. The study showed a significant increase in prevalence of both residents with a diagnosis of dementia and residents with behavioural disturbance compared to figures from UK care homes reported a decade earlier (Bowman et al. 2004). Similarly, findings from a population cohort study found that the oldest old are most likely to transition from home to care homes when they have cognitive impairment with a substantial number of transitions occurring in the last year of life (Perrels et al. 2014), and admission to the care home therefore being for end-of-life care. This admission to care homes at a later stage reflects the UK policy agenda to support people to stay independent for longer (UK *Care Act 2014*; Humphries et al. 2016; NHS England 2019). Thomas et al. (2017) suggest that transfers from hospital or hospice settings to care homes for end-of-life care have become an increasingly common part of UK clinical practice.

In light of the national and international context of an ageing population, the role nursing homes have in providing palliative and end-of-life care to older people is becoming increasingly significant. The number of deaths in England and Wales has been predicted to rise by 25.4% between 2014 and 2040, with more people dying in older age; the percentage of deaths among those aged eighty-five and over is expected to rise to 53.2% by 2040, increasing from 38.8% in 2014 (Etkind et al. 2017). Alongside this change in demographics is an expected substantial increase in the number of people living with dementia, forecast to rise by 40% between 2013 and 2025 and by 156% between 2013 and 2051 (Prince et al. 2014). As older people with dementia are significantly more likely to die in a care home than older people without dementia (Houttekier et al. 2010; PHE 2016) this sector is likely to have an important role in the future provision of end-of-life care. Swagerty (2014) predicted that more than 40% of adults in the United States of America (US) will die in nursing homes by 2030, increasing from 25% in 2014.

The British Geriatrics Society (2011) has suggested that for many nursing home residents a palliative approach rather than a sole focus on conventional management of long-term conditions is best. A palliative approach is considered to be an approach that applies the principles of palliative care but provided by the usual care team rather than a specialist palliative care team (Sawatzky et al. 2016). More than a decade ago Abbey et al. (2006) advocated that care homes would become “hospices of the future” (p.56), seeing this as inevitable given demographic changes and also appropriate if care homes are supported. The development of palliative care provision within long-term care settings is of increasing importance across all European countries (Froggatt et al. 2016). In the UK, there has been a development of education programmes focusing on the organisational change required to provide high quality palliative and end-of-life care in the care home setting, such as the Gold Standards Framework Care Homes (GSFCH) programme (National Gold Standards Framework [GSF] Centre 2020a) and Six Steps to Success (The End of Life Care Partnership 2021). However, the education input of these focuses solely on the care home staff, yet Seymour et al. (2011) suggested that provision of good end-of-life care in nursing homes not only requires internal capability but also effective external support. Therefore, in addition, there should be a focus on challenging wider system practices.

1.3 Advance care planning

ACP is a process of discussing and documenting wishes and preferences for future care (National End of Life Care Programme [NEOLCP] 2011; Pollock and Wilson 2015). ACP does not solely concern discussions about end-of-life issues but planning for any situation where an individual is no longer able to communicate their wishes and preferences (Froggatt et al. 2008). However, ACP is particularly applicable to end-of-life care decision-making. Silveira et al. (2010) found that many older Americans needed to make decisions about medical treatment at the end of their life but lacked capacity to do so. In the UK, ACP has become integral to end-of-life care provision, promoted through the work of the National Health Service (NHS) End of Life Care Programme (NHS England 2021) and in national strategy documents including the End-of-Life Care Strategy (DH 2008) and the Ambitions for Palliative and End-of-Life Care framework (National Palliative and End of Life Care Partnership 2015).

Introduction and Rationale for the Study

ACP has evolved from a position in the later stages of the last century when advance directives dominated (Thomas 2018), particularly in the US, where care providers became obliged to inform patients of their health-care decision-making rights and their rights in relation to advance directives under the Patient Self Determination Act of 1990 (Castle and Mor 1998). This Act was passed in the wake of two high profile court cases involving decisions regarding the withdrawal of life-supporting technology from young women left in a persistent vegetative state (Silveira and Rodgers 2018). It reflected a wider societal shift towards consumer-led healthcare with a move away from a paternalistic model towards one of autonomy and the conviction that decisions should respect patient self-determination, even when patients no longer have capacity to make their own decisions (Teno et al. 1994a). However, over time it has been recognised that advance decisions are only one component of the broader aspect of ACP (Teno et al. 1994b; Ratner et al. 2001) and so the focus of ACP has shifted away from obtaining refusal of treatment from a minority of patients to identifying the preferences for care for the majority of patients (Murray et al. 2006). ACP is usually considered to take place in anticipation of a future deterioration in a person's condition, with the associated loss of decision-making capacity and/or ability to communicate wishes to others (NEOLCP 2011), and is underpinned in England and Wales by the UK *Mental Capacity Act 2005* with regard to decision-making when individuals lack mental capacity to make decisions for themselves. Legislation in other countries also supports the refusal of unwanted medical treatments, including in the US (Silveira and Rodgers 2018) and Australia (Detering and Clayton 2018).

However, ACP has been found to have a role not just in preparing for incapacity but also in assisting individuals to prepare for death (Singer et al. 1998; Russell 2016). The evolving understanding of ACP identifies a broader role including assisting individuals to relieve burdens on loved ones and focusing on relational aspects and the context of the individual's life as they approach death (Martin et al. 1999; Russell 2016). Research and practice developments have led to changes in how ACP is defined, culminating in the development of two consensus statements on ACP (See Figure 1.1). Both were developed using a Delphi consensus process to reach agreement across an international, multidisciplinary panel of ACP experts. Sudore et al. (2017) developed their definition with fifty-two experts from four countries and Rietjens et al. (2017) involved 109 ACP experts from across Europe, Australia and North America. Both statements broaden the definition away from just refusal of treatment to include discussion of values and goals, with the definition of Rietjens et al. (2017) going further by explicitly mentioning the need to address concerns across the physical, psychological and spiritual domains.

Definition statement by Sudore et al (2017)

“(1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

(2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

(3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.”

Extended definition by Rietjens et al (2017), supported by the European Association for Palliative Care

“Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals’ concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.”

Figure 1.1: International consensus definitions of ACP

Engaging with a process of ACP is considered a key priority for care home settings, both in the UK (NHS England 2016) and internationally, such as in Australia where the national Respecting Patient Choices programme has been implemented in nursing homes (Detering and Clayton 2018). Indeed, ACP is highlighted as an important component in delivery of high-quality end-of-life care in care home educational initiatives (The End of Life Care Partnership 2021; National GSF Centre 2021a). ACP has particular importance for individuals who may lose their mental capacity in the future meaning they would no longer be able to express their wishes themselves (McGlinchey et al. 2014). Given that more than 70% of care home residents have some level of cognitive impairment (Bowman et al. 2004; Gordon et al. 2014) this highlights the relevance of ACP to nursing homes. However, concerns about mental capacity and associated communication difficulties are identified as a common barrier to engaging residents living with dementia in ACP (Flo et al. 2016; Beck et al. 2017).

Two reviews of existing research suggest that commencing ACP in nursing homes may be too late for those living with dementia (Robinson et al. 2012; Beck et al. 2017). Yet, Mignani et al. (2017) identified consistent evidence from research studies showing that residents with cognitive impairment can be involved in ACP, when it is approached appropriately. Indeed, staff are expected to initiate ACP in this setting and have also been identified as having a role in the revising and evolving of the process (Beck et al. 2017). One difficulty frequently reported in the research literature that limits involvement of people with dementia in ACP is the lack of identification of dementia as a terminal illness, both by professionals and by families (Flo et al. 2016; Beck et al. 2017; Reeves et al. 2019), and an unpredictable illness trajectory leading to uncertainty about prognosis (Dixon et al. 2018; Reeves et al. 2019). Both challenge the recognition of the need for ACP.

1.4 Multi-professional approach to palliative and end-of-life care

A multi-professional approach is a key feature of the nationally and internationally recognised model of palliative care delivery. Internationally, the World Health Organization (2002) stated that palliative care "uses a team approach to address the needs of patients and their families" (p. 84) and highlights the focus of palliative care on physical, psychological, social and spiritual support for patients. It is recognised that patients have a common set of needs across these domains when approaching the end-of-life irrespective of their diagnosis, which can be met through holistic, multidisciplinary care exemplified by hospice and specialist palliative care (Butler et al. 2012). The involvement of a multi-professional team in provision of both generalist and specialist palliative care is also emphasised in national strategy and guidance. The End-of-life Care Strategy (DH 2008) acknowledged the wide range of professionals who might be involved in care delivery and the National Institute for Health and Care Excellence Quality Standard for End-of-life Care for Adults stated that both generalist and specialist services need to "have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support" (2011, p.65).

1.5 Multi-professional input to nursing homes

Multi-professional care is also recognised as the gold standard model for care of older people (Davies and Higginson 2004; Flicker 2013; Burns and Nair 2014; Ellis and Sevdalis 2019), being central to Comprehensive Geriatric Assessment (Parker et al. 2018) Indeed, collaboration between dementia specialists and specialist palliative care is considered best-practice for provision of end-of-life care for people with dementia (Lillyman and Bruce 2016). However, multi-professional involvement in nursing homes occurs less often when compared to other settings in the UK, such as hospitals and hospices, and also compared to nursing homes in some other countries. There is variation between countries as to which disciplines are involved in nursing home care, which are available on site and which are provided by visiting professionals.

An international survey revealed that eight out of the thirty countries from which responses were received had a physician-led model of care whereby a doctor with administrative responsibilities, such as a medical director, oversees care (Tolson et al. 2013). Although in Belgium, there is at least one physician employed by the nursing home to coordinate medical care, the majority of medical care provision replicates the UK model of visiting General Practitioners (GPs) (Gilissen et al. 2018). On-site physicians are provided in Italy, Norway and The Netherlands (Froggatt et al. 2016), with nursing home medicine a recognised medical specialty in the Netherlands and each nursing home physician looking after around one hundred nursing home residents (Conroy et al. 2009). However, a notable difference between Dutch and UK nursing homes is their size, a typical Dutch nursing home accommodating between 150 and 200 residents (ibid). Nursing homes in fourteen of the thirty countries, including in the UK, used a nurse-led model of care (Tolson et al. 2013), although there was variation between these countries with regard to other disciplines available on site. For example, in Australia the team employed by a nursing home includes physiotherapists and speech therapists (Australian Government 2021), whereas in the UK most nursing homes only directly employ the nursing team and activities staff. In Belgium, nursing homes are required to have a small number of palliative care nursing hours mandated by number of beds (Gilissen et al. 2018) and Dutch nursing homes have a large on-site multidisciplinary team including social workers and spiritual caregivers, alongside facilities to manage more acute illness such as provision of intravenous therapy (Conroy et al. 2009).

In the UK, the majority of professionals providing care in nursing homes other than the nursing staff are visiting professionals, not employed directly by the nursing home. Nursing homes rely on external services to provide healthcare, from either NHS or private sources (Meehan et al. 2002; Hanratty et al. 2019). There is a range of generalist and specialist NHS services, and a large variety of health professionals, that care homes might access but care homes can find it difficult to access these services (Meehan et al. 2002; Davies et al. 2011; Iliffe et al. 2016). Many UK nursing home residents have poor access to timely and appropriate health care services, including GP services and other services for chronic disease management (Clark 2009; British Geriatrics Society 2011, 2015). This was borne out in my clinical practice experience whilst working with nursing homes prior to commencing the study, with many of the homes I worked with appearing to operate in isolation from mainstream services and frequently struggling to achieve access to services such as dietetics and speech and language therapy. Access to multi-professional services in nursing homes was first highlighted as an issue of concern in 2000 by a Joint Working Party Report (Royal College of Physicians et al. 2000). However, Iliffe et al. (2016) identified that inequities in the distribution of NHS resources to the care home population persist.

NHS support for nursing homes varies across the UK, with services evolving according to local priorities and innovation (Glendinning et al. 2002; Goodman et al. 2013a; Iliffe et al. 2016). Uncertainty about the boundaries between care home responsibilities and NHS responsibilities and how the two sectors should work together can lead to gaps in service provision, with a poor fit between resident needs and the services they can access (Gage et al. 2012). Although there is no legal obligation for care home residents to be treated any differently from the general population (Gordon 2015), models of care specifically designed to support care homes have developed. These include locally enhanced medical services, such as attachment of one general practice to a home or funded provision of additional anticipatory care (Donald et al. 2008). Some care homes purchase medical care, establishing their own agreement with a GP practice to register all residents (Donald et al. 2008; British Geriatrics Society 2011). Other models include care home specialist nurses or community matrons providing case management linked to primary care and multidisciplinary in-reach teams (British Geriatrics Society 2011). However, there remains a lack of clear evidence as to which models are most successful in achieving the best outcomes for older people living in nursing homes and a need to evaluate the effectiveness of the range of differing approaches to providing support to care homes that have developed across the UK (Donald et al. 2008; British Geriatrics Society 2011).

The importance of greater integrated working between NHS services, local authorities and social care providers has been a key feature of recent policy and strategy documents, including the UK *Health and Social Care Act 2012*, the Five Year Forward View (NHS England 2014a) and the Ambitions for Palliative and End-of-Life Care framework (National Palliative and End of Life Care Partnership 2015). Yet integration between care homes and NHS services has been shown to be lacking and generally only achieved at the level of individual working relationships and the resident level of care (Davies et al. 2011; Gage et al. 2012; Goodman et al. 2013a; Goodman et al. 2017). Such integration is primarily informally negotiated and based on trust and confidence in the staff involved (Goodman et al. 2013a). The British Geriatrics Society (2016) reported that services commissioned to support care homes tend to be transient, a consequence of lack of engagement of the homes in the design, development and implementation. NHS work with care homes is often undertaken on the terms of the health services, dictated by health service defined problems and priorities, rather than those of the care home or residents (Davies et al. 2011; Gage et al. 2012; Goodman et al. 2013a; Goodman et al. 2017). Indeed, concerns were expressed by care home staff early in their involvement in one of six Enhanced Healthcare in Care Homes vanguards in England that this would be a health-dominated programme, imposed from above (Stocker et al. 2018). The Enhanced Health in Care Homes Framework aims to improve integrated working (NHS England and NHS Improvement 2020).

Partnership working between nursing home staff and visiting professionals is complicated by nursing homes being situated within the social care sector, with potential for conflicts of professional interests and organisational culture (Holtom 2001; Lymbery 2005). Health sector staff often have low levels of respect for the experience, knowledge and skills of care home staff (Davies et al. 2011; Gage et al. 2012; Goodman et al. 2017; Stocker et al. 2018). Yet, research suggests that developing and sustaining relational working between visiting health professionals and care home staff is important to improve how the NHS and care homes work together (Goodman et al. 2013a; Goodman et al. 2016).

1.6 Rationale for the study and research questions

In the UK, research examining end-of-life care provision in the care home setting has suggested that the quality of a home's interrelationships with professionals from the wider health and social care system determines the quality of the end-of-life care they provide (Addicott 2011; Seymour et al. 2011). However, there is limited understanding of what multi-professional working relationships or models of care to support nursing homes should look like, particularly in relation to end-of-life care.

ACP offered a suitable vehicle for this research to explore the nature of multi-professional relationships in regard to end-of-life care as ACP conversations may address a range of issues that affect all dimensions of human experience and require the expertise of many professional disciplines (Connor et al. 2002). The importance of multi-professional working in ACP is supported by the findings of research undertaken in nursing homes in Australia which highlighted multi-professional involvement as a key requirement for successful implementation of ACP (Jeong et al. 2010). The model of service delivery implemented facilitated cross service boundary working, using case conferences for discussion of treatment options and enabling shared written communication between the care home, hospital, palliative care and medical staff. A survey of nursing home managers in England also suggested that nursing homes rely on external professionals for ACP, particularly to ensure the implementation of a resident's wishes (Froggatt et al. 2008).

This study explored multi-professional working within the nursing home setting using ACP as an exemplar of end-of-life care practice to address the following research questions:

- What factors influence multi-professional involvement in the ACP process within nursing homes?
- How does multi-professional working impact the ACP process in nursing homes?

The way multi-professional working was defined for the purpose of the study is outlined on page xv, alongside the terms multi-disciplinary and inter-professional which are used interchangeably in the literature and as part of clinical discourse to describe professionals working together as a team or group (Leathard 2003; Reeves et al. 2010).

The definition of ACP adopted for the study, as outlined on page xv, was as described by the NEOLCP (2011), and was the accepted definition of ACP in the UK at the outset of the research. However, for the purpose of the study, this was extended to incorporate the processes by which an individual's expressed wishes are implemented, based on views articulated by care home managers indicating that multi-professional involvement is significant in both ascertaining and implementing wishes expressed by nursing home residents (Froggatt et al. 2008).

1.7 Aim and objectives of the study

The aim of this study was to examine multi-professional working practices and the impact these have on the ACP process in nursing homes, to inform the development of pragmatic approaches to improve the effectiveness of ACP practice and enhance multi-professional working in end-of-life care provision more generally in the nursing home setting.

To achieve this aim my objectives for the study were to:

- Investigate the involvement of health and social care professionals in the ACP process within two nursing homes.
- Analyse the impact of different levels of involvement and approaches to partnership working on the ACP process.
- Develop a conceptual model of multi-professional practices that enhance ACP in nursing homes and factors that promote or inhibit engagement of different professionals in ACP.

1.8 Structure of the thesis

This chapter has presented the background and rationale for the study. Chapter two provides an in-depth review of the literature published between 1990 and 2020 on multi-professional working in the nursing home setting in relation to ACP. Chapter three discusses the methodology, research design and methods, including the recruitment processes, data collection procedures and approach to data analysis. It also details ethical considerations and processes incorporated to ensure rigour. Chapter four provides pen portraits of the two nursing homes and the six participant residents. Chapters five, six and seven each present one of three themes developed through analysis of the data: ‘Disjointed System’, ‘Enacting ACP’ and ‘Professional Reach’. These are brought together in the conceptual framework ‘Running Side by Side’ which is discussed in chapter eight in the context of the related literature. The final chapter outlines how the study findings add to the current knowledge base, the implications for practice, education, policy and research, and the strengths and limitations of the study.

Chapter 2 Literature Review

2.1 Introduction

This chapter presents a review of the literature relating to multi-professional involvement in ACP within the nursing home sector. The process and methods employed to identify and appraise relevant literature are outlined. The literature was investigated to ascertain themes and patterns and to identify gaps in the evidence base. The findings of the review are structured using the four themes identified: the work involved in the ACP process, the expertise required to do this and who does or could provide this; the key characteristics of multi-professional working that enhance the ACP process; facilitators and barriers to multi-professional involvement in ACP; and the impact of multi-professional involvement on the ACP process. The review provided the rationale for the development of the research questions and study aim and objectives. An initial literature review was completed to inform the research proposal which has been updated during the study, with the review presented in this chapter including literature published before the end of September 2020.

2.2 Design and method of literature review

2.2.1 Aim and objectives

This focused review of the extant literature was undertaken using the approach outlined by Hawker and colleagues (2002) to systematically review literature from different paradigms, acknowledging the contribution of both qualitative and quantitative research to the evidence base in healthcare. The aim of the review was to critically appraise the literature relating to multi-professional working in ACP or end-of-life care within the nursing home setting and its methodological quality. Although the focus of my study was multi-professional involvement in ACP, I broadened the remit of the literature review to include end-of-life care. This enabled inclusion of papers discussing processes through which ACP is implemented, such as end-of-life care decision-making, and papers where aspects of ACP were included but not classified as such to be identified, such as those relating to end-of-life care case conferences. The objectives of the literature review were:

1. To report how multi-professional involvement in ACP (including both ascertaining and implementing resident future wishes) in the nursing home setting was described in the literature.
2. To identify and review literature reporting how multi-professional involvement impacts on ACP (including both ascertaining and implementing resident future wishes) in nursing homes.

2.2.2 Search strategy

The search terms, taken from the objectives outlined above, were multi-professional, multi-disciplinary, inter-professional, ACP, end-of-life care, palliative care and nursing home(s). Searches were completed using a wide range of electronic databases as the topic crosses the boundaries of the social science and healthcare literature. The Allied and Complementary Medicine Database (AMED), British Nursing Index (BNI), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (EMBASE), International Bibliography of the Social Sciences (IBSS), MEDLINE, PsycINFO and Web of Science Core Collection were each searched. Subject headings were used where these were supported by the database and were combined with keyword searches of abstracts. Subject headings were not supported in AMED and Web of Science, with keyword searches used instead. Subject headings and keywords that mapped to the search terms were used. Due to a lack of consistency between the various databases a search strategy was developed for each database individually. A complete list of search terms used in each database is provided in Appendix A. Table 2.1 provides the results of the searches in the individual databases.

All citations were imported into EndNote® software. Duplicates were filtered automatically using the software and through manual screening. EndNote® and Microsoft Excel® were used to organise and record the search and screening results.

2.2.3 Inclusion and exclusion criteria

The review included literature published between 1 January 1990 and 30 September 2020. The year 1990 was chosen as the starting point as the UK *NHS and Community Care Act 1990* introduced changes to funding and long-term care provision that continue as the basis for the current care home market. The Patient Self Determination Act of 1990 was also passed in the US making it mandatory for nursing homes (amongst other healthcare organisations) to provide information about advance directives to patients reimbursed by Medicare or Medicaid (Castle and

Mor 1998). Citations were excluded if they were not published in English, as funding was not available for translation costs.

All available abstracts were screened to identify literature that met the following inclusion criteria:

- Papers that related to ACP and/or provision of care at the end-of-life.
- Papers that related to the nursing home setting (or equivalent international setting) or to multiple settings including nursing homes but where this setting was specifically mentioned.
- Papers that had a major or minor focus on two or more professional groups providing care together or referred to two or more professional groups working together within the findings or discussion. At least one of these professional groups was required to be one that would be considered a ‘visiting professional’ in a UK nursing home. All professionals except nursing home nurses, care assistants and activities staff are usually employed by external organisations and so are considered ‘visiting’ professionals.

Table 2.1: Electronic database search results

Electronic database	**Search 1: Nursing Homes**	**Search 2: Advance Care Planning OR End of Life Care**	**Search 3: Multi-professional Working**	**Search 4: Search 1 AND Search 2 AND Search 3**	**Search 5: Search 4 Limited to: Language: English**	**Search 6: Search 5 less duplicates within database**
AMED	1789	18733	10183	70	70	67
BNI	18615	34761	42042	295	295	275
CINAHL	43453	68077	188247	372	363	354
EMBASE (1980+)	60951	374939	367164	939	861	851
IBSS	1478	1224	41125	6	5	5
MEDLINE	38876	81832	258759	334	293	293
PsycINFO	14733	23550	96463	199	188	188
Web of Science	54660	739161	722145	1028	944	942

Citations for papers related to nursing home and hospice collaboration in the US were excluded. The issues that arise from the regulatory and organisational arrangements for the provision of specialist palliative care to US nursing homes are not relevant to the UK setting. Citations for papers that studied end-of-life management of one specific healthcare condition or symptom such as Huntingdon’s Disease or pain were also excluded, unless the abstract specifically referred to findings that related to ascertaining or implementing resident wishes.

The potential relevance of a paper was not always clear from the abstract. As noted by Hawker et al. (2002), structured abstracts are less common in the social science and nursing literature, which sometimes made it difficult to clearly assess relevance. In these cases, the full paper was accessed and assessed. In some cases abstracts were missing and therefore titles and subject headings were assessed. Forty-one citations were excluded on this basis. Where it was not possible to determine whether the content had some relevance from the title and subject headings, the full paper was accessed. Five citations were excluded as they were lists of conference abstracts with no relevant titles. Where citations were for individual conference abstracts and the content of the abstract was relevant, attempts were made to find papers published reporting these studies. Some had been identified through the search; in the other cases no published papers were identified.

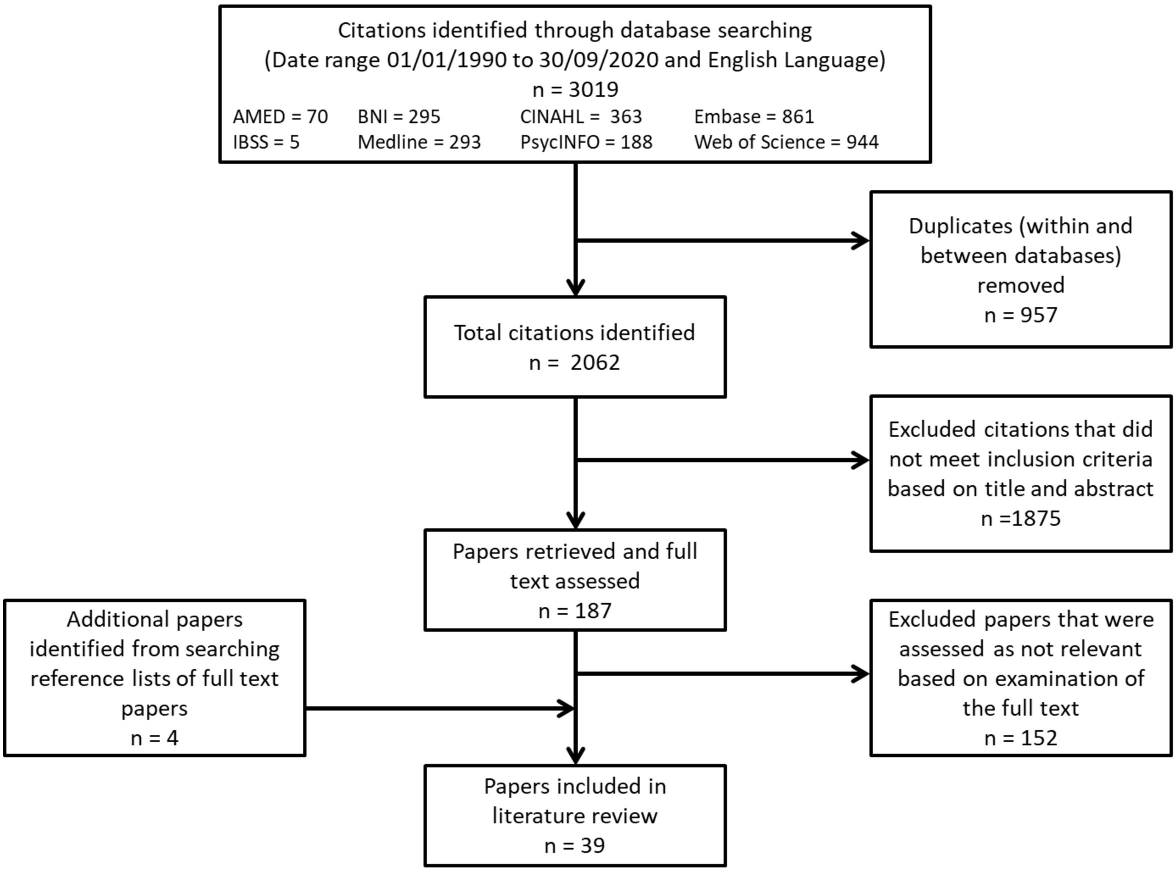

Figure 2.1: Summary flowchart of literature search and appraisal process

The reference lists of all the full text papers reviewed were read to identify additional relevant research not identified through database searching. Abstracts were then located and assessed. Where considered relevant, the full paper was appraised for inclusion in the literature review. All full text papers were assessed for relevance to the aim and objectives of the review using a form devised to facilitate this process (Appendix B). A summary flowchart of the search and appraisal process with the outcomes of each stage is provided in Figure 2.1

2.3 Assessment and critique of papers

2.3.1 Assessment of papers

Thirty-nine papers were accepted for inclusion in the review. These were scrutinised using the questions outlined in Figure 2.2. Papers were also assessed for methodological rigour, using the tool developed for this purpose by Hawker et al. (2002) for review of literature from different paradigms. The tool is provided in Appendix C. The tool scored papers between nine and thirty-six, where a score of nine represented the poorest quality study and thirty-six represented the highest quality study. The scores for all thirty-nine papers were between twenty-three and thirty-three. The quality scores were not used to exclude articles from the review but to inform interpretation of the findings. Brief details of each study and my critique including methodological rigour score are displayed in Appendix D.

2.3.2 Critique of research designs

A range of research designs were used. Two of the studies each generated two papers included in the review, giving a total of thirty-seven separate studies. Twenty-eight studies used qualitative approaches, two used quantitative approaches, six utilised mixed methods and one was an integrative review of existing research. Qualitative methods utilised were primarily interviews or focus groups, but there was also one ethnographic study, one grounded theory and two which used qualitative case study designs. Three studies used action or co-research methodologies and two used multiple qualitative methods. The dominance of qualitative approaches was appropriate due to the exploratory nature of many of the studies and their focus on investigating views and experiences in relation to a broad range of topics associated with end-of-life care in nursing homes. These included experiences of decision-making, implementation of ACP programmes and end-of-life care practice more generally. Most of these studies used small samples. In some studies the sampling strategy was unclear or not sufficiently justified, with sampling limitations not always acknowledged. A coherent and appropriate approach to analysis was outlined for most studies, although in many it was not obvious whether the impact of the researcher on the data, as interviewer or observer, had been considered. The mixed methods studies all used surveys either as the sole method, using both quantitative and qualitative questioning, or combined with interviews or case studies. The survey design and response rates were explicated, although criteria for sampling of and within case studies were not outlined. It was not always possible to clearly identify the analytical processes undertaken in these studies, although findings were well supported by data. The two quantitative studies were a randomised partial crossover trial, comparing teams established to manage advanced illness with usual care in nursing homes (Chapman and Toseland 2007), and a survey that, although not explicitly acknowledged, appeared by the results to have used a quantitative approach only, which limited the findings of the study investigating barriers to ACP and differences between physicians and nurse practitioners (Burgess et al. 2011). Most studies reported from the professional viewpoint. Only five studies included the views of residents and/or relatives (Forbes 2001; Shield et al. 2005; Jeong et al. 2010; Hall et al. 2011; Kaasalainen et al. 2013).

1. How is multi-professional involvement in ACP (ascertaining and/or implementing resident wishes) within the nursing home portrayed in the literature?
2. What are the experiences of residents, families and staff of multi-professional involvement in both ascertaining and/or implementing resident wishes in nursing homes?
3. What expertise and professional disciplines does the literature suggest is required for ascertaining and/or implementing resident wishes in the nursing home setting?
    a. Involvement of which professional disciplines have been explored in the literature in relation to ascertaining and / or implementing resident wishes in nursing homes?
    b. How is the expertise required to ascertain and/or implement wishes explored in the literature and from whose perspective?
    c. Who does the literature suggest can provide this expertise?
3. What characteristics of multi-professional working does the literature suggest are important to enhance the quality of ACP (ascertaining and/or implementing resident wishes) and how does the literature suggest that these characteristics impact the quality of end-of-life care provided?
4. What factors does the literature suggest make multi-professional working in ascertaining and/or implementing resident wishes more or less effective in the nursing home setting?
5. What is the impact of either good multi-professional working or a lack of multi-professional working on ascertaining and/or implementing resident wishes in nursing homes?

Figure 2.2: Questions used to appraise the full text papers

Only eleven of the studies (twelve papers) set out to investigate multi-professional working in some capacity (Froggatt and Hoult 2002; Froggatt et al. 2002; Ling 2005; Travis et al. 2005;

Chapman and Toseland 2007; Dreyer et al. 2011; Badger et al. 2012; Gorlén et al. 2013; Phillips et al. 2013; Luckett et al. 2017; Wilson and Seymour 2017; Park et al. 2019). The majority of studies had a more general focus on ACP or end-of-life care, with multi-professional working reported in the findings. Of those that explored multi-professional working, two investigated case conferencing (Phillips et al. 2013; Luckett et al. 2017), two explored collaboration between nursing home nurses and doctors (Dreyer et al. 2011; Gorlén et al. 2013), two surveyed specialist palliative care Clinical Nurse Specialists (CNSs) (Froggatt and Hoult 2002; Froggatt et al. 2002; Ling 2005), four studied the team providing care (Travis et al. 2005; Chapman and Toseland 2007; Wilson and Seymour 2017; Park et al. 2019) and one examined the impact of an education programme on collaboration between nursing home nurses and other professionals (Badger et al. 2012). Most of these used qualitative methods to explore experience and views in depth and generated some useful insights into aspects of multi-professional working. The two studies of CNSs used a survey design which was appropriate to seek insight from a greater number of CNSs, as in the UK each nursing home is likely to work with only one or two specialist palliative care CNSs. One of the studies investigated the effectiveness of a new multi-professional team structure and this appropriately used a quantitative design as they set out to study the impact of the care provided by the team on symptom management (Chapman and Toseland 2007). The study design had an acknowledged flaw that limited the findings. However, it was the description of how the team worked in achieving reduction in symptom burden, outlined in the discussion section, which added to the evidence on multi-professional-working, describing how useful the team was in improving perceived quality of care more generally.

2.3.3 Relevance and transferability of international research to UK setting

Only twelve of the thirty-nine papers originated from the UK. Table 2.2 provides details of the number of papers by country of origin. The integrative review included papers from several countries so is excluded from this table. Given the different health systems operating in other countries, papers from outside the UK were assessed as to relevance and transferability of the findings to the UK setting. As outlined in section 1.5, there are differences in how multi-professional services are provided in the nursing home setting between countries. For example, in the US, a team including social workers, physiotherapists and a medical director is employed by the nursing home. However, the majority of studies related to multi-professional working between doctors and nurses, and many countries have a similar system to the UK GP system, where doctors are visiting professionals. Even in countries such as Belgium and the US where a doctor is employed by the nursing home to oversee medical care, primary care is provided by visiting physicians. An awareness of any differences has been used to consider how the study findings translate to the UK. For example, Dreyer et al. (2011) reported poorer teamwork consequential to what was described as doctors holding low percentage positions, referring to doctors who were employed by the nursing home for one day per week. However, the paper reported that the two doctors this applied to were responsible for the care of between twenty-two and thirty-six residents. Although nursing homes in Norway may provide higher acuity care than nursing homes in the UK, this represents significantly higher doctor time than is available in the UK.

Table 2.2: Country of origin of papers included in the literature review

Country of Origin	Number of Papers
Australia	4
Belgium	1
Canada	1
Denmark	1
Korea	1
Ireland	2
Norway	4
Sweden	2
UK	12
US	10

2.4 Synthesis of findings

Reading the papers several times with close attention to the questions in Figure 2.2 enabled patterns to be identified and a comparison of similarities and differences between the study findings made. The outcomes of the literature review were organised under the following themes:

1. The work involved in the process of ascertaining and/or implementing resident wishes, the expertise required to do this and who does or could provide this.
2. The key characteristics of multi-professional working that enhance the process of ascertaining and/or implementing resident wishes.
3. Facilitators and barriers to multi-professional involvement in ascertaining and/or implementing resident wishes.
4. The impact of multi-professional involvement on the process of ascertaining and/or implementing resident wishes.

2.4.1 The work involved in the process of ascertaining and/or implementing resident wishes, the expertise required to do this and who does or could provide this

There was limited reference in the reviewed studies to the work undertaken by professionals to ascertain and implement resident wishes in the nursing home setting; less than half of the papers provided these details. The areas of work identified from the literature were: Discussion of prognosis and treatment options; agreeing transition to palliative/end-of-life care; resolving conflict; dealing with complex or ethical decision-making; dealing with psychological issues or grief and loss; and assessment of physiological status and symptoms. The papers referring to each of these areas of work are outlined in Table 2.3. Only three papers directly referred to the work undertaken to ascertain wishes. Hanson et al. (2002) and Brodtkorb et al. (2017) specifically identify the need for medical treatment options to be discussed. Both papers reported qualitative studies, each involving two care homes (n=26 and n=77 participants), both reporting the determination of medical treatment options as a priority across two different countries, thus reflecting a key aspect of ACP outlined in international definitions (Rietjens et al. 2017; Sudore et al. 2017). A qualitative interview study involving nurses and physicians (n=29) working in nine Swedish nursing homes found that exploration of a resident's preferences was facilitated by discussion of their disease and functional status (Kastbom et al. 2019).

Several studies mentioned the work required for the process of decision-making at the end-of-life (Hanson and Henderson 2000; Hanson et al. 2002; Bern-Klug et al. 2004; Travis et al. 2005; Watson et al. 2006; Lopez 2009; Dreyer et al. 2011; Gjerberg et al. 2011; McDermott et al. 2012; Cornally et al. 2015). End-of-life care decision-making can involve implementing previously stated wishes and in the case of a resident with capacity to make decisions it would be reasonable to expect preferences to be ascertained as part of the decision-making process. Participants in these studies were all nurses and doctors, except for participants in Cornally et al. (2015) study who were senior managers. No explanation was provided why other health and social care participants were not included. Limiting involvement to doctors and nurses resulted in a focus on biomedical aspects of ACP work. The remaining studies (Chapman and Toseland 2007; Phillips et al. 2008; Kaasalainen et al. 2013; Luckett et al. 2017) reported work undertaken in the context of end-of-life care more generally. No new aspects of work were identified from these studies; rather they provided further evidence that the identified areas of work associated with ascertaining and implementing wishes, such as dealing with complexity, are important in the provision of end-of-life care.

Table 2.3: Table showing the work required of professionals in ascertaining and implementing resident wishes

Study authors and date	**Discussion of prognosis and treatment options**	**Agreeing transition to palliative/end-of-life care**	**Resolving conflict**	**Dealing with complex/ challenging/ ethical decision-making**	**Dealing with psychological issues/grief and loss**	**Assessment of physiological status and symptoms**
Bern-Klug et al. (2004)	X	X	✓	X	✓	✓
Brodtkorb et al. (2017)	✓	X	X	✓	X	X
Chapman and Toseland (2007)	X	X	X	X	✓	✓
Cornally et al. (2015)	X	X	X	✓	X	X
Dreyer et al. (2011)	✓	X	X	X	X	✓
Gjerberg et al. (2011)	✓	✓	X	✓	X	X
Hanson and Henderson (2000)	✓	X	X	✓	X	✓
Hanson et al. (2002)	✓	X	X	✓	X	X
Kaasalainen et al. (2013)	✓	X	X	X	X	X
Kastbom et al. (2019)	✓	X	X	X	X	✓
Lopez (2009)	X	✓	X	X	X	X
Luckett et al. (2017)	✓	X	X	X	X	X
McDermott et al. (2012)	✓	X	X	X	X	X
Phillips et al. (2008)	X	X	X	✓	X	✓
Travis et al. (2005)	X	✓	✓	X	X	X
Watson et al. (2006)	X	✓	X	X	X	X

Table 2.4: Table providing details of the papers which suggested disciplines were or should have been involved in end-of-life care within nursing homes and the papers which linked disciplines directly to an identified area of work required in ACP

Professional Discipline / Service	**Papers which suggest the discipline is involved or should be involved in end-of-life care provision in the nursing home setting**		**Papers which link the discipline directly with an area of expertise required to do the work of ascertaining or implementing wishes**	
GPs, Primary Care Physicians or Nursing Home Doctors	Addicott (2011)	Ling (2005)	Bern Klug et al. (2004)	Physiological status & symptoms
	Badger et al. (2012)	Lopez (2009)		
	Bern-Klug et al. (2004)	Luckett et al. (2017)	Brodtkorb et al. (2017)	Prognosis & treatment
	Brodtkorb et al. (2017)	McDermott et al. (2012)	Cornally et al. (2015)	Complex/ethical decisions
	Burgess et al. (2011)	Phillips et al. (2009)	Dreyer et al. (2011)	Prognosis & treatment
	Chapman & Toseland (2007)	Phillips et al. (2013)	Gjerberg et al. (2011)	Prognosis & treatment
	Cornally et al. (2015)	Seymour et al. (2011)		Transition to palliative care
	Dreyer et al. (2011)	Shield et al. (2005)		Complex/ethical decisions
	Froggatt et al. (2008)	Travis et al. (2005)	Hanson & Henderson (2000)	Prognosis & treatment
	Furman et al. (2006)	Watson et al. (2006)		Complex/ethical decisions
	Gorlén et al. (2013)	Wilson & Seymour (2017)	Hanson et al. (2002)	Prognosis & treatment
	Gjerberg et al. (2011)			Complex/ethical decisions
	Hall et al. (2011)		Kastbom et al. (2019)	Prognosis & treatment
	Hanson & Henderson (2000)		Lopez (2009)	Transition to palliative care
	Hanson et al. (2002)		Luckett et al. (2017)	Prognosis & treatment
	Hov et al. (2009)		McDermott et al. (2012)	Prognosis & treatment
	Jeong et al. (2010)		Travis et al. (2005)	Transition to palliative care
	Kastbom et al. (2019)			Resolving conflict
	Lee et al. (2017)		Watson et al. (2006)	Transition to palliative care
Nurse Practitioners	Burgess et al. (2011)	Lopez (2009)	Kaasalainen et al. (2013)	Prognosis & treatment
	Hanson et al. (2002)	Shield et al. (2005)	Lopez (2009)	Transition to palliative care
	Kaasalainen et al. (2013)			

Professional Discipline / Service	Papers which suggest the discipline is involved or should be involved in end-of-life care provision in the nursing home setting		Papers which link the discipline directly with an area of expertise required to do the work of ascertaining or implementing wishes	
Specialist Palliative Care Services	Addicott (2011) Badger et al. (2012) Froggatt & Hoult (2002) Froggatt et al. (2002) Hall et al. (2011) Jeong et al. (2010)	Lee et al. (2017) Ling (2005) Phillips et al. (2008) Phillips et al. (2009) Seymour et al. (2017)	Phillips et al. (2008)	Complex / ethical decisions Physiological status & symptoms
Geriatric or Psychogeriatric Specialist Doctors	Jeong et al. (2010) Phillips et al. (2009)			
Social Workers	Bern-Klug et al. (2004) Burgess et al. (2011) Chapman & Toseland (2007) Forbes (2001) Froggatt et al. (2008)	Furman et al. (2006) Hanson et al. (2002) Ling (2005) Lopez (2009)	Bern-Klug et al. (2004) Chapman & Toseland (2007) Lopez (2009)	Resolving Conflict Psychological issues & loss Psychological issues & loss Transition to palliative care
Out of Hours (OOHs) Medical Providers	Addicott (2011) Badger et al. (2012) Brodtkorb et al (2017) Jeong et al. (2010)	Lee et al. (2017) McDermott et al. (2012) Seymour et al. (2011)		
Nurse Specialist Case Conference Coordinator	Jeong et al. (2010) Luckett et al. (2017)			

The literature emphasised the involvement or the need for involvement of GPs (or equivalent) or nursing home physicians in the provision of end-of-life care in nursing homes compared to other professional groups. This is highlighted in Table 2.4, which provides details of the different visiting professional groups involved or thought should be involved in end-of-life care provision in nursing homes and the specific disciplines linked to a type of required work. Interestingly, two studies suggested potential benefits from involvement of geriatric specialist doctors and psychogeriatricians in end-of-life care planning and multidisciplinary meetings (Phillips et al. 2009; Jeong et al. 2010). However, this recommendation is not supported by the data generated by one study; this involvement was considered beneficial by just one of the thirteen GPs participating in the study (Phillips et al. 2009). Involvement of these specialist doctors as part of multidisciplinary discussions was a component of a conceptual framework for the successful implementation of ACP proposed by Jeong et al. (2010). However, full assessment of the robustness of this conceptual framework is limited because no information is provided about the number of residents, relatives and nurses who were involved in the study from which the framework was developed. Both these studies were Australian where case conferences are a regular part of care for residents with complex needs, and so the findings would not be readily replicated in the UK nursing home setting where case conferences are not part of routine nursing home practice.

Doctors were identified most frequently as the discipline with the expertise required to deliver the work of discussing prognosis and treatment options (see Table 2.4). One Canadian paper suggested that nurse practitioners could also do this work (Kaasalainen et al. 2013). This study explored the role of the nurse practitioner in provision of palliative care in five long-term care homes, using focus groups and individual interviews to garner views from a diverse range of participants including doctors, nurses, nurse practitioners, managers, Allied Health Professionals, personal care workers, residents and relatives. Nurses and care workers described the nurse practitititioners' advanced skill, particularly in relation to palliative care knowledge such as prognostication, as a great resource. However, these findings do not currently transfer to the UK nursing home setting because nurse practitioner involvement in nursing home care is not common practice. OOHs doctors were identified specifically in some papers. However, this was not in relation to the work they do or the expertise they provide, but about the challenges faced with their involvement in provision of end-of-life care in nursing homes. These issues are discussed in section 2.4.3.

Specialist palliative care was discussed in several papers, with the UK literature primarily referring to the role of the CNS. Two UK studies investigating outcomes following implementation of the

GSFCH programme[1] identified that the support of specialist palliative care with provision of end-of-life was valued by nursing home staff (Hall et al. 2011; Badger et al. 2012). Palliative care teams were also reported as having a significant role in assisting staff to meet resident preferences in four UK care homes in case study research, exploring factors that supported residents to stay in the homes for end-of-life care (Addicott 2011). However, one of the difficulties in some papers was distinguishing findings that related to nursing home care from those relating to residential home care. Two of the case study homes were residential homes and two were nursing homes and it was not possible to determine whether this finding applied to one or both setting types. None of these papers mentioned the expertise that specialist palliative care can provide, although nurses and carers in an Australian study, investigating perceptions of a multi-component palliative care intervention, discussed their role in managing symptoms and complex decision-making (Phillips et al. 2008). However, in this study again it was not possible to distinguish whether findings related to one or both of low care residential aged care facilities (approximately equivalent to a UK residential home) and high care residential aged care facilities (approximately equivalent to a UK nursing home). In other studies, managing challenging, complex or ethical decision-making was an expertise aligned with the doctor role (Hanson and Henderson 2000; Hanson et al. 2002; Gjerberg et al. 2011; Cornally et al. 2015; Brodtkorb et al. 2017).

Specialist palliative care staff participating in the study by Lee et al. (2017), looking at end-of-life care for people with dementia, identified with an indirect role in ACP through supporting other professionals to lead discussions. Although nursing home providers did participate, this research was not specific to nursing homes, with the focus being on care of people with dementia in any setting, but this finding reflects the role of specialist palliative care providers in providing education to nursing home staff identified in other studies (Froggatt and Hoult 2002; Froggatt et al. 2002; Ling 2005; Cronfalk et al. 2015). Two of these papers report the same mixed-methods survey study, one presenting only quantitative findings, which investigated the work undertaken by UK palliative care CNSs in nursing homes (Froggatt and Hoult 2002; Froggatt et al. 2002), with the study by Ling (2005) a replication of this survey study undertaken in Ireland. The findings were similar except that a much higher percentage of UK CNSs were involved in educational activities in nursing homes than in Ireland. Cronfalk et al. (2015) investigated nursing home staff attitudes to an educational programme delivered by specialist palliative care practitioners that was being developed in one part of Sweden; it was not clear whether other programmes existed

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[1] GSFCH is a quality improvement programme for care homes designed to deliver transformational change using the GSF, an evidence based systematic approach to improving the organisation and coordination of care for people in their last year of life (National GSF Centre 2021a).

in other parts of the country. Although the educational role identified in these studies does not directly relate to the work of ACP, education programmes have been shown to increase confidence in facilitating ACP discussions (O'Brien et al. 2016). This educational role with nursing homes was unique to specialist palliative care professionals.

A particular weakness in the evidence base was an understanding of the importance of nursing home nurses' expertise in the provision of end-of-life care in nursing homes. Nursing home nurses featured in all the reviewed studies, yet there was minimal discussion about the specific knowledge or skills they required. Where this was discussed (n=3 studies) it was limited to assessment of physiological status and symptoms (Hanson and Henderson 2000; Bern-Klug et al. 2004; Dreyer et al. 2011). Medical participants in these studies identified their dependence on nursing assessments to support their decision-making. However, these three studies report nursing expertise from solely a medical perspective, so may not be indicative or fully inclusive of the expertise considered important by nursing home nurses in the provision of end-of-life care. Neither do the studies make explicit what level of knowledge of physiology and symptomatology was required, given the role of specialist palliative care services in managing symptoms and providing educational support identified above.

However, there is evidence that nursing home nurses are involved in ascertaining wishes in ACP practice. A UK study by Froggatt et al. (2008) suggested they were frequently involved. This study invited five hundred care home managers to be involved in a survey, achieving a 42% response rate of useable questionnaires (n=213), and undertook follow-up in-depth interviews with fifteen managers. The findings reported registered nurses (RNs) being involved in 40% of care homes. As only 31% (n= 66) of managers were from nursing homes and no figures were provided for involvement of District Nurses, it was not clear whether nurses in all the nursing homes were involved. From a small-scale study investigating enablers and barriers to involvement in future care discussions experienced by the multidisciplinary team in one US nursing home, Furman et al. (2006) recommended that nurses should be jointly responsible for ACP discussions with doctors. However, the expertise required to have these discussions was not discussed and the study focus was limited to the medical components of ACP. Kastbom et al. (2019) reported that nurses found that raising questions about wishes and preferences with residents and families prior to an ACP discussion with a physician facilitated the process, with physician participants reporting having confidence in the assessments made by nurses when they explored ACP with residents. However, again the knowledge and skills nurses required to have these discussions was not mentioned. A study involving twenty-six nursing home staff from two Norwegian nursing homes, investigated how healthcare workers were influenced by and dealt with ethical challenges in end-of-life care

(Brodtkorb et al. 2017). Participants, including seventeen RNs, six enrolled nurses, two physiotherapists and one sociologist, questioned the competence of enrolled nurses to have discussions relating to medical treatment and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR). This finding may have relevance in the UK as the role of nurse associate develops in nursing homes.

Nursing home nurses were also considered instrumental to decisions about whether active treatment would be considered or a palliative care approach adopted, although yet again the expertise required to have these conversations was not explicitly identified. These conversations often involved consensus building between all professionals involved in a resident's care and relatives, as discussed in section 2.4.2.4. Gjerberg et al. (2011) explored relationships between nursing home staff and family members using a postal survey (n=364 Norwegian nursing homes; response rate: 78%). They found nurses were involved in conversations with family members about the health status of residents but reported a need for physician support with informing relatives about the background to the medical and ethical assessments. Travis et al. (2005) found that once the nurses had reached consensus that a transition to palliative care was indicated, physicians had a visible and intensive role in discussing this with residents and relatives. Lopez (2009) investigated how decisions were made by US nursing home nurses about whether active treatment should be pursued or a palliative care approach should be taken in response to acute illness. She interviewed ten nurses from four nursing homes and found that a majority of nurses did not consider supporting families with decision-making was their role, identifying this as a role for either a doctor or social worker.

Social workers were the only professional discipline identified in the literature with expertise in dealing with psychological issues and grief and loss, although the evidence presented was extremely limited. In addition, there was paucity of evidence to support their role in managing conflict and in helping residents and families express wishes and preferences for future care. Neither was their expertise in managing psychological issues and grief and loss expressly linked to ascertaining or implementing wishes (Bern-Klug et al. 2004; Chapman and Toseland 2007). Chapman and Toseland (2007) compared usual care for residents with advanced dementia in two large US nursing homes with an intervention delivered by a multidisciplinary advanced illness care team who specifically addressed four domains of care: medical, meaningful activity, psychological and behavioural issues. The study used a randomised partial cross-over design, but there was an acknowledged design flaw leading to spill-over of treatment effect to the control group. However, the intervention resulted in improvements in agitated behaviour and pain, with social workers within the team having a specific role in managing behavioural, psychological and family issues. Bern-Klug et al. (2004) interviewed twelve physicians and although social worker involvement was not raised directly by the participants, they highlighted a lack of emotional-preparedness amongst family as an issue they faced in their practice, something the authors suggested could be addressed by the involvement of social workers in family support, conflict resolution, dealing with grief and loss and helping with decision-making, Interestingly, Travis et al. (2005) found doctors to have the dominant role in managing conflicts within families or between family members and staff, whereas social workers were not mentioned despite being study participants alongside nurses and physiotherapists. On the other hand, multidisciplinary participants in the study by Furman et al. (2006) identified social workers as having a role in helping residents and families express wishes and preferences for future care. It should be noted that these four studies referencing social workers are all US studies, where social workers are part of the nursing home team, which is not the case in the UK. However, as identified by Seymour et al. (2011), although not an integrated part of nursing home care, social workers regularly visit nursing homes in the UK and make an important contribution towards the wider health and social care system which influences the quality of end-of-life care in nursing homes. This mixed method study included ten case studies and a postal survey of 180 nursing homes. Twenty-nine of the eighty-two homes that responded indicated that they received some or a lot of support from social workers. However, the role undertaken in nursing homes was not specified. A survey of care home managers suggested that social workers were involved in ACP in the UK; however, the level of involvement was not quantified (Froggatt et al. 2008).

2.4.2 Key characteristics of multi-professional working that enhance the process of ascertaining and/or implementing resident wishes

The review identified four key and interrelated characteristics of multi-professional working which enhanced the ACP process. These are communication, collegial relationships, consensus building and a coordinated approach. Table 2.5 provides details as to which of the four characteristics were identified in each of the individual papers.

2.4.2.1 Communication

Communication between nursing home staff and external health and social care professionals was reported as important to ensure resident end-of-life care wishes were respected (Addicott 2011). Good communication between nursing home doctors and nurses was found to be crucial in facilitating treatment decision-making (Hanson et al. 2002). Conversely, problematic communication made ethical decision-making more challenging (Brodtkorb et al. 2017) and led to tension between professionals and disciplines (Forbes 2001; Cronfalk et al. 2015). GP participants in a qualitative interview study identified that problems with communication, such as availability of documentation and nurses' knowledge of a resident's history, impacted informational continuity and were a major factor influencing UK GPs' decision-making about whether to admit frail nursing home residents to hospital (McDermott et al. 2012). Interestingly, as well as effective inter-professional communication being a component of multi-professional working which supported ACP, Addicott (2011) concluded that ACP also supported better communication suggesting ACP was a useful trigger for instigating and structuring effective communication with residents and other professionals. Additionally, Cornally et al. (2015) found that implementing an ACP programme, offering a structured approach to end-of-life care planning, enhanced communication.

Nevertheless, there was limited explanation about factors influencing 'good' or 'difficult' communication. However, one study referred to interactions involving 'open' communication, where nurse practitioners and nurses asked questions of each other to collectively solve clinical problems, as being collaborative and having the potential to improve the quality of end-of-life care (Kaasalainen et al. 2013). Three studies referred to one-sided communication. Two studies found nurses used language specifically designed to influence medical decisions to achieve what they perceived necessary to deliver high quality care. Hanson and Henderson (2000) found that nurse participants in their focus group study constructed physician-specific communication styles. The 'Satisfying All Sides theory', a grounded theory generated by Lopez (2009), proposed that nurses used coded language in their communication with doctors and relatives to create a plan aligned to a resident's expressed wishes. This language emphasised the preferred outcome, such as stressing resident discomfort or need for greater expertise if transfer to hospital desired. Hov et al. (2009) found that nurses felt uncomfortable when a doctor made a decision based on their opinion without discussion or assessment of the patient, in an interview study of fourteen nurses from two Norwegian nursing homes which explored experiences of withdrawing or withholding life-sustaining treatment discussions.

The importance of both written communication as well as verbal communication was reported. Appropriate documentation regarding outcomes of discussion and decisions, that were accessible to all staff, was essential to keep everyone informed and ensure wishes were implemented (Travis et al. 2005; Furman et al. 2006; Kastbom et al. 2019). In a Norwegian study, specifically investigating professional collaboration about dying residents between nurses and doctors, good nursing documentation was found to be necessary to enable doctors to provide appropriate treatment as well as creating a platform for coordinating communication with relatives (Dreyer et al. 2011). However, it is possible that their recruitment strategy may have impacted this outcome. Involvement was limited to one doctor and one nurse from each of nine nursing homes and one nurse from a tenth home and was not explained except to involve a wide range of nursing home settings. Thus, the data from the nurse and doctor from each home was treated as representative of all staff, whereas another nurse or doctor in the same home may have had different experiences of collaboration than the participant. However, the authors claimed that data saturation was obtained.

In another study, UK GPs identified that clearly documented resident wishes was a key factor in their decision-making about whether to admit nursing home residents to hospital (McDermott et al. 2012). Nurses and physicians in a Swedish study reported that ACP was complied with if it was clearly written, in a way that could not be misunderstood or subjectively interpreted, and available to staff (Kastbom et al. 2019). End-of-life care documentation was identified as a factor influencing positive evaluation of implementation of the Six Steps to Success education programme[2] in one UK region. This enhanced communication between the home staff and external professionals, by providing the information needed to support decision-making (O'Brien et al. 2016). However, Lee et al. (2017) found that even where ACP was documented, challenges in implementing the resident's wishes could still occur when the document had not been shared with other providers such as the ambulance service.

One study suggested that good communication ensured consistent information was provided to residents and relatives and made it more likely that appropriate medical treatment and care was delivered during the dying process (Hanson et al. 2002). Yet, nurses sometimes felt they were caught in the middle of a to and fro exchange between family and doctors (Lopez 2009; Brodtkorb et al. 2017). An interview study with family members close to a deceased nursing home resident found information from doctors and nurses was wished for but that communication with doctors was often perceived as poor and some family members reported that they had never met the doctor (Shield et al. 2005). However, these findings may be influenced by the impact of time delay on recall; there was a delay of between one and two years between the resident's death and the family member's participation in the study. Worthy of note, although only mentioned in one paper, is the language barrier to communication that exists for many care home staff in the UK because English is not their first language (Hall et al. 2011).

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[2] Six Steps to Success Programme is an education programme based on the six steps of the end-of-life care pathway outlined in the End-of-Life Care Strategy (DH 2008), which aims to enhance end-of-life care through facilitating organisational change (The End-of-Life Care Partnership 2021).

Table 2.5: Table providing details as to which of the four characteristics of multi-professional working were identified in each paper

Study authors and date	**Communication**	**Collegial relationships**	**Consensus building**	**Coordinated approach**
Addicott (2011)	✓	✓	X	X
Badger et al. (2012)	✓	✓	X	X
Bern-Klug et al. (2004)	X	X	✓	X
Brodtkorb et al. (2017)	✓	X	X	X
Burgess et al. (2011)	X	X	X	✓
Cornally et al. (2015)	✓	X	X	X
Cronfalk et al. (2015)	✓	X	X	✓
Dreyer et al. (2011)	✓	X	✓	✓
Forbes (2001)	✓	X	✓	X
Froggatt et al. (2008)	X	✓	✓	X
Furman et al. (2006)	✓	X	✓	✓
Gorlén et al. (2013)	✓	✓	X	X
Hall et al. (2011)	✓	X	X	✓
Hanson and Henderson (2000)	✓	X	✓	✓
Hanson et al. (2002)	✓	✓	✓	X
Hov et al. (2009)	✓	X	✓	X
Kaasalainen et al. (2013)	✓	X	X	X
Kastbom et al. (2019)	✓	X	✓	✓
Lee et al. (2017)	✓	✓	X	X
Lopez (2009)	✓	X	X	X
Luckett et al. (2017)	X	✓	X	X
McDermott et al. (2012)	✓	X	X	X
O'Brien et al. (2016)	✓	✓	X	X
Park et al. (2019)	X	X	✓	X
Phillips et al. (2008)	X	X	X	✓
Phillips et al. (2013)	✓	X	✓	✓
Seymour et al. (2011)	✓	✓	X	✓
Shield et al. (2005)	✓	X	X	X
Travis et al. (2005)	✓	X	✓	X
Watson et al. (2006)	✓	✓	X	X
Wilson and Seymour (2017)	✓	✓	X	X

2.4.2.2 Collegial relationships

Nursing home managers reported that good relationships with other professionals played a role in ensuring a high standard of end-of-life care practice and implementation of resident wishes (Froggatt et al. 2008). Good working relationships were reported as developing over time (Seymour et al. 2011), with longer term relationships considered beneficial to the development of collaborative working (Badger et al. 2012). Similarly, participants in the study by Lee et al. (2017), who worked with people with dementia in either residential settings or primary care, highlighted successful relationships with GPs as key to collaborative working in the provision of end-of-life care.

An ethnographic study investigated anticipatory prescribing in four community nursing teams and four nursing homes. Participants from two nursing homes working with just one allocated GP practice suggested this enabled development of better working relationships (Wilson and Seymour 2017). Similarly, Lee and colleagues (2017) reported a planned weekly GP round was valued by staff for developing working relationships. An issue raised in one study was that sometimes having too many different people involved could make communication difficult (Seymour et al. 2011). However, other studies reported mixed opinion on whether working with a larger or smaller number of doctors was preferable (Badger et al. 2012; Gorlén et al. 2013). In these two studies some participants expressed a preference to build good relationships with one doctor or one GP practice, whilst others felt they gained from the broader professional discussions possible when there were several doctors working with their residents.

Addicott (2011) reported ways in which care home staff had improved their working relationships with external stakeholders, with strategies such as providing as much detail as possible when contacting GPs, being proactive in resolving problems when they arose and including external providers in ACP. Increasing competence and confidence in managing palliative care was another strategy identified in the reviewed literature. As a result of attending the Six Steps to Success Programme, communication by care home staff with the multi-professional team improved, which had gone some way to raising the external professionals’ confidence in the abilities of home staff (O'Brien et al. 2016). Knowledge gained through education programmes was reported as improving communication alongside relationships with GPs (Gorlén et al. 2013) and with specialist palliative care providers (Badger et al. 2012). This included further improvements in relationships, even when good relationships with GPs were reported at the outset (Badger et al. 2012).

The literature identified trust as a key factor underpinning collegial relationships (Seymour et al. 2011; Luckett et al. 2017; Wilson and Seymour 2017). Luckett et al. (2017) explored health professionals' perceptions of the benefits of case conferences in ten Australian nursing homes. GP engagement with case conferencing was reported to be facilitated by establishment of trust through an ongoing relationship with the Palliative Care Planning Coordinator. However, although forty professionals from a range of disciplines participated in qualitative interviews, reporting was biased towards the views of Palliative Care Planning Coordinators, thereby limiting the evidence provided to support their claims. Wilson and Seymour (2017) suggested strategies that promoted trust included clarifying understanding of differing responsibilities and open communication. However, this study combined findings from two types of setting, community and nursing home, and any differences between the perceptions of community nurses and nursing home nurses were not specified. Increased competence and confidence of nursing staff was also identified as a factor in developing trust. In an action research study, investigating barriers to implementing an end-of-life integrated care pathway in eight nursing homes, nursing staff used action learning sets to consider ways of overcoming barriers to collaborative working with GPs (Watson et al. 2006). In the action learning sets, nurses looked at how requests to GPs were worded, considered assumptions they were making about GPs and thought through ways that options could be made more explicit when making decisions about end-of-life care. This approach was reported as effective in building up trust and improving collaboration. Having an appropriate level of competence to assess residents' needs and appropriately refer to GPs was also mentioned (Seymour et al. 2011). However, it was reported that in the absence of an established relationship, specialist end-of-life care education or experience engendered greater levels of trust from GPs in the area of anticipatory prescribing, with specialist palliative care nurses able to mediate for nursing home nurses (Wilson and Seymour 2017).

Commitment was another element of a good working relationship identified, but with limited evidence. A study investigating the perceptions of nurses and care staff (n=16) in three Danish nursing homes found commitment to both the palliative care approach and to individual residents made collaboration with GPs satisfactory when providing end-of-life care (Gorlén et al. 2013). Nurses who participated in a focus group study, investigating terminal care in two US nursing homes, reported lack of doctor involvement and commitment to their nursing home residents frustrating, with the doctors recognising an unwillingness to visit more often. This interfered with teamwork (Hanson et al. 2002).

2.4.2.3 Coordinated approach

Two factors were identified which enhanced a coordinated multi-professional approach to ACP. The first was professionals being aware of the skills and responsibilities of the different disciplines in the team, so everyone contributes appropriately. A lack of coordination and involvement between disciplines was identified as a major barrier to initiating discussions about goals of care (Furman et al. 2006). Likewise, Burgess et al. (2011), in an online survey investigating barriers to ACP in US Skilled Nursing Facilities, suggested that low rates of ACP were connected to under recognition of team member efforts, although no data was presented to support this claim. Describing the role of the physician in provision of end-of-life care in nursing homes, Hanson and Henderson (2000) discussed the physician integrating the insights of other disciplines, including social work and nursing, with their own knowledge of prognosis and treatments. They suggested that the combined understanding of the different disciplines could help residents and families with end-of-life decisions. Physicians and nurses participating in the study by Kastbom et al. (2019) also reported that there was a need for the views of physicians to be integrated with those of the resident and family members.

One strategy identified for achieving combined understanding by discipline groups was establishment of a multidisciplinary care planning forum (Phillips et al. 2008). However, the success of this strategy was dependent on GPs' understanding of the roles of other disciplines (Phillips et al. 2013), although evidence to support this conclusion was limited. Cronfalk et al. (2015) found that tensions could exist between professionals because unnecessary misunderstandings occurred when care was not coordinated and areas of responsibility were not clear, but that where communication was adequate this could lead to team members gaining a better understanding of each other's role. Furman et al. (2006) also suggested that lines of responsibility were a problem due to a lack of accountability by physicians for ensuring goals of care discussions happened routinely. However, Dreyer et al. (2011) found that where there was consensus between the doctors and nurses alongside good communication and cooperation, responsibilities could be clarified. This suggested that effective communication underpins good coordination.

The second component identified as influencing coordinated multi-professional working was information-sharing, although the evidence in the reviewed literature was limited. In the paper by Seymour et al. (2011) a need for information-sharing is illustrated in several participant quotes. Drawing on his experience of working in different nursing homes, one participant GP stressed information-sharing was influential to good working relationships. Qualitative comments about barriers to end-of-life care taken from the survey part of the study also included remarks about a need for more information-sharing including information about services that could be accessed, resources available and more information from GPs about residents, for example, post hospital treatment. The benefit of this latter information-sharing was also highlighted by a nursing home manager participant in a study investigating the benefits and barriers to implementing the GFSCH programme with nine nursing homes, who commented on how their GP had given the home printed medical histories for all of their residents (Hall et al. 2011).

2.4.2.4 Building consensus

Achieving consensus so that all professionals involved in a resident's care worked to the same goals was portrayed in several studies as key to high quality end-of-life care for nursing home residents (Forbes 2001; Bern-Klug et al. 2004; Travis et al. 2005; Furman et al. 2006; Dreyer et al. 2011; Phillips et al. 2013; Kastbom et al. 2019; Park et al. 2019). This consensus also needed to be reached with residents' families (Bern-Klug et al. 2004; Phillips et al. 2013; Kastbom et al. 2019). Indeed, Kastbom et al. (2019) found a latent theme underpinning the ACP process for nurses and physicians was a need to defend oneself against tacit accusations of maleficence, with a broad agreement on ACP between residents, family members, nurses and physicians therefore required.

Building consensus was not explicitly reported as a characteristic of multi-professional working that influenced ACP per se, rather the review suggested that shared understanding enhanced end-of-life care planning and recognition that residents are approaching end-of-life (Bern-Klug et al. 2004; Travis et al. 2005; Dreyer et al. 2011; Park et al. 2019). Bern-Klug et al. (2004) identified consensus as integral to good end-of-life care from the perspective of the US physicians they interviewed. Park et al. (2019) explored an interdisciplinary approach to palliative care in nursing homes in South Korea in an interview study involving nurses (n=11), physiotherapists (n=6), occupational therapists (OTs) (n=2) and social workers (n=10) working in five nursing homes and found that it was necessary for the team to find consensus to set care goals for residents. Travis et al. (2005), investigating how treatment futility was recognised in two US nursing homes in a small focus group study involving nurses, social workers and physiotherapists, described how a hierarchical order of consensus building occurred with staff sharing observations and assessments until agreement was reached. Dreyer et al. (2011), however, found that consensus building on individual resident cases was dependent on availability of physicians, which could result in a generalised agreement between the nurses and physicians on the approach to life-prolonging treatment being applied inappropriately.

The study of one US nursing home using ethnographic methods to describe end-of-life care by Forbes (2001) found residents and family members had many unmet end-of-life care needs and that even when a resident had completed ACP, care was not necessarily provided in accordance with expressed wishes. The author suggested this was due to a lack of communication, teamwork and agreement between staff, residents and families which led to conflicting interpretations of the wishes expressed. However, the relevance of these findings to UK settings is limited due to the dominance of issues specific to the regulatory climate of US nursing homes at the time of the study. Furman et al. (2006) suggested that consensus on the goals of care can improve teamwork and Kastbom et al. (2019) found that nurses and physicians reported that discussion with other team members was important when making care decisions to manage the risk of accusations of maleficence. The findings of a survey and interview study of UK care home managers showed that a shared understanding was considered helpful in the implementation of resident wishes, ensuring nursing home staff, family and external health providers were working to the same goal when a resident was no longer able to communicate their own wishes (Froggatt et al. 2008). This demonstrated the importance of consensus and communication in implementing resident wishes.

Bern-Klug et al. (2004) highlighted the importance of consensus as both a process and an outcome, shared understanding developing into shared goals, and the need for a working definition so all team members understand the terms in the same way. Indeed, the terms consensus, shared understanding and agreement were used interchangeably in the literature, along with other similar language. Two papers, reporting different aspects of one study, referred to mutual understanding of care plans, with shared communication and decision-making between the nursing team and doctors, to allow the team to provide compassionate support and ensure provision of consistent messages to residents and families (Hanson and Henderson 2000; Hanson et al. 2002). Hov et al. (2009) suggested that nursing home nurses often worked with uncertainty unless a clear understanding of the rationale for a decision and a clear treatment goal was in place.

Dreyer et al. (2011) investigated decision-making and found that collaboration provided a key platform for attainment of general agreement between professionals regarding treatment plans. However, they did not explicitly define the term collaboration, although it was discussed in terms of communication and cooperation between professionals. This therefore supported the findings of Forbes (2001) which demonstrated that an absence of consensus, teamwork and communication led to poor quality end-of-life care. These two studies also evidenced an interrelationship between the four characteristics of multi-professional working identified from the literature, but further research is required to fully operationalise what these characteristics mean in the nursing home setting and the context of ACP specifically.

2.4.3 Facilitators and barriers to multi-professional involvement in ascertaining and/or implementing resident wishes

Several facilitators and barriers to multi-professional involvement in ACP were identified from the literature. These are shown in Figure 2.3 and discussed in relation to their impact on multi-professional involvement generally as well as in relation to ACP.

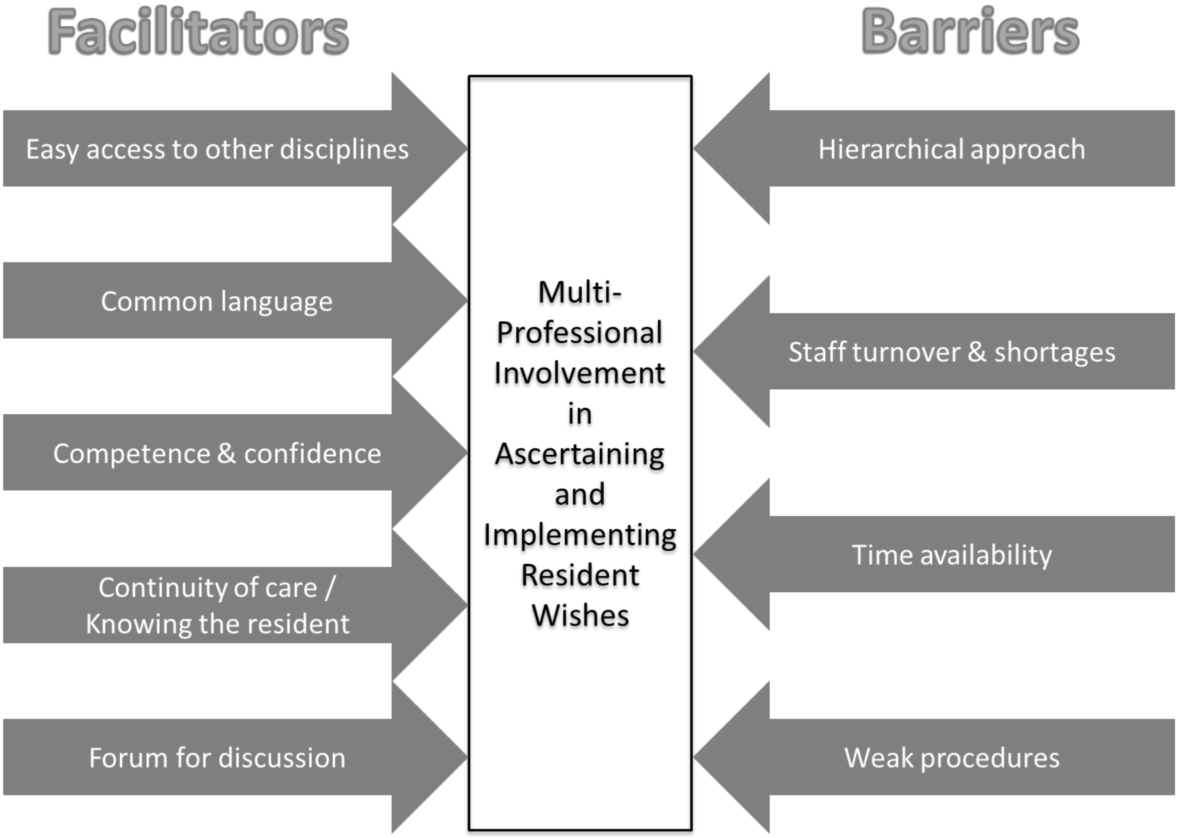


Figure 2.3: Diagram showing the facilitators and barriers to multi-professional involvement in ascertaining and/or implementing resident wishes in nursing homes identified in the literature

The effectiveness of multi-professional communication and collaboration was reported to be impacted by the level of knowledge and competence of the professionals involved, with Froggatt et al. (2002) reporting this as the factor most frequently perceived by specialist palliative care CNSs to shape their work with care homes. Indeed, in a study with a focus on end-of-life care in dementia, specialist palliative care staff raised concerns about the willingness and ability of GPs to become involved in discussions around ACP (Lee et al. 2017). Evaluations of educational programmes facilitating organisational change in relation to palliative care in the UK support this. Better multi-professional team communication was a key outcome of the increased palliative care knowledge brought about by both the GSFCH programme (Hall et al. 2011; Badger et al. 2012) and the Six Steps to Success programme (O'Brien et al. 2016). This was supported by other studies which found that a lack of education was perceived as creating opportunities for interpersonal conflict regarding end-of-life care issues (Forbes 2001) and that a level of expertise so that nurses could assess patient needs and appropriately refer to GPs was a condition of the development of trust that underpinned collegial relationships (Seymour et al. 2011). In a Norwegian study, doctors emphasised the competence of nurses as a key influence on the quality of the cooperation between them (Dreyer et al. 2011). However, a UK study which looked at anticipatory prescribing practice suggested nurses believed that GPs sometimes dismissed their knowledge and skills (Wilson and Seymour 2017).

Nurses reported that gaining knowledge improved their communication, equipping them to articulate arguments particularly in difficult cases (Gorlén et al. 2013; Cronfalk et al. 2015). Speaking the language of palliative care enabled nursing staff to better discuss care and verbalise their assessments clearly (Phillips et al. 2008). Although education programmes like the GSFCH programme and Six Steps to Success are aimed at nursing home staff, the literature suggested that it is not just the knowledge of nurses that enhanced communication but that doctors' understanding of palliative care also impacted multi-professional working. It was suggested that a GP's lack of palliative care knowledge led to nurses having a negative experience of cooperation with GPs (Gorlén et al. 2013) and the perceived resistance by some GPs to attend palliative care case conferences was attributed in part to lack of expertise (Luckett et al. 2017). The language used therefore needs to be a common language as it is necessary for all professionals to understand it; otherwise it has the potential to cause conflict between providers (Phillips et al. 2008; Cronfalk et al. 2015).

The evaluations of UK care home educational initiatives also highlighted that the knowledge gained through participation in the programmes increased the confidence of nursing staff (Hall et al. 2011; Badger et al. 2012; O'Brien et al. 2016). These findings were supported by a Swedish study reporting staff attitudes to competence-building programmes in palliative care (Cronfalk et al. 2015). Increased confidence enhanced multi-professional communication because nursing staff felt able to challenge GPs, rather than 'going along' with doctors' decisions even to the detriment of the resident (Watson et al. 2006). Care home staff described how increased confidence empowered them to achieve the care that they thought was right for a resident (O'Brien et al. 2016). The ability to challenge health professionals who recommend admitting a resident to hospital was considered a key factor in a care home's capacity to successfully honour ACP (Addicott 2011).

Competence and confidence gained through educational programmes such as the GSFCH programme and Six Steps to Success also helped to create a more equal partnership between the nursing home staff and professionals with whom they collaborated, lessening discriminative attitudes and overcoming perceptions of unequal status that could limit communication and trust (Badger et al. 2012; O'Brien et al. 2016). There was evidence of an imbalance of power between doctors and nurses, based on the traditional hierarchy of healthcare teams, with doctors reluctant to take direction from nurses (Wilson and Seymour 2017) and nurses feeling inferior when doctors ignored their opinions (Hov et al. 2009; Wilson and Seymour 2017). Brodtkorb et al. (2017) found this led to nurses experiencing uncertainty and being caught between having too much responsibility and too little authority.

The literature highlighted the need for lines of accountability to be clarified to provide a standardised framework for ACP in which all professionals involved can operate and collaborate, to avoid lack of ownership, diffusion of responsibility and poor coordination (Furman et al. 2006; Burgess et al. 2011; Cronfalk et al. 2015). Burgess et al. (2011) emphasised the importance of consistency with regard to documentation of ACP, finding ACP was documented by different professionals in different locations whereas it needed to be accessible to all staff, so it was available in case of acute illness or deterioration (Furman et al. 2006). The study by Kastbom et al (2019) found the use of different medical records systems by nursing homes and primary care physicians caused difficulties with information-sharing and was considered a barrier to both developing and implementing an advance care plan. Guidelines to better manage communication with residents and families regarding end-of-life care were also mentioned (Brodtkorb et al. 2017), with too many episodes of futile treatment blamed on weak processes (Dreyer et al. 2011). In the UK, where multiple organisations as well as multiple professionals can be involved, this is not straightforward, with a lack of procedures to ensure resident wishes can be shared with health and social care professionals and adhered to (Addicott 2011). Participants in a study investigating the impact of the GSFCH education programme on collaboration between nursing home staff and other professionals suggested that the structure and processes implemented helped joint working, with the tools used recognised by professionals working in other settings also using the GSF (Badger et al. 2012).

Access to professionals was found to be a central component of multi-professional communication in a study of anticipatory prescribing practice in the community and nursing home settings (Wilson and Seymour 2017). Yet, the literature contained frequent reports of nursing home staff experiencing difficulties accessing both doctors (Hanson and Henderson 2000; Gorlén et al. 2013), in particular OOHs medical providers (Seymour et al. 2011; Badger et al. 2012), and specialist palliative care services (Badger et al. 2012). Findings from a survey of specialist palliative care CNSs suggested that care homes did not access their service as they were not aware of the service and CNSs lacked time to raise their profile with the home staff (Froggatt and Hoult 2002). Two other studies reported findings which suggested that palliative care educational initiatives had assisted in raising awareness of specialist palliative care services in nursing homes. Following provision of education, Phillips et al. (2008) found nurses were more likely to seek support from the palliative care team and Badger et al. (2012) described improved relationships, with support more freely available and less reactive than previously.

Access was also impacted by availability. Two main factors were reported as limiting availability for multi-professional working in nursing home: time and staffing. Table 2.6 provides details of the papers that report these as a barrier and the professional disciplines to which they applied. Table 2.6 categorises whether these barriers related to multi-professional working in the area of ACP, end-of-life care more generally or case conferences. Case conferences are an approach to multi-professional working that feature in the Australian literature in particular, as Australian regulations specify that anyone with a terminal condition or complex needs is eligible for medically led case conferencing (Luckett et al. 2017).

Findings from two North American studies suggested that greater availability of nurse practitioners in the nursing home compared to doctors meant that they were more familiar with the residents, improving engagement in ACP and collaborative working with nursing home staff (Burgess et al. 2011; Kaasalainen et al. 2013), identifying how knowing residents can improve multi-professional working. Nursing home nurses advised that when doctors do not know the resident well this can result in poor decision-making and a failure to implement residents' wishes, a particular problem with OOHs medical provision (Badger et al. 2012; Brodtkorb et al. 2017; Lee et al. 2017; Kastbom et al. 2019). Indeed, Jeong et al. (2010) suggested that GPs in Australia were an essential part of the multidisciplinary team required for successful ACP due to their long-term relationship with residents and families. The importance of continuity to enable both physicians and nurses to acquire knowledge of residents to facilitate ACP discussions was reported by Kastbom et al. (2019), with the participant physicians valuing involvement of the nurses who often had a closer relationship with the resident and family members and were therefore more comfortable asking questions about end-of-life care wishes. Doctors interviewed in a US study also highlighted the importance of the nursing team knowing the resident to aid communication within the team, which could be impacted by a lack of continuity due to staff shortages and turnover (Bern-Klug et al. 2004). One strategy for promoting continuity and coordination of care advocated by Phillips et al. (2008) is the establishment of a multidisciplinary care planning forum.

Table 2.6: Table showing the papers that report time constraints or staff shortages as a barrier to multi-professional working for one or more disciplines

Study authors and date	**Time constraints**	**Staff shortages**
Ascertaining or implementing wishes		
Burgess et al 2011	Doctors Nurse practitioners	N/A
Dreyer et al 2011	Doctors	N/A
Furman et al 2006	Doctors Nursing home nurses	N/A
Hanson et al 2002	Doctors	N/A
Kastbom et al 2019	Doctors Nursing home nurses	N/A
End-of-life care more generally		
Bern-Klug et al 2004	Doctors	Nursing home nurses
Brodtkorb et al 2017	Doctors	N/A
Forbes 2001	N/A	Nursing home nurses
Froggatt et al 2002 Froggatt and Hoult 2002	Palliative Care CNSs Nursing home nurses	N/A
Hall et al 2011	N/A	Nursing home nurses
Ling 2005	N/A	Nursing home nurses
Shield et al 2005	N/A	Nursing home nurses
Case conferences/multi-professional meetings		
Luckett et al 2017	Doctors Nursing home nurses	Nursing home nurses
Phillips et al 2008	Nursing home nurses	N/A
Phillips et al 2013	Doctors	N/A

Several studies discussed the need for a forum for discussion (Watson et al. 2006; Phillips et al. 2008; Phillips et al. 2009; Dreyer et al. 2011; Gilissen et al. 2018). A small focus group study involving thirteen Australian GPs from seven GP practices investigated their perceptions of providing palliative care to residents of residential aged care facilities and found that there was support for multi-professional meetings to enhance provision to this sector (Phillips et al. 2009). Watson et al. (2006), in their action research study, noted that an absence of a forum for discussion between nursing home staff and other professionals led to nursing home staff being isolated and carrying a lot of responsibility for decision-making. There was some evidence to suggest that forums such as multi-professional meetings or case conferences had benefits including building rapport and relationships between the participating professionals (Seymour et al. 2011; Wilson and Seymour 2017), providing learning opportunities (Luckett et al. 2017) and fostering appropriate decision-making (Phillips et al. 2008; Dreyer et al. 2011). However, staff involved in multi-professional resident review meetings implemented as part of the GSFCH reported difficulties in engaging GPs with such meetings (Hall et al. 2011). Difficulties with GP attendance at case conferences was also reported by Luckett et al. (2017), although this was partially resolved through employment of a senior nurse to assist in coordinating multi-professional engagement, a strategy also reported by Jeong et al. (2010). In their work to develop a Theory of Change map outlining a hypothetical pathway of pre-conditions required for successful ACP in nursing homes, to inform development of ACP interventions, Gilissen et al. (2018) identified multidisciplinary meetings as an intervention necessary to ensure expressed wishes are shared with all professionals involved in a resident's care. However, this study was undertaken in Belgium where there is a wider multi-professional team employed by the nursing home than in the UK, meaning such meetings might be easier to arrange than would be the case in the UK as they would not involve as many visiting professionals. It was not clarified whether such meetings are already a feature of nursing home care in Belgium.

Multi-professional care planning meetings or case conferences were identified as a suitable forum for ACP discussions in particular to discuss and agree goals of care (Furman et al. 2006; Phillips et al. 2009; Jeong et al. 2010; Luckett et al. 2017). An integrative review of studies investigating case conferencing for nursing home residents with advanced dementia concluded that case conferencing allowed prospective planning for end-of-life care and could improve care by facilitating better communication and coordination, although evidence to support the study conclusions was limited (Phillips et al. 2013). The studies reviewed in this study provided no information about the format of or the multi-professional team members participating in these case conferences or multi-professional meetings, identified as a gap in the literature by the authors.

2.4.4 The impact of multi-professional involvement on the process of ascertaining and/or implementing resident wishes

The literature reviewed provided limited evidence to support or refute that multi-professional involvement in ACP in nursing homes has a positive impact. How this limited evidence suggested that multi-professional involvement could impact ACP and lead to better outcomes for residents and their families is summarised in Figure 2.4 and discussed below.

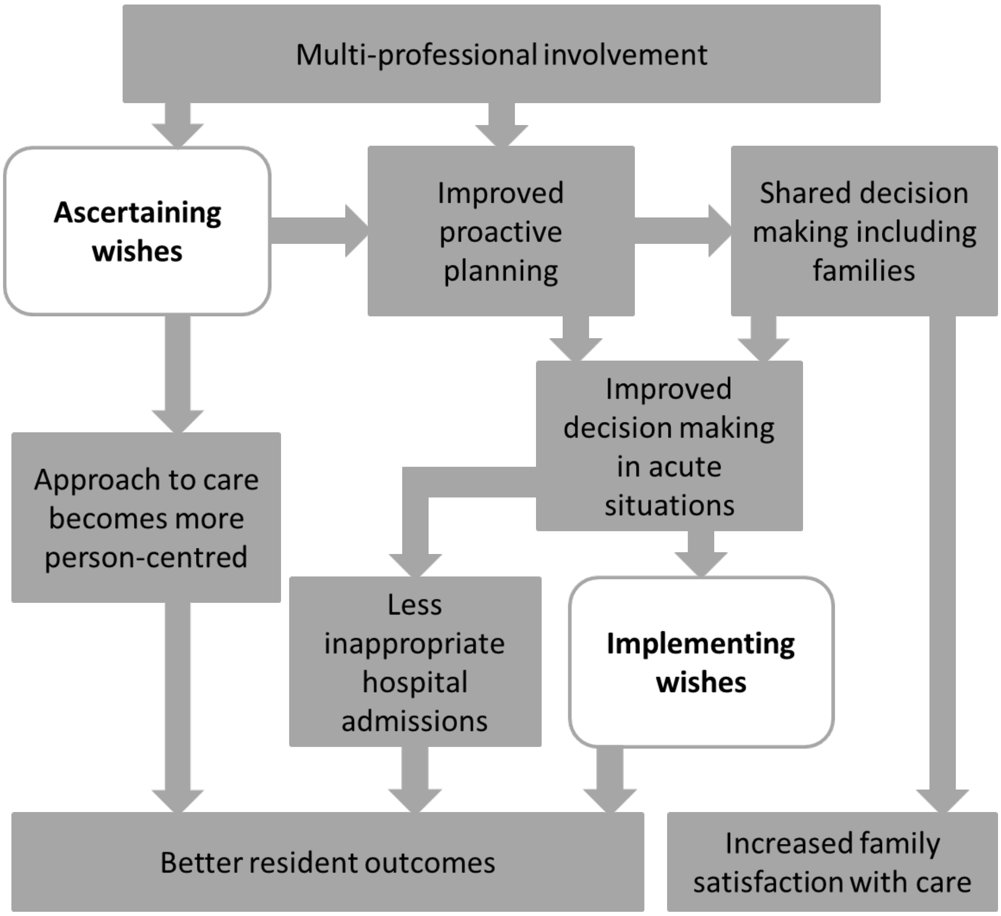


Figure 2.4: Diagram representing how the limited available evidence suggested multi-professional involvement could impact ACP and lead to better outcomes

Managers of UK care homes surveyed about ACP practice in their home cited visiting professionals as influencing the process of implementing ACP more frequently than ascertaining wishes (Froggatt et al. 2008), which was a common theme in the literature. Only one study reported findings related to ascertaining wishes and this was limited to establishing family wishes as the study related to residents with advanced dementia (Luckett et al. 2017). Findings suggested that ACP discussions with family members of residents with advanced dementia, in a multi-professional case conference, improved understanding of both staff and family and led to a more person-centred approach to care. Dreyer et al. (2011) also suggested that weak collaboration between doctors and nurses led to care being less resident centred, but this related to ethical decision-making rather than ascertaining wishes.

Proactive planning to ensure an agreed care plan was in place was reported as an outcome of multi-professional working which had a positive impact on the implementation of ACP, in particular planning involving doctors and the nursing home nurses (Bern-Klug et al. 2004; Addicott 2011; Gorlén et al. 2013). This was supported by study findings that identified an absence of discussion of preferences between professionals, residents and families meant staff were unprepared to deal with acute problems which could result in decisions that led to decreased quality of care for residents and their families (Brodtkorb et al. 2017).

The literature suggested that better proactive planning may, in turn, lead to better management of acute changes in a resident's condition and reduce inappropriate hospital admissions. An investigation of the influence of organisational factors on decision-making found the nursing homes studied had different patterns of professional coordination between doctors and nurses and that better coordination led to improved proactive planning which, in turn, led to better management of acute situations; if coordination was poor then the nurses had to handle such situations with little prior preparation (Dreyer et al. 2011). Participants in the study by Gorlén et al. (2013) suggested that proactive planning was necessary because it was difficult to make appropriate decisions in an acute situation. One study reported that the primary reason for ACPs not being successful in avoiding inappropriate interventions or hospital admissions was a lack of pre-planning with GPs alongside nurses lacking confidence in the enforcement of the ACP in a crisis situation (Addicott 2011). Likewise, Lee et al. (2017) found that hospital admissions could occur contrary to a resident's expressed wishes if ACP had not been shared, for example, with the ambulance service, or the validity of the ACP was questioned by external professionals. One participant in the study by O'Brien et al. (2016) suggested that as a consequence of a comprehensive education programme, the home staff would have everything in place and the confidence to say an ambulance was not required and prevent unnecessary hospital admission.

If proactive planning involved relatives then additional benefits were reported, including shared understanding of the goals of care and acceptance of the medical situation (Bern-Klug et al. 2004; Phillips et al. 2013) and greater involvement in decision-making by family members (Luckett et al. 2017). This had the potential to reduce conflict with families (Phillips et al. 2009; Dreyer et al. 2011) and ensured families were given consistent messages by staff (Hanson et al. 2002; Furman et al. 2006). Coming to a shared understanding was also reported to assist with relatives' emotional preparation for the death of their loved one (Bern-Klug et al. 2004) and planning earlier in the disease trajectory was recommended to allow families time to absorb and reflect on information about their loved one's condition (Luckett et al. 2017).

2.5 Summary of key findings

2.5.1 Key findings and gaps in the literature

The evidence base relating to multi-professional involvement in ACP within nursing homes was generally weak, as there was limited evidence and some evidence was poorly supported. The literature clearly identified a role for doctors in the ACP process, particularly for medical concerns such as prognostics and treatment planning. However, there was limited understanding of other work that is done in undertaking ACP and the disciplines which are best placed to do this. The range of work areas identified, from the few papers providing this information, identified that no individual team member alone can meet the needs of older people and their families (Jeong et al. 2010) and the importance of involving in ACP all those who have played a significant role in a resident's care (Froggatt et al. 2008).

Four characteristics of multi-professional working were identified, but they were not mutually exclusive. Good communication underpinned the others and was the foundation of good multi-professional working, but what this should look like was not clear. Several barriers to and facilitators of multi-professional working were also identified. The benefits of increased knowledge were well supported by the available literature, primarily from the UK, which showed this improved multi-professional communication and working relationships. However, the literature also suggested that stronger frameworks for multi-professional working may be needed, alongside accessible services. Given there are many models of provision of external healthcare support to nursing homes across the UK, there was a gap in the UK literature regarding which might work best in terms of providing accessibility and availability, and approaches to ensuring opportunities for multi-professional discussion exist. However, evidence to support whether multi-professional involvement in ACP in nursing homes has any beneficial impact was limited.

2.5.2 How the study addresses the gaps in the literature

By addressing the research questions detailed in Section 1.6, this study specifically explored the impact of multi-professional involvement on ACP within nursing homes, addressing an area where there is limited knowledge in the current literature. Through an investigation in two nursing homes supported by visiting professionals with different models of service delivery the study addressed additional gaps in the literature. By exploring the impact of these different approaches to multi-professional working, this study has increased understanding of who is involved in UK nursing homes and how they work together, and identified barriers and facilitators to multi-professional working in this context.

2.6 Chapter summary

This chapter has reported the findings of literature published between January 1990 and September 2020 on multi-professional involvement in ACP and end-of-life care within nursing homes. The findings have been reported under four theme headings: the work to be done, key characteristics, facilitators and barriers, and the impact of multi-professional working in this context. The findings have shown that the evidence was limited particularly in understanding the impact of multi-professional working, but also in the other areas in relation to the UK nursing home setting. The next chapter outlines the research design of the study which sought to address some of the existing gaps in the literature.

Chapter 3 Methodology, Research Design and Methods

3.1 Introduction

This chapter outlines the methodology, underpinning philosophy, and data collection methods used in the design and conduct of this study to investigate multi-professional working in ACP in nursing homes, and the rationale for selecting an ethnographic approach. This chapter describes gaining access to the field, recruitment, data collection and data analysis methods. The ethical considerations informing the research design and the approach to ensuring rigour in the research process are also discussed.

3.2 Methodology and research design

This exploratory study sought to gain greater insight into multi-professional working in UK nursing homes and its impact on the ACP process. Knowledge of the complex array of social processes and interactions between health and social care professionals, residents and their relatives was required to achieve a broad understanding of multi-professional involvement in ACP. These are bounded by the particular organisational contexts in which they occur. An ethnographic approach was therefore appropriate for this study "to capture the complexities of social interaction in a naturalistic rather than experimental way" (Pope et al. 2013, p. 4). This facilitated direct experience and examination of the social setting (Atkinson et al. 2007) and focused on understanding the meanings motivating the actions of professionals involved in ACP (O'Reilly 2012).

3.2.1 Philosophical stance

An interpretive philosophical position was adopted for the study. Interpretive research seeks to understand the meanings human beings attribute to their behaviour and the external world (della Porta and Keating 2008), with a focus on understanding from the inside rather than explaining from the outside (Outhwaite 2005). The ontological perspective taken was one of reflexive-realism, a pragmatic approach recognising that the study findings will, to some degree, represent aspects of the world (O'Reilly 2009) whilst acknowledging the existence of multiple social realities (Crotty 2003). The adopted epistemological position was that the type of knowledge sought required multiple perspectives. This drew on constructivist epistemology with the underlying assumption that individuals develop subjective meanings of their experiences which are varied and multiple, with knowledge therefore needing to account for the complexity of views (della Porta and Keating 2008). Constructivism also positions the researcher as an active participant in the creation of understanding and knowledge (Blaikie 2000), recognising that interpretation of the data flows from the researcher’s personal, cultural and historical experiences (Crotty 2003). Therefore, interpretation was informed by my tacit knowledge of ACP and nursing homes, gained from my experience of working as a CNS in palliative care.

3.2.2 Ethnographic approach

Ethnography lends itself well to an interpretivist stance (O'Reilly 2009), aiming to describe, interpret and understand the characteristics of a particular social setting with all its cultural diversity and multiplicity of voices (Holloway and Todres 2003). Culture is a system of knowledge used by human beings to interpret experience and organise behaviour (Spradley 1979) and humans make sense of their world based on their historical and social perspectives and the meanings bestowed on them by their culture (Crotty 2003). In this study culture is defined as the ideas, beliefs, knowledge and patterns of behaviour that characterise a particular group of people (Fetterman 2010). Nursing home care depends on services from health and social care professionals employed by different organisations, which affords potential for clashes of organisational culture (Holtom 2001). Culture is a central analytic concept that informs ethnography (Schwandt 2001) and a significant concept in the area of this study.

Spradley (1979) suggests that in ethnographic study, cultural inferences are made from three sources: what people say, the way people act and the artefacts people use. This is reflected in the three methods for data collection used in this study, namely observation, interviews and documentary analysis. The decision to use multiple methods was underpinned by epistemological beliefs that a comprehensive understanding of multi-professional working and its impact on ACP cannot be achieved using just one method. Interviews alone would have provided different perspectives on multi-professional involvement in the ACP process, potentially offering valuable insights but only a partial picture would have been gained. Observation, an essential source of information in ethnography (Gobo and Molle 2016), enabled multi-professional working relationships and team working practices to be seen first-hand, allowing the social processes to be studied as they occurred. However, the nature of both multi-professional working and ACP in the nursing home setting means timings of these are difficult to predict, making observation difficult to plan. Documentary analysis provided a way to increase understanding of aspects of the ACP process that it was not possible to observe, alongside providing insight into organisational structures and processes impacting ACP and multi-professional working.

Hammersley and Atkinson (2007) stated that there needs to be a balance between the breadth and depth of investigation when selecting the number of sites for an ethnographic study. For this study two nursing homes were included as participating sites. The rationale for this decision was that involving more than one nursing home provided a greater breadth of data which made the findings more meaningful, making possible comparison between multi-professional inputs such as medical provision and nursing home team organisation. Two homes provided the breadth needed without compromising the required depth. Ideally, an ethnographer stays in the setting for six months or more, to be able to observe patterns of behaviour over time (Fetterman 2010), because whether a phenomenon is seen as a one-time event or recognised as part of an ongoing cycle, depends on the length of observation (Orlikowski and Yates 2002). My research was designed to allow a period of fieldwork of six to seven months in each nursing home, to achieve adequate depth of investigation.

3.3 Gaining access to the field

The two nursing homes were purposively sampled and selected because they could inform an understanding of the research problem (Creswell and Poth 2018). A wide range of health and social care professionals could be involved in a nursing home resident’s care, depending on the needs of the individual resident, the available service provision in the locality and the level of involvement provided to nursing homes by individual service providers. Two nursing homes were selected because they had different input from visiting professionals, particularly in terms of the number of GPs that the homes worked with. The nursing homes were both within the boundaries of one County Council but in two different geographical areas; this provided variation in terms of healthcare provision to nursing homes as they were located in different Clinical Commissioning Groups (CCGs) and with different specialist palliative care providers. Both geographical areas were outside the catchment area in which I worked as a Palliative Care Nurse Specialist providing education to care home staff at the outset of the study. Having prior knowledge of a nursing home through my clinical role would have made it difficult for me to adopt the role of outsider, a necessary component of ethnography.

Inclusion and exclusion criteria were set to ensure the selected care homes were registered with the CQC to provide nursing care to adults, were already using ACP in practice and had a large enough population of residents eligible to participate in the study (Table 3.1). Nursing homes providing care solely to residents with dementia, mental illness, learning disabilities or with alcohol or drug dependency were excluded because these conditions can affect mental capacity, limiting the number of residents in these homes with the ability to fully participate in ACP.

Nursing homes rated as inadequate by CQC at the time of initial approach were also excluded. This was to avoid ethical dilemmas I might have faced as a RN if I were to have observed poor standards of care and would have made it difficult to separate the roles of nurse and researcher (Seymour et al. 2005).

Table 3.1: Nursing home inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Care homes registered to provide nursing care with CQC • Care homes located within one of two localities within the County Council's boundaries • Manager states that ACP forms part of the nursing home's clinical practice	• Care homes providing care solely to residents with dementia, mental illness, learning disabilities, alcohol or drug dependency • Care homes rated as inadequate by CQC

Access to the nursing homes was negotiated in one locality at a time. Recruitment of the second nursing home took place after fieldwork in the first home was completed. The decision to delay recruiting a second nursing home was to allow for the potential for significant changes to occur between the outset of the study and when data collection commenced in the second home, a period of many months. The nursing home sector experiences high management and staff turnovers which can impact on the quality of care (Ekosgen 2013; Skills for Care 2016) and could have impacted on the appropriateness of a home recruited at the outset to participate in the study several months later.

Identifying potential nursing homes to be included in the study was determined in conjunction with the specialist palliative care education facilitator in each locality, who agreed at an early stage in the study design to act as intermediaries. These professionals work with the nursing homes and provided information regarding ACP practice within the homes and healthcare provision to each home, to assist with the identification of appropriate homes. In the first locality, a list of five potential homes was drawn up by the intermediary identifying key factors such as how many GPs they worked with, the number of residents receiving nursing care and ACP implementation progress. Following discussion with the intermediary the homes were ranked in the order they would be approached. Recruitment of a home working with just one or two GP practices was prioritised in the first locality. This decision was informed by knowledge that more homes work with multiple GP practices. In the second locality, the intermediary suggested which home should be approached, based on her knowledge of the organisations and the requirement for the home to be working with three or more GP practices.

The two intermediaries made the initial approach to the nursing homes and provided the nursing home manager with a copy of the study information sheet (Appendix E). They spoke with a senior member of the nursing home staff and if they expressed interest in participating then I was informed. In both localities, the manager of the first home approached expressed interest in participating and a letter inviting the home to participate in the study (Appendix F) was sent to them, accompanied by the study information sheet and nursing home consent form (Appendix G).

Telephone contact with the managers was attempted ten to fourteen days from the date of the letter, although it took between three days and three weeks before contact was made with the managers directly. This reflects recruitment barriers encountered with nursing homes reported elsewhere (Jenkins et al. 2016). I arranged a face-to-face meeting with the managers and met both the manager and one or more other members of the management team to discuss the study in both homes. In the first locality, the manager consented for the home to participate in the study at this meeting. In the second locality, the home declined to participate. Therefore, the intermediary approached another home and consent was provided by the manager of this home, subsequent to my meeting with both her and the deputy manager. Where managers consented to participate, arrangements were made for details of the study to be provided to an appropriate senior manager of the corporate organisation that the nursing home was part of to gain organisational approval.

After consent and organisational approval had been obtained, I visited nursing home A on nine separate occasions and nursing home B on eight separate occasions, each over a two-month period. This time was spent introducing the study and recruiting nursing staff before fieldwork commenced. I attended and discussed the study at a residents' meeting in both homes and in nursing home A, a short outline of the study was included in the home's newsletter. In nursing home A, I attended and discussed the study at a staff meeting and in nursing home B, I provided a one-page summary of the key parts of the study information sheet to be shared at a staff meeting. This time spent in the homes enabled me to develop a rapport with staff and some residents and gain a broader consent to undertake the research from those living and working in the nursing home.

3.4 Recruitment of participants

3.4.1 Identification of potential participants

Initially the nursing home manager, deputy manager and all RNs, both day and night staff, were invited to participate in the study. Care assistants and other nursing home staff were identified with assistance from the managers. Staff were excluded if they were not directly employed by the nursing home, such as agency staff (see Table 3.2). Following general observation in nursing home A, discussion with nursing staff and review of participating resident notes, I decided that other professional groups from within the nursing home staff such as activity coordinators, domestic staff and chiropodists would not be invited to participate. This decision was because their involvement in ACP was thought to be negligible. In nursing home B, activity staff were involved in ACP and so they were invited to participate.

Table 3.2: Inclusion and exclusion criteria for participants

Participant type	Inclusion criteria	Exclusion criteria
Health and social care professionals	• Provide care to residents within a participating nursing home. • Involved in key ACP events within the nursing home or involved in the care of a participating resident.	
Nursing home staff	• Involved in key events relating to ACP, involved in the care of a resident participating in the study or identified as a key informant by colleagues.	• Not directly employed by the nursing home.
Relatives	• Nominated by a resident participating in the study.	
Residents	• Resident in a participating nursing home. • Had prior involvement in ACP.	• Residents who lacked mental capacity to be involved in the ACP process and/or to consent to participate in the study.

In nursing home A, the two GPs who provided medical cover from one surgery through a weekly GP round were identified by the nursing home manager as key stakeholders and invited to participate at the outset of the study. A palliative care CNS was identified after a few weeks as another professional who provided regular input to the home. Another GP, palliative care CNS and a social care professional were identified due to their involvement in the care of participating residents. In nursing home B, all GPs from the main surgery were invited to participate at the start of the study. A GP from another surgery was identified as he provided care to one of the participating residents. Also identified from their involvement with participating residents were a palliative care CNS and a long-term condition CNS.

Residents were identified through discussions with nursing staff about prognosis, ACP history and involvement of professionals in their care. Inclusion and exclusion criteria were set to ensure that only residents who had the mental capacity to be involved in ACP discussions and had already participated in the ACP process were approached (see Table 3.2). Nursing home staff helped to identify those whose ACP trajectory may be particularly informative, so the residents recruited had a range in number of professionals involved and had different engagement in ACP. A mixture of both newly admitted and existing residents further into their ACP trajectory, including some residents who were thought to be approaching end-of-life within the study timeframe, were approached to take part in the study. Each resident recruited was asked to nominate one or more relative to be invited to participate in the study.

3.4.2 Recruitment process

All potential participants were provided with written information. This included an invitation letter, a participant information sheet, a study consent form and an interview consent form. There were separate invitation letters, information sheets and study consent forms for each group of participants – nursing home staff, residents, relatives and visiting health and social care professionals (See Appendix H, Appendix I and Appendix J for the resident documentation and Appendix K for the interview consent form).

The written information advised the potential participant that they could contact me directly if they wished or they could inform nursing home staff named in the letter whether or not they were interested in being involved. If a response was not received within two weeks of the date of the invitation letter, then with the exception of visiting health and social care professionals this was followed up with the potential participant by a member of the nursing home staff. Visiting health and social care professionals were contacted directly by phone. If a potential participant expressed an interest in taking part in the study, I arranged to meet with them and if they agreed to participate a consent form was completed.

A specific process for recruiting professionals visiting participating residents from the OOHs service to the study was in place due to the one-off nature of the urgent service that they provide. This allowed initial verbal consent to be provided, with full written consent sought retrospectively. However, no OOHs professionals were involved in the care of participating residents, so this process was not used.

3.4.3 Sample achieved

A total of four nursing home managers/deputy managers, six nursing home nurses, eight care assistants, one activities coordinator, three GPs, three specialist nurses and one social worker were recruited to the study. Two participants (nursing home staff) withdrew from the study part-way through the fieldwork due to leaving their post and being absent due to long-term sick leave (see Table 3.3).

Table 3.3: Number of nursing home staff and visiting health and social care professionals approached to participate in, recruited to and who withdrew from the study

Professional discipline	Approached to participate	Consented to participate	Withdrew from study
Management	4	4	0
RNs – days	15	6	1
RNs – nights	6	0	0
Care assistants – days	14	7	0
Care assistants – nights	1	1	0
Activities staff	2	1	1
Doctors	8	3	0
Specialist nurses	4	3	0
Social care professionals	1	1	0
TOTAL	55	26	2

More than 70% (n=15) of nurses and just under 50% (n=7) of care assistants declined to participate in the study (see Table 3.3). Most provided no feedback on why they did not wish to take part but three mentioned time constraints. Cleary (2004) reported other barriers to recruiting nursing home staff which may also have contributed. These included viewing outsiders observing their practice as a threat and concern that the research may cause more work. Recruiting night staff was particularly problematic, although a night care assistant was recruited in nursing home A and in nursing home B, day staff rotated on to nights on occasions which made it possible to shadow one of the participating RNs during a night shift. However, the poor level of recruitment of permanent night staff may have limited the insight gained in relation to multi-professional working practices and ACP overnight. Although, it was possible to gain some understanding from the night care assistant, she confirmed that it would be the RNs who would lead ACP during the night. The approach and view of multi-professional working and ACP at night of the nurse who primarily worked during the day may have been different from those more familiar with night work routines.

The challenge faced in recruiting doctors was time availability. Two GPs who visited a participating resident on an ad hoc basis advised that a lack of time precluded their participation. The two GPs providing regular input to nursing home A consented to participate but stated at the outset that they would not have time for a formal interview. However, I was able to engage both in naturally occurring talk and informal interviews when they were in attendance at the home. This made it possible to explore insights into their practice beyond what would have been possible through observation of their interaction with residents and nursing staff alone.

Recruitment of residents to the study was also challenging. Many residents lacked the mental capacity to engage in ACP limiting potential participants to recruit to the study, an anticipated issue based on reports of the prevalence of cognitive impairment amongst care home residents (Bowman et al. 2004; Gordon et al. 2014). Of those approached, less than 30% (n=6) consented to participate in the study (see Table 3.4), representing higher refusal rates than found in a review of recruitment of older people to fourteen clinical trials in a range of settings (McMurdo et al. 2011). One resident rapidly deteriorated and died three weeks after being invited to participate and another’s condition deteriorated leading to a lack of mental capacity to participate. There was no direct feedback on the reason why the other fourteen residents declined to participate. However, the manager of nursing home A reported that she believed they were deterred by the prospect of being interviewed and the proposed duration of the interview. This informed changes to the study information sheets prior to data collection in nursing home B, as my experience of the interviews in nursing home A was that they were shorter than had originally been anticipated. However, this did not impact the recruitment rate in nursing home B, which was identical to that in nursing home A. I was told by the manager that the son of one of the residents in nursing home B who declined to participate, had advised that his mother was ‘not up to it’.

Table 3.4: Number of residents and relatives approached and recruited to the study

	Approached to participate	**Consented to participate**
Residents	22	6
Relatives	6	4
TOTAL	28	10

Six residents were recruited to the study, three from each nursing home. Five were existing residents who had been living in their nursing home for between six months and three and a half years prior to recruitment to the study. The sixth resident was admitted midway through the fieldwork in that home and recruited shortly after this. The anticipated prognoses of the residents ranged from between a few weeks and a year or more at the start of data collection. One resident died during the study, having been admitted with a terminal illness. One relative was recruited for each of four residents, all children of the residents. Four residents nominated one relative, one nominated two relatives and the sixth resident chose not to nominate any family members. Two relatives declined to participate due to time availability and living a distance from the nursing home. Table 3.5 provides a basic profile of the residents and relatives recruited.

Table 3.5: Profiles of residents and relatives recruited to the study

Resident Pseudonym	Gender	Age at start of data collection	Relative
Barbara	Female	90	Not recruited
Charles	Male	89	Daughter
Jack	Male	79	Daughter
Joyce	Female	93	Son
Norman	Male	85	Not recruited
Peggy	Female	92	Son

3.5 Data collection

Data collection commenced in nursing home A when five staff had been recruited to the study and when three staff had been recruited in nursing home B, as this provided sufficient participants to enable me to visit the home regularly. In both homes the approach to initial data collection was what Fetterman (2010) described as the “big net approach” (p.35) observing day to day practice and routines, thereby gaining knowledge about which visiting professionals were involved regularly and who was involved from the nursing home when they visited, as well as information about how ACP was implemented in the home. This included shadowing nursing staff, except when they were undertaking direct clinical care with residents, and observation of staff handovers and discussions.

3.5.1 Observation

I was present in nursing home A for more than three hundred hours on sixty-two separate occasions and nursing home B for more than two hundred hours on fifty-one separate occasions, with data collected over six to seven months in each home. This included visits both day and night and on all days of the week as outlined in Table 3.6. On each occasion, I was present in the nursing home for between forty-five minutes and twelve hours, with the majority of visits between four and six hours in length. Whilst in the nursing home, I undertook direct observation and other research activities such as reviewing documents or formal interviews. When not involved in these activities, I undertook tasks such as writing up field notes or planning visits using the rotas.

Table 3.6: Table showing the breakdown of hours spent in each nursing home by days of the week and time of day

Time	**Between 8 am and 2 pm**			**Between 2 pm and 8 pm**			**Between 8 pm and 8 am**	
Day	**Weekday**	**Saturday**	**Sunday**	**Weekday**	**Saturday**	**Sunday**	**Weekday**	**Weekend**
Nursing home A	78 hours	6 hours	15 hours	187 hours	-	13 hours	4 hours	12 hours
Nursing home B	81 hours	9 hours	4 hours	99 hours	4 hours	2 hours	-	12 hours

In nursing home A, when not directly observing, I based myself in the nurses' office which was near the management offices and from which the main corridors of the home could be seen. From here, I could maintain awareness of what was happening in the home, thereby indirectly observing, and was also aware of when participating staff members became available to be observed. The nurses' office was also a hub for communication, both between nursing home staff team members and with external providers, and offered opportunities to observe multi-professional communication using several communication mediums: face-to-face, telephone, fax and email.

Due to the geographical layout of the building of nursing home B, set over three floors and with two nurses' offices located on each of two floors separated from the manager's office and the main entrance of the home, there was no particular place from which to observe general comings and goings as in nursing home A. Therefore, when I was not involved in direct observation, I would either move around the home and between floors to locate other study participants or base myself in one of the nurses' offices or communal spaces, unless they were being used by non-participant staff. The approximate breakdown of time allocated between direct and indirect observation and other research tasks in both homes is shown in Table 3.7.

Decisions regarding when to observe were informed by salient events involving multi-professional working such as the GP round in nursing home A, when participating nursing home staff were on duty and my availability to visit the nursing home. The main direct observations were of daily routines, such as medication rounds and completion of documentation, and one-to-one or group discussions relating to care provision or care planning. In nursing home A, a considerable amount of direct observation also included those aspects of the regular GP round involving just the GPs and nursing home nurses who had consented to participate in the study and those when a participating resident was being reviewed by the GP. More observation took place in the mid-morning to late afternoon period as that was the time during which professionals were most likely to visit. It was not possible to observe all relevant situations when I was in the home as not all staff members had consented to participate in the study so, for example, some GP rounds in nursing home A could not be observed because those involved were not all study participants and no nurse team handovers could be observed in nursing home B as they all included staff who had not consented to participate. I therefore obtained details retrospectively from a participant wherever feasible. It was also only possible to directly observe interactions between GPs and residents in nursing home A and a specialist nurse and a resident in nursing home B, as the other professionals who consented to participate in the study only visited the participant residents once, with this visit occurring prior to their involvement in the study.

Table 3.7: Table showing approximate percentage of time spent on direct observation, indirect observation and other research tasks in both homes

Nursing home	Total time	Approx. % direct observation	Approx. % indirect observation	Approx. % recruitment, formal interviews & document analysis
Nursing home A	315 hours	56%	35%	9%
Nursing home B	211 hours	71%	15%	14%

In nursing home A, a significant amount of time was spent indirectly observing whilst staff were involved in direct clinical duties and also because the nurses' rota sometimes changed at short notice meaning participating staff were not on duty when expected. In nursing home B, more time was spent in direct observation, although this did include brief periods when I would remain outside a resident's room whilst the person I was observing engaged in personal care activities. I usually shadowed one member of staff per shift, but when the person I was shadowing was involved in more extended personal care, such as wound dressings or accompanying non-participant professionals, I used the time to make more general observations about office contents, noticeboards and happenings in the home.

Using the typology proposed by Gold (1958), I primarily took the role of complete observer, with my participation being minimal. Any participation undertaken was in the role of a general helper, for example assisting a nurse by fetching items from the office or assisting in carrying items from one part of the home to another. However, Delamont (2004) suggests that 'participant' observation is not limited to real participation and doing what those being observed are doing but is about interacting with them whilst they do it. I was, at times, brought into the professional discussions I was observing. I used my research diary to reflect on how the participants viewed me as both nurse and researcher acknowledging that my clinical role as a palliative care specialist influenced their behaviour and reviewing how my participation in the discussions may have influenced what was said (see Section 3.8.2).

I made brief, unstructured notes during or as soon as possible after periods of observation. These were recorded in an overt way so note-taking came to be part of what participants expected of my role. However, as advised by Emerson et al. (2007), I did this sensitively to try to avoid detracting from the ordinary goings-on and interfering with relations with participants. These notes were then typed up as full, elaborated field notes either during periods of informal observation in the nursing home, immediately on returning home at the end of the day or as soon as possible after returning home if this was not achievable, for example after a night shift.

3.5.2 Interviews

Interviews were not all formal, pre-arranged meetings. Informal conversations also took place within periods of observation: opportunistic questions and answers (O'Reilly 2009). I categorised these conversations as naturally occurring talk and informal interviews. Naturally occurring talk involved asking questions that were integrally related to what was being observed at the time, thereby led by the situation. Informal interviews were characterised by more general questions related to the research questions, asked whilst observing day to day routines, with the questions directed by me rather than the situation. Data from these conversations were recorded within field notes.

Formal interviews were used to seek individual views and experiences and to explore further issues identified during observation and/or from document review. Unlike the informal interviews, they had more purpose, and I took more control of the direction of the communication, with a more asymmetrical relationship than the casual conversations (Spradley 1979; Rapley 2004). The interviews were semi-structured, utilising a topic guide with question guidelines set in advance (Appendix L) but allowing flexibility to vary the questions between participants dependent on answers to open-ended questions and to explore related points of interest from observations or previous informal interviews. The topic guide was developed using the research questions and the aim and objectives of the study, with additional areas of interest arising as the study progressed being raised as questions within these topics.

Sampling decisions were made about which participants to invite to take part in a formal interview. All participating relatives and residents were invited to be interviewed. The exception was one resident who was in his last few weeks of life when recruited to the study. Involvement in the study of four visiting professionals was limited to a formal interview, with only two GPs and a specialist nurse involved in observations. This was because these four professionals had either visited a participant resident prior to their involvement in the study or were involved in nursing home visits on an ad hoc basis and did not visit during the fieldwork. With the nursing and care staff, selections were made based on the need to explore further issues that had been discussed more informally and availability for interview. Due to the nature of their work it was not possible to interview the staff member only working nights. Sampling decisions are summarised in Table 3.8.

Sixteen individual interviews were completed, and one interview included both a resident and relative as this was their preference. The interviews were conducted face-to-face at a time agreed with the participant(s). For nursing home staff the timing of the interview was fitted around their work duties, with one interview being interrupted due to an urgent work issue. This interview was stopped and re-started after a short break. Three resident interviews were also interrupted by staff needing to complete care tasks; these were all brief interruptions that did not lead to the interview being stopped for more than a few minutes. All interviews were conducted in the nursing home, except those with visiting professionals which took place at their place of work. Individual interviews lasted between twenty-five and forty minutes and the joint interview with the resident and family member lasted fifty-five minutes. All formal interviews were audio-recorded and transcribed verbatim.

3.5.3 Documentary review

Nursing home documents and resident notes were reviewed. The documents were read in full, and notes made regarding content relevant to the research topic, with content copied verbatim where it appeared particularly significant. The documents were read at intervals throughout the study to ensure any changes made to the documents were identified. Where nursing home documents were not in the public domain, these were included with the written permission of the nursing home manager.

Table 3.8: Table showing sampling decisions made with regard to formal interviews

Participant type	**No. of participants**	**No. interviewed**	**Sampling decisions**
Nursing home staff: Management	4	3	Important to get management perspective and management views not easily obtainable through informal interviewing. One manager appeared to not wish to be interviewed as avoided arranging a time.
Nursing home staff: Nurses	6	2	Difficult to arrange time for interviews, and some nurses I had spent significant time with and had answered the majority of my questions informally. One left the home shortly after joining the study.
Nursing home staff: Other Staff	9	0	Work commitments made it difficult to pre-plan an allocated time for an interview so informal interviewing was utilised.
Residents	6	5	Useful opportunity to explore issues in more detail. One resident was too weak and fatigued for an interview as he was in his last weeks of life but engaged in short brief informal interactions.
Relatives	4	3	Main opportunity for exploring topic. It was not possible to schedule a time with one relative.
Visiting professionals	7	5	Main opportunity to meet with majority of professionals to explore topic in detail except two professionals who did not have time to commit to an interview but for whom it was possible to interview informally.

Consent was provided by all six participating residents for their nursing home notes to be read. Documentary data provide information about situations which cannot be examined by direct questioning or observation (Hammersley and Atkinson 2007) and was of particular importance in understanding resident trajectories where care provision needed to be reviewed in retrospect. As ethically it would have been inappropriate to have access to their full notes, as these record all aspects of their lives not just the topic of interest, it was agreed by the Research Ethics Committee (REC) that access would be limited to end-of-life care plans, multi-professional communication sheets and ACP documentation. As the nursing home notes did not exactly align to these descriptions, this was discussed at the outset with the nurses to identify the documents that could be accessed. Pragmatic decisions were made in ascertaining which documents within each home's notes matched most closely, for example, including care plans relating specifically to a life limiting illness.

Nursing home documents reviewed are listed in Table 3.9. Sampling decisions were made as to which documents to include. For example, the resuscitation policy was included due to the potential for DNACPR to be referenced in this and policies referring to the keyworker role, because this role had been highlighted as potentially important in ACP through observation and interviews. Any policy relating to end-of-life care, ACP, multi-professional or keyworker involvement in care, care after a resident had died or resuscitation was read.

Table 3.9: Table of documents reviewed

Type of Document	Nursing Home A	Nursing Home B
Internal Policy or Protocol	• Advance Care Planning Policy • Death of a Service User Policy • End of Life Care Policy • Keyworker Policy • Resuscitation Policy	• Advance Care Planning and Advance Decision to Refuse Treatment Policy & Guidelines • Care Planning Policy • Death and Dying Policy • Resuscitation Policy • Visiting Allied Health Professionals Policy
Internal Information Documents	• Evidence from completion of palliative care education programme	• Organisational guidance on documentation • ACP Leaflet
CQC Reports	• CQC report published pre-fieldwork • CQC report published within 12 months of end of fieldwork	• CQC report published pre-fieldwork • CQC report published within 12 months of end of fieldwork

3.6 Data analysis

3.6.1 Approach to analysis

Data analysis is not a separate stage of the research process, but an iterative process with data collection, analysis and writing up inextricably linked (Fetterman 2010; O'Reilly 2012; Gobo and Molle 2016). By using an iterative approach, data analysis was used to inform the refinement of ongoing data collection. Hammersley and Atkinson (2007) suggested that there is no standardised procedure for analysis of ethnographic data. Analysis is about making sense of the data by “summarising, sorting, translating and organising” (O'Reilly 2009, p. 13). The analytic process adopted achieved this through thematic analysis, documentary analysis, mapping resident ACP trajectories and comparison of data across the two nursing homes. An inductive approach to analysis was taken, with the aim of generating an analysis from the bottom up rather than shaped by existing theory (Boyatzis 1998).

3.6.2 Thematic analysis

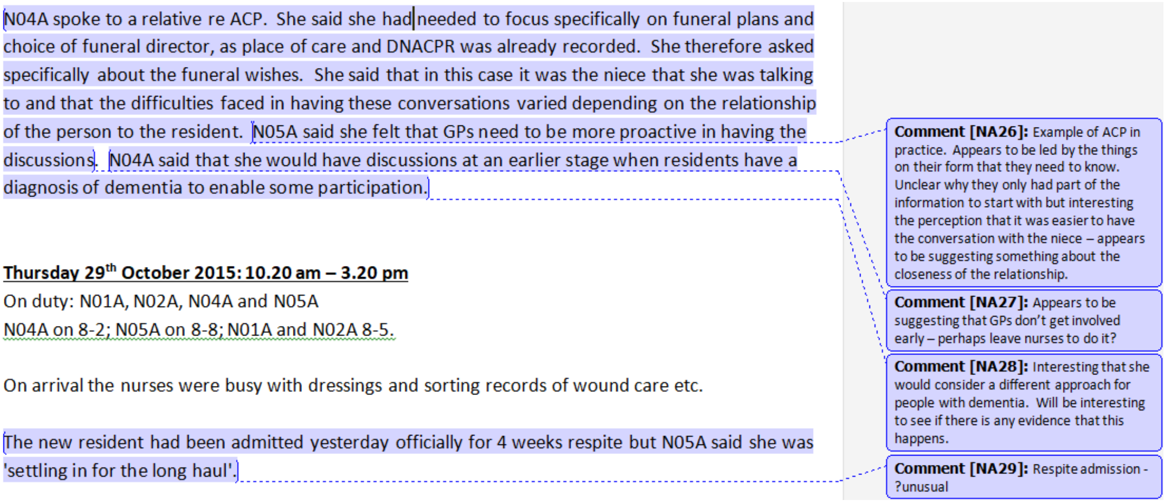
Thematic analysis is a descriptive approach to qualitative data analysis, used to describe the data set in rich detail (Braun and Clarke 2006; Howitt 2013). As such it is appropriate for an ethnographic study, fitting with Geertz’s definition of doing ethnography as being interpretive work of thick description (Geertz 1973). A theme is a pattern found in the data that as a minimum describes and organises the data but may also interpret aspects of the phenomenon (Boyatzis 1998). Ethnographic analysis seeks patterns of thought and behaviour (Fetterman 2010). The thematic analysis process as outlined by Braun and Clarke (2006, 2012) was broadly the process followed to analyse the data. However, Miles and Huberman (1994) suggested that data analysis is customised and revised, so this process was adapted to allow for the iterative approach used in the study and integration of the documentary, resident trajectory and nursing home comparative analyses.

Braun and Clarke (2006, 2012) divided the process of undertaking a thematic analysis into six separate phases. Although these phases, outlined below, suggest a linear process it is a recursive process with movement between phases for purposes of refinement and clarification (Braun and Clarke 2006; Howitt and Cramer 2014).

3.6.2.1 Phase 1: Familiarisation with the data

This was completed at regular stages throughout the intertwined processes of data collection and analysis. After each period of observation full field notes were written up and I undertook transcription of all audio-recordings, providing initial steps in the process of familiarising myself with the data. The researcher transcribing data themselves is recommended for thematic analysis as this ensures the process of becoming acquainted with the text starts at an early stage (Howitt and Cramer 2014).

While writing up field notes, or on re-reading these which I did regularly throughout data collection, I made notes of points of potential interest using the comments facility available in Microsoft Word®. I added notes about the data such as things I needed to find out more about, what I considered might be going on and how the data related to the research question. An example of comments applied to observational data collected in October 2015 is shown in Figure 3.1.



N04A spoke to a relative re ACP. She said she had needed to focus specifically on funeral plans and choice of funeral director, as place of care and DNACPR was already recorded. She therefore asked specifically about the funeral wishes. She said that in this case it was the niece that she was talking to and that the difficulties faced in having these conversations varied depending on the relationship of the person to the resident. N05A said she felt that GPs need to be more proactive in having the discussions. N04A said that she would have discussions at an earlier stage when residents have a diagnosis of dementia to enable some participation.

Thursday 29th October 2015: 10.20 am – 3.20 pm
On duty: N01A, N02A, N04A and N05A
N04A on 8-2; N05A on 8-8; N01A and N02A 8-5.

On arrival the nurses were busy with dressings and sorting records of wound care etc.

The new resident had been admitted yesterday officially for 4 weeks respite but N05A said she was 'settling in for the long haul'.

Comment [NA26]: Example of ACP in practice. Appears to be led by the things on their form that they need to know. Unclear why they only had part of the information to start with but interesting the perception that it was easier to have the conversation with the niece – appears to be suggesting something about the closeness of the relationship.

Comment [NA27]: Appears to be suggesting that GPs don't get involved early – perhaps leave nurses to do it?

Comment [NA28]: Interesting that she would consider a different approach for people with dementia. Will be interesting to see if there is any evidence that this happens.

Comment [NA29]: Respite admission - ?unusual

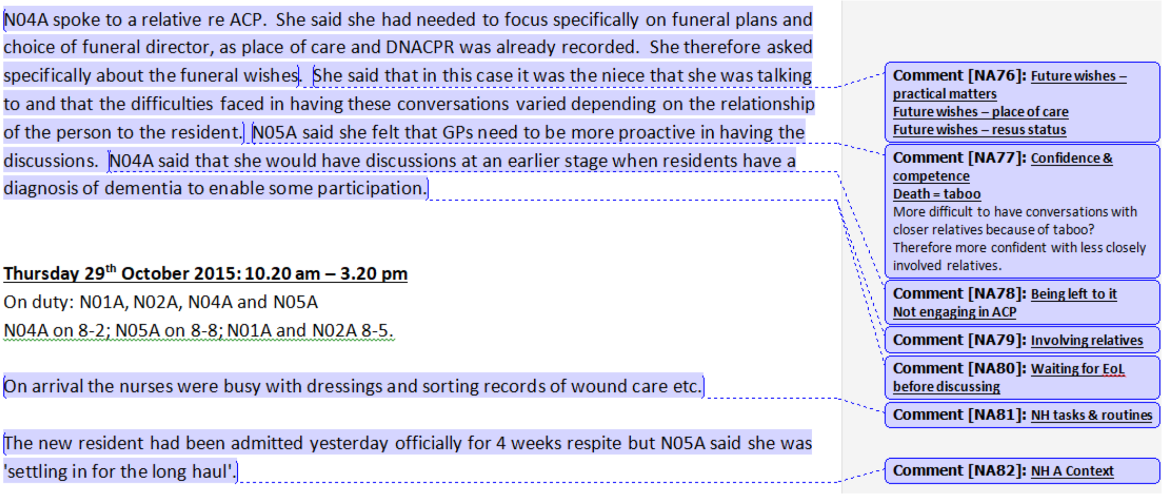
Figure 3.1: Comments applied to field notes.

3.6.2.2 Phase 2: Generating codes

In order for patterns to be identified the data is sorted and coded (O'Reilly 2012). The approach to coding adopted was based on the methods of first and second cycle coding described by Miles et al. (2019) which map to the description of ethnographic analysis as commencing with a deconstructive or exploratory phase and progressing to a constructive phase, where the data are reassembled into a new pattern (Gobo and Molle 2016). I coded all data including field notes, interview transcripts and data from documents. Codes were applied to chunks of data, guided by the thoughts in my comments. The following primary approaches to coding as defined by Saldana (2016) were used: Descriptive, which summarises the topic of a segment of data, and in vivo, which uses a word or words of the language found in the data. Coding was initially completed using the comments facility in Microsoft Word®. The section of field notes shown with comments in Figure 3.1 is shown with coding in Figure 3.2.

I developed a coding scheme which included definitions to describe the type of data attributable to each code, to ensure there was consistency in the process of coding and to assist in identifying potential overlap between codes. As coding is an evolving process, modifications are required as new material is incorporated (Braun and Clarke 2013). The initial coding schema was therefore revised and updated as further data were coded, with codes being added, deleted, subdivided, merged or amended as the data corpus increased in size.

After coding all data collected from Nursing Home A, this was entered into NVivo® 11. This provided a method of consistency checking the coding whilst spending further time familiarising myself with the full picture of the data. The same process was repeated with data collected from Nursing Home B. The software was used to assist with data management.



N04A spoke to a relative re ACP. She said she had needed to focus specifically on funeral plans and choice of funeral director, as place of care and DNACPR was already recorded. She therefore asked specifically about the funeral wishes. She said that in this case it was the niece that she was talking to and that the difficulties faced in having these conversations varied depending on the relationship of the person to the resident. N05A said she felt that GPs need to be more proactive in having the discussions. N04A said that she would have discussions at an earlier stage when residents have a diagnosis of dementia to enable some participation.

Thursday 29th October 2015: 10.20 am – 3.20 pm
On duty: N01A, N02A, N04A and N05A
N04A on 8-2; N05A on 8-8; N01A and N02A 8-5.

On arrival the nurses were busy with dressings and sorting records of wound care etc.

The new resident had been admitted yesterday officially for 4 weeks respite but N05A said she was 'settling in for the long haul'.

Comment [NA76]: Future wishes – practical matters
Future wishes – place of care
Future wishes – resus status

Comment [NA77]: Confidence & competence
Death = taboo
More difficult to have conversations with closer relatives because of taboo? Therefore more confident with less closely involved relatives.

Comment [NA78]: Being left to it
Not engaging in ACP

Comment [NA79]: Involving relatives

Comment [NA80]: Waiting for EoL before discussing

Comment [NA81]: NH tasks & routines

Comment [NA82]: NH A Context

Figure 3.2: Coded section of field notes.

3.6.2.3 Phase 3: Searching for themes

On completion of data collection in nursing home A and coding of the data set, I then utilised second cycle coding to identify categories which integrated sets of these codes. Second cycle coding, or pattern coding, is a way of grouping the first cycle codes into a smaller number of categories (Miles et al. 2019). These codes involved a greater degree of interpretation (Howitt 2013). The complete list of first cycle codes and their descriptions was reviewed to clarify any codes that did not work exactly as portrayed and to identify areas of similarity or overlap. The codes were then grouped into categories by writing brief code details onto index cards and sorting into category piles. Initial, tentative themes were generated by clustering the categories around broad topics and issues (Braun and Clarke 2012).

As data collected from nursing home B were coded, the categories were refined further. On completion of data collection in nursing home B and with the entire data corpus coded, additional first cycle codes had been identified and so second cycle coding was re-examined. Mind maps were used to consider relationships between categories, representing my thoughts and informing refinement of the tentative themes and construction of potential new themes. A map drawn as part of this process is shown in Figure 3.3. The map was redrawn frequently as the themes were developed as part of a recursive process moving between phase 3 and phase 4 of the thematic analysis.

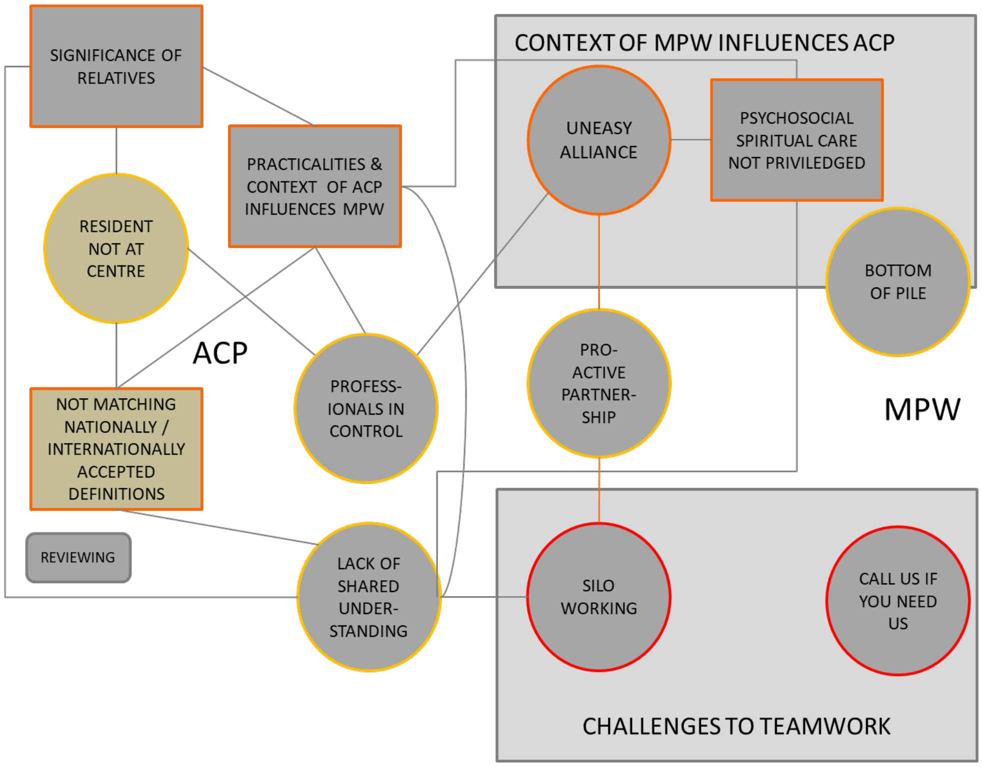


Figure 3.3: Mind-map produced as part of the theme construction process

3.6.2.4 Phase 4: Reviewing themes

This phase commenced when a set of candidate themes had been devised to reflect and describe meaningful patterns in the data. "A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set" (Braun and Clarke 2006, p. 82). During this phase, these themes were reviewed and checked against both the coded extracts and the data corpus (Braun and Clarke 2012). The quality review of the themes against the data ensured there were sufficient data to support the theme and coherence between data represented by the theme. This review led to a return to phase 3 to redraw the boundaries of the themes repeatedly so as to more meaningfully capture the data. Some themes were merged, and sub-themes became themes in their own right. Once the themes worked with regard to the coded data, the themes were reviewed in relation to the entire data corpus, and further refinement occurred. At the end of this phase a thematic map represented the themes and how they fitted together with the developing overall story (Figure 3.4).

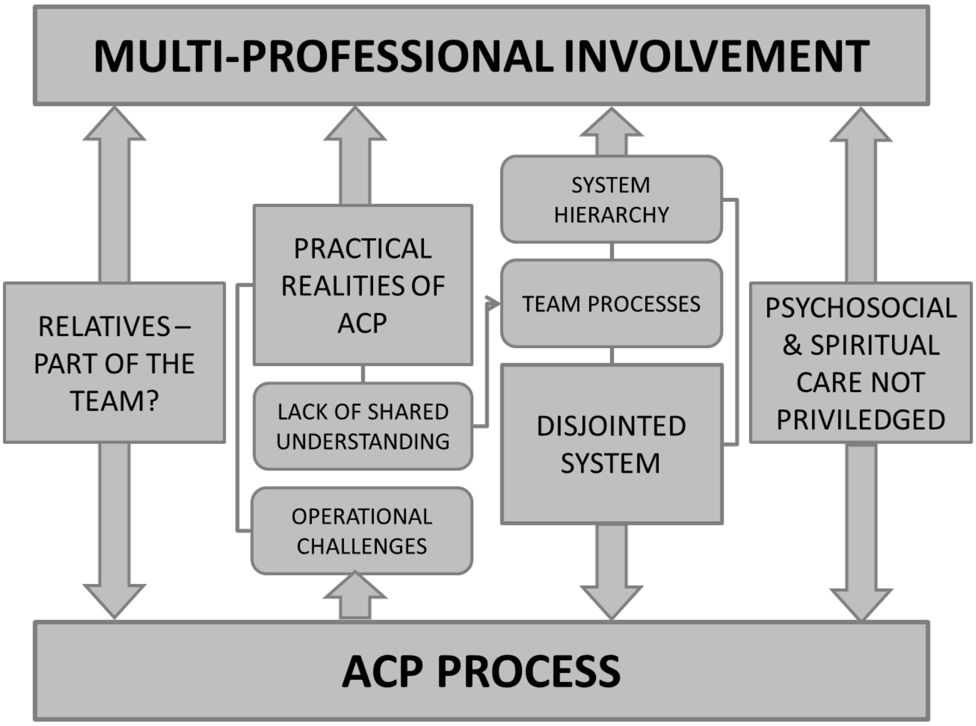


Figure 3.4: Thematic map from the end of phase 4 of the thematic analysis

3.6.3 Mapping resident ACP trajectories

The analysis included plotting a visual display of the ACP trajectory of each of the participant residents. Visual displays are useful tools in ethnographic research (Fetterman 2010). Data from interviews, field notes and resident notes were used to chart the trajectories. These show the different care settings that each resident transitioned through and in which of these settings ACP was undertaken, changes in health status and whether these triggered ACP, the people involved at each stage of each resident's trajectory and the topic areas of future planning that each resident had discussed. The six resident trajectories are presented in Chapter 4 alongside a pen portrait of each resident.

The aim of this analytic process was to explore ACP and multi-professional involvement at the level of individual residents and to allow the different trajectories to be compared and contrasted. A matrix was developed to highlight variation and patterns across the six trajectories. This included comparisons relating to the type of future planning completed and in which setting, the place of care where most ACP was completed, professionals involved in ACP and which particular topics they were involved in discussing, family involvement and the level of that involvement, and documentation of ACP. Fit with the findings of the thematic analysis was explored and tested as the findings were integrated.

3.6.4 Documentary analysis

Data from the nursing home notes of the participant residents were used alongside field notes and interview data to inform the plotting of the resident trajectories described in section 3.6.3. In this way the documents were used as a resource, as data to be drawn down and used as fact (Prior 2011). It was recognised that the nursing home notes were not transparent representations of professional practice, rather socially constructed within professional conventions (Atkinson and Coffey 2011). However, where the notes reported on aspects of the resident trajectory that it had not been possible to observe or ask questions about, these were the only data available to inform the trajectories. These data and data from policies and the other documents reviewed, as outlined in section 3.5.3, were also coded and formed part of the thematic analysis, thereby triangulated with observational and interview data.

Specific documentary analysis was undertaken on the internal policies and procedures of the two homes. Policies are cultural artefacts as a construction of organisational routines and processes but also composed as a representation of the values of the nursing homes and nursing home organisations. Prior (2011) suggested that every document stands in dual relation to fields of action. In this way, the policies were both a repository of organisational instructions and process descriptions and also an agent open to manipulation and/or used to support further action. The documentary analysis, therefore, aimed to understand how policies translated into practice in the nursing homes and explore what this revealed about the culture. A form was developed for this purpose (Appendix M), guided by suggested approaches to policy analysis described by Shaw et al. (2004). This included consideration of the purpose, content and intended audience of the policy, overt and explicit meaning in relation to both ACP and multi-professional working and meaning reflecting national or local rhetoric and ideology. Each of ten policies and one set of guidelines were analysed individually using this form before being combined into one document that also offered a comparison between nursing home A and nursing home B.

3.6.5 Comparative analysis of data from the two nursing homes

Data collection in nursing home B emphasised similarities and differences between this setting and nursing home A. Matrices provide a systematic way to compare and contrast data (Miles et al. 2019) and so a matrix was developed to enable direct comparison between the two nursing homes. This contrasted the models of multi-professional support, including GP and palliative care provision; internal nursing home organisation, including leadership, organisational structure and building layout; external organisational context, including organisational support and availability and accessibility of health and social care resources; and ACP processes, including documentation and involvement of relatives.

3.6.6 Integration of analyses

The resident trajectory analysis, documentary analysis and comparative analysis of data from each of the homes were integrated with the thematic analysis at phases 5 and 6. Phases 5 and 6 of thematic analysis involve defining and naming the themes and producing the report. As the analysis required to define and name themes necessarily requires writing, it is acknowledged that there is not a clear distinction between these phases (Braun and Clarke 2012). These phases were therefore essentially merged with integration of analyses as the final stage of the analysis process. The full process detailing each data source and the analysis undertaken is shown in Figure 3.5.

The themes were initially reviewed, with brief descriptions written to summarise the essence of the theme. These were tabulated bringing together the code and category descriptions, with data extracts, to enable the coherence of each theme to be appraised. Table 3.10 was developed for the sub-theme of 'Significance of relatives', initially a theme on its own. The themes were reviewed and refined through writing of narratives for each theme. As well as identifying the narrative for each theme, during phase 5 the broader overall 'story' to be told about the data in relation to the research questions is considered (Braun and Clarke 2006) and at this stage the fit between the other analyses was assessed. Coherence at the level of each theme was examined and each theme was reviewed in light of the other analyses. However, as I completed the analyses concurrently with the later stages of the thematic analysis, the interpretation of the data in each of the separate strands of analysis was inevitably informed by the other strands prior to this. For example, the theme 'significance of relatives' (Table 3.10) was reinforced from early in the mapping of resident trajectories by the prominence of family on all of the trajectories.

In this way, all of the different analyses were combined to ensure the study findings integrated both the micro and macro perspectives, in terms of organisational and individual resident experiences. The themes were then reviewed in relation to each other, and the overall analysis refined through consideration of how they fitted together into an explanatory conceptual framework. The refinement included bringing themes together as sub-themes of a broader theme. For example, the theme 'significance of relatives' became a sub-theme of 'professional reach'. Braun and Clarke (2012) suggest sub-themes are useful where there are overarching patterns within the data but aspects of the theme are represented in a variety of ways. The theme names were changed on several occasions during this process. Phase 6 of the thematic analysis was completed with the final writing up of the findings.

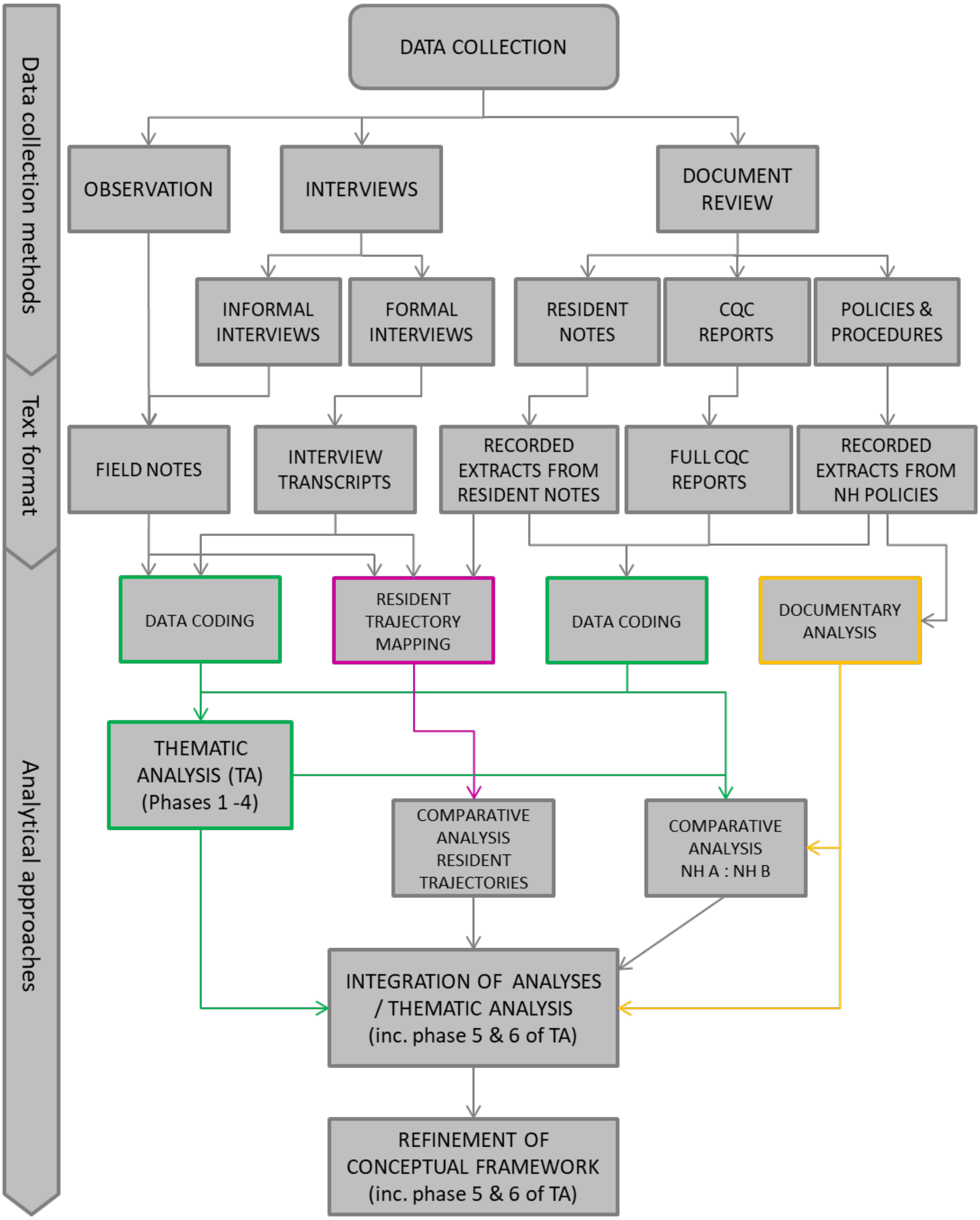


Figure 3.5: Flowchart of data analysis process

Table 3.10: Table detailing the construction of the sub-theme ‘significance of relatives’

Sub-theme: Significance of Relatives			
Relatives play a significant role in nursing home care, including ACP and appear to be both important and influential. They appear to influence MP working and MP decision-making, impacting on whether wishes are honoured. They could be considered part of the team involved in ACP but are also recipients of care from the multi-professional team.			
Included categories:			
Relatives = important Relatives are important in provision of end-of-life care in nursing homes, particularly for residents who lack mental capacity to participate themselves, as they have knowledge of the resident and both they and the residents frequently wish for their involvement in decision-making. **Relatives = influential** Relatives can influence multi-professional working and the ACP process both positively and negatively.			
Code Name	**Description of coded content**	**Example extract**	**Category**
Discussing wishes only with family	Data identifying residents having discussions about future wishes that do not involve professionals, only family members or a significant other.	[Manager] said that the request for the [DNACPR] form completed today had come from the daughter as she had discussed it with the resident. (Field notes – Visit 048)	Relatives = important
Future wishes – appointing a proxy	Data identifying appointment of a proxy as part of future planning.	I asked whether they have many residents who have Lasting Power of Attorney (LPA) for health and welfare, and she showed me the list; there was at least 7. (Field notes – Visit 062)	Relatives = important
Liaising with relatives	Data that demonstrate the liaison with families by the nursing home team and/or professionals - to keep them updated, request information, etc. that occurs or is wished for.	“They did come and see Dad once, but they didn’t follow up with me at all.” (Relative 2)	Relatives = important
Involving relatives	Data identifying when professionals have involved relatives with their discussions of future wishes and the impact of this.	[Nursing home nurse] said there had been some discussion with the daughter [of a resident who had deteriorated rapidly] about place of care, but the son-in-law had reassured his wife that the nursing home was the best place for her. (Field notes – Visit 047)	Relatives = Influential
Relatives influencing collaborative working	Data identifying how the involvement of relatives has impacted either positively or negatively on multi-professional working.	She [manager] appeared frustrated that the views of the family … were heard louder than the views of the nursing home staff. (Field notes – Visit 031)	Relatives = Influential

Unrealistic expectations	Data that identifies that relatives are perceived to have unrealistic expectations regarding prognosis, the impact of this and how this is/could be managed	*"I mean I've never gone into a conversation with um the [daughter] of [resident] because she just can't seem to to be able to even think that far ahead nor for parents passing away."* (Nursing home nurse 5)	Relatives = Influential
Honouring wishes	Data identifying honouring of resident choices and preferences, how this is achieved or if it is not why not	*"One of the worst things is when you've got family saying no, no he has to go to hospital, he has to go to hospital, and you know that's not what the resident wants."* (Manager 3)	Relatives = Influential

3.6.7 Refinement of the conceptual framework

Three conceptual themes were developed through the analyses: Disjointed System; Enacting ACP and Professional Reach. Disjointed system describes the structure and organisation of care between nursing homes and visiting professionals in which ACP occurs. Enacting ACP portrays how the enactment of ACP impacted on multi-professional involvement in the ACP process. Professional reach denotes the limited breadth of both team membership and what is recognised as ACP. These findings are presented in subsequent chapters.

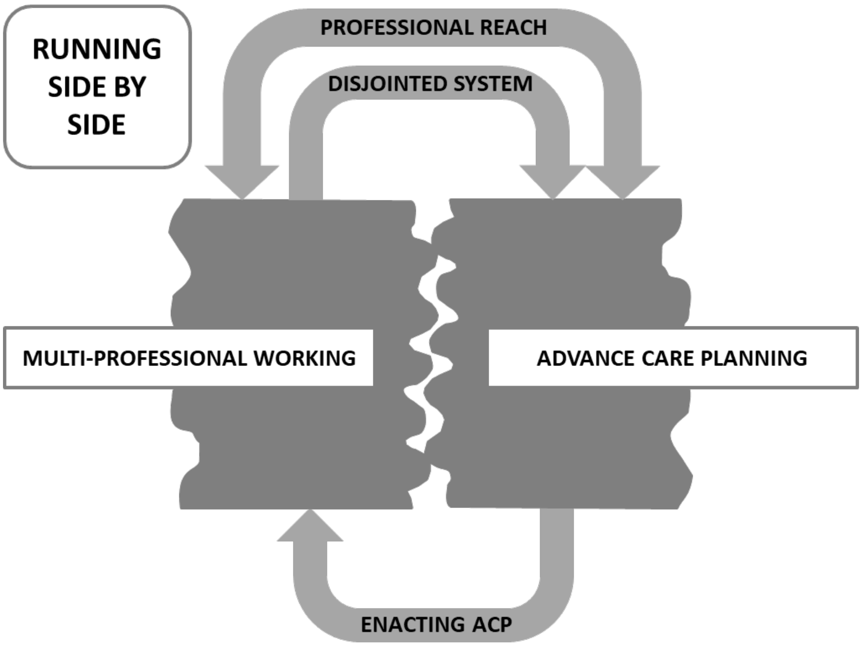


Figure 3.6: Conceptual framework – Running Side by Side

It was clear from the analyses that the three themes were not discrete and that there was overlap and relationships between them. They were brought together as components of a conceptual framework, Running Side by Side (Figure 3.6). This framework depicts the interrelationship between ACP and multi-professional working and the impact of the conceptual themes on both of these. Chapter 8 outlines and critically examines this theoretical interpretation of the findings.

3.7 Ethical considerations

3.7.1 Ethical and research governance approvals

The study was reviewed and given favourable opinion by the National Social Care REC in January 2015 (REC reference 15/IEC08/0004). Amendments to the study were submitted in January 2017, relating to changes in my employer and supervisory team, and amendments to the length of interviews which were approved in February 2017. As the study potentially involved staff from nine health and social care organisations, it was also subjected to the research governance procedures of these organisations. This included one County Council, four NHS organisations, two independent hospices and two OOHs medical provider organisations. Both nursing homes recruited to the study were part of a group of homes. Therefore, organisational permission for the study was also gained, although neither organisation had formal research governance procedures.

3.7.2 Informed consent

Written consent was obtained from all participants at the outset of their involvement in the study. However, due to the longitudinal nature of ethnographic research, written consent could not be a once and for always action (Goodwin 2006). Therefore, verbal confirmation of ongoing consent was obtained from nursing home staff and from residents, relatives and visiting professionals at the point of initial contact on any particular day. This was especially important for the residents, as although they had the mental capacity to consent to participate, due to forgetfulness, some needed reminding about the specifics of the study from one occasion to the next. Specific written consent was obtained from the nursing home manager to access nursing home documentation (Appendix G) and from residents to access their nursing home notes (Appendix J). Specific written consent was also obtained for each formal, audio recorded interview (Appendix K).

To ensure participants were able to give informed consent, all participants were provided with written information. Opportunities were also provided to discuss the study with me either face to face or over the phone. All those taking part in the study had at least ten days between receipt of the invitation letter and completion of the formal consent form. Participation was voluntary and participants were reminded that they were free to withdraw from the study at any time without having to give reasons and to withdraw consent for their anonymised data to be used in study reports.

On several occasions, nursing home staff members who had not provided consent to participate in the research inadvertently entered and became part of a scenario being observed. In these situations, the staff members were aware of my presence and that I was observing the situation. Had the individual's contribution to these situations warranted recording in field notes, then retrospective consent to use these data would have been sought. However, as these contributions did not add anything further to the data collected from those who had provided consent to participate, these were not included in the field notes.

3.7.3 Confidentiality and anonymity

All participants were assigned a unique code under which data were stored. All field notes were written, and audio-recordings and transcripts labelled, using these codes. Places, names and other identifiable information were not recorded in field notes and were removed at the point of transcription of audio-recordings. This ensured the data were anonymised, to reduce the risk of individuals being identified. Data that identify the participant and link the participant to their unique code was stored separately from the research data in an electronic password protected file only accessible by the researcher, which was permanently deleted on completion of the study. All data have remained confidential to the research team and precautions have been taken to ensure that nursing homes and participants were not identifiable from any research data used in this thesis or the study report for participants. This has included labelling quotes using randomly allocated numbers for each category of participant, with the numbering not linked to the nursing home to which the participant was associated. In addition, different identifiers have been used for the resident profiles and the resident quotes, as due to the small number of participants it is possible that residents could be identified from their profile by people who knew them well such as family members and nursing home staff. This therefore prevents specific data being linked to them. Such precautions will continue to be taken for any further research data placed in the public domain through publication.

3.7.4 Sensitivity of topic area

The study focuses on ACP, with the end-of-life care issues that may be raised as part of this process sensitive and potentially distressing. As part of the consent process, all participants were informed that the study related to an aspect of end-of-life care and only residents who had already commenced ACP were approached to participate in the study, so that they had already given some thought to end-of-life care issues. I attempted to identify reasons why approaching the topic with a resident or relative might cause distress at any particular time, for example a recent bereavement, through regular dialogue with the nursing staff. I also opened conversations on less sensitive issues and more general enquires about how they were, which led to one resident informing me of a bereavement himself and enabled me to avoid asking questions relating specifically to end-of-life care on that occasion.

3.7.5 Loss of mental capacity

Although only residents with the mental capacity to be involved with ACP and able to provide informed consent were recruited to the study, the nature of care towards the end-of-life meant loss of mental capacity during the fieldwork period could occur. Residents were asked to indicate on the consent form whether they consented for data collection to continue even if they had lost the capacity to provide ongoing consent and if they did, to nominate a consultee. One resident did lose capacity to provide ongoing consent due to deteriorating conscious levels but as the resident died within two days of this occurring, it was not possible to seek consultee advice on whether the resident should remain in the study. The last GP visit to this resident was therefore not observed.

3.8 Research rigour

3.8.1 Trustworthiness

There has been much debate on how rigour in qualitative research should be judged (Seale 2002; Rolfe 2006; Hammersley 2007; Reynolds et al. 2011). Established criteria suggested by Lincoln and Guba (1985) assess the trustworthiness of qualitative research in terms of credibility, transferability, dependability and confirmability. Credibility refers to the congruence between the findings and the actual experiences of the participants. Transferability is the ability to transfer the findings to a different setting or context. Dependability is about the coherence of the entire research process. Confirmability concerns the degree to which the findings are shaped by the respondents. This output-oriented approach to demonstrating rigour is demonstrated through the use of techniques considered to be indicators of rigour (Reynolds et al. 2011). The techniques employed to ensure the trustworthiness of this study included prolonged engagement with the participants and persistent observation, for example, prioritising attendance at the GP rounds and observation at times of day when multi-professional working was most likely to be observed. Triangulation of methods of data collection and data analysis was used. Provision of dense contextual description, including pen portraits of the nursing homes and participant residents, ensures relevance to other contexts can be assessed.

Reynolds et al. (2011) suggest that these techniques need to be used alongside process-oriented approaches to quality assurance, which include mechanisms that facilitate enactment of rigour throughout the research process. To achieve this detailed description of decisions and processes for sampling, recruitment, data collection and data analysis have been outlined. I have maintained an audit trail from data to findings, which consisted of a coding diary identifying each decision made relating to coding and categorisation decisions, with codes, categories and themes tabulated in the later stages to test coherence. The coding diary included documentation of memos, my reflections and thought processes about the data (Miles et al. 2019). Some memos were also recorded in field notes using the comments facility in Microsoft Word® where initial analytic thoughts occurred ”in process” (Emerson et al. 2011, p. 79). The findings were developed through a thorough process of engagement with the data and are provided using as thick description as possible, supported by the raw data.

3.8.2 Reflexivity

A key process-oriented strategy used to enhance quality was reflexivity. Reflexivity is an acknowledgment of the role and influence of the researcher on the research project (Liamputtong and Ezzy 2005) and refers to a continuous process of reflection by which the researcher becomes more transparent about their influence on the research (Darawsheh 2014). Reflexive researchers acknowledge that findings are an outcome of their interpretation (Jootun et al. 2009) and so there is a need for researchers to make explicit how a particular interpretation has been reached (Ingleton and Seymour 2001). I brought to the research my own cultural knowledge and assumptions, in particular that gained as a nurse, as a palliative care specialist and from mid-way through the study as the daughter of a nursing home resident. Spradley (1979) talked about being imprisoned by such cultural knowledge without knowing it; the knowledge becomes taken for granted. This knowledge will have influenced my decision-making throughout the study and a research diary was therefore used to support identification of this tacit knowledge and make transparent its impact on the study.

A constructivist epistemology acknowledges that the researcher's prior knowledge and beliefs influence the research process (Blaikie 2000) and reflexivity involved questioning my position in relation to the research process (Delanty 2005). My knowledge and experience as a specialist palliative care nurse and from working with the nursing home sector, helped conceive the study. However, it also influenced what data to collect and how it was collected. My understanding of ACP from a specialist palliative care perspective impacted on decisions made early on in the study design, such as including reference to end-of-life care in the participant information sheets. At least initially, my professional experience as a nurse directed where I looked to collect data, the events prioritised and the design of the study around such events. My research diary was used to reflect on the research process, recording thoughts, feelings and underlying assumptions. This assisted in revealing how my taken for granted nursing knowledge influenced my interpretations both in the field and at later stages of analysis. I found applying a research lens rather than a nursing lens a challenge throughout the study, but this was assisted both through reflection and through challenge by and discussion with my supervisors. The extract below taken from my research diary reveals how on re-reading and reflecting on my field notes, I was able to identify how my nursing knowledge meant observations were not always fully explicated, limiting interpretation to a nursing perspective, in this case assuming meaning based on use of common nursing language.

> Reviewing last month's field notes, I have noted observations recorded on [date] refer to denial. [Nursing home nurse] is talking about [resident] being in denial and I have recorded this without questioning what she was meaning by this. I have drawn on my tacit knowledge and assumed we shared understanding of this term, which may not have been the case. The notes recorded provide limited information to ascertain why she thought this or what the impact of this was in terms of ACP or multi-professional working. [Extract from research diary – 8 January 2018]

In the field, I was open with participants regarding my nursing and specialist palliative care background. This may have given me credibility, assisting with access to both the nursing homes and professional participants. However, I recognised that how participants framed their accounts of practice could be impacted by my background and there were times when this challenged the boundaries between being a nurse and a researcher.

> It felt awkward again this afternoon during the discussion about the dying resident. The managers were trying to get my advice on the management of the resident and trying to draw me into the discussion about the case. … It felt uncomfortable because … just listening to their discussion of what was happening I could feel their … need to understand better the decisions being made. It felt uncomfortable that I wasn't able to support them with this. I have struggled with the approach taken with this resident … I am only hearing one side of the story. I am aware that I find myself 'siding' with the nurses …. I need to strip back the professional connection with this and interpret it from the viewpoint of research into multi-professional working that is happening/is not happening. [Extract from research diary – Visit 031]

This situation, which happened mid-way through the first fieldwork period, highlighted the importance of being clear about my role being a researcher not a nurse with participants, reiterating this as necessary. It also raised my awareness of power dynamics that might be at play in interactions between me and nursing home staff, not just from my role as researcher but also due to my specialist nurse background. I worked hard in both homes to build a rapport with participants and although it was not apparent in day-to-day interactions with them, I was aware that if they perceived me as a 'specialist' this may impact their contribution to the research.

3.9 Chapter summary

This chapter has justified ethnography as a means to research the questions posed in Chapter 1. It has outlined the methods used for recruitment, data collection and analysis. Ethical considerations and the approach to ensuring research rigour have also been discussed. The process of selecting the two nursing homes as study sites and recruiting staff, residents, relatives and visiting professionals from each home have been described. Sampling and data collection processes have been explained in relation to the three methods of data collection used: observation, interviews and documentary analysis. The analytical process integrating thematic analysis, documentary analysis, mapping of resident trajectories and cross-site comparisons have been described and illustrated. The next chapter provides contextual details about the two nursing homes and the six participant residents, alongside their trajectories mapped as part of the analysis. The subsequent chapters present and discuss the findings generated and discuss the interpretation of these findings in relation to the conceptual framework introduced in this chapter.

Chapter 4 Pen Portraits

4.1 Introduction

This chapter presents pen portraits of the two nursing homes in which the research took place and the six participant residents. These portraits provide contextual background to the findings. The pen portrait of each of the nursing homes offers a brief description of the home and a sense of what multi-professional involvement in ACP and end-of-life care more generally looked like. The resident pen portraits introduce the six participant residents whose experience of ACP and multi-professional involvement was explored in detail. Each resident's ACP trajectory is also displayed. As described in section 3.6.3 of the last chapter, mapping of the ACP trajectories for each participant resident and exploring the variations and parallels between them formed part of the analysis.

Due to the small numbers of participant residents, within this chapter the residents are given a fictitious name to preserve their anonymity and prevent association with resident quotes used in the subsequent chapters which are assigned to a resident number. All other identifiable features such as place names have also been removed. The resident pen portraits are presented in alphabetical order of the pseudonyms used.

4.2 Nursing Home A

Nursing home A was a large home[3] and had been rated as Good by CQC. It was situated in a rural location on the outskirts of a large town, both in size and population, and in a Local Authority ranking in the top twenty-five per cent in the Index of Multiple Deprivation (Ministry of Housing Communities & Local Government 2019). It was a purpose-built premises with the majority of the building one storey and over eighty percent of resident rooms located on the ground floor. Most of the residents were female, with seventeen percent the highest percentage of male residents during the fieldwork. Nearly all residents were in their eighties and nineties with the eldest resident aged one hundred and three at the end of the fieldwork. The resident population was predominately White British. The home had less than the national average number of residents in

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[3] Based on the criteria used by the NHS Choices website where less than 10 beds equates to a small home, between 11 and 50 beds equates to a medium home and greater than 50 beds equates to a large home (NHS Choices 2019).

receipt of Local Authority funding (Competition and Markets Authority 2017). The majority of the residents were self-funding, with a few funded by NHS Continuing Healthcare[4] funding.

There was a central office next to the main entrance to the home, with the administration office and the manager's office adjacent and both these offices accessed through the main office. This office was a focal point for relatives, professionals and deliveries, and residents also frequently used a seating area outside the office. The office also provided an information hub for staff, where resident notes, policies and details of other services were stored. Communication with professionals mostly took place in this area, where any information needed was on hand.

The home was fully occupied with more than ten people on the waiting list for the duration of the fieldwork. Most residents had longer than average stays based on national estimates (Forder and Fernadez 2011). Two of the longest stay residents had both lived in the home for twelve years. The home admitted residents for both permanent placement and also for respite care. There were two residents admitted for respite care during the fieldwork. The manager reported that many residents admitted for respite care subsequently became permanent residents, as was the case for one of the residents during the study.

The home was part of a small group of homes[5]. There were organisational policies in place and support available from the head office team. The home had a manager with the deputy manager providing cover in her absence. They managed and had oversight of everything that happened in the home and were both involved with provision of clinical care, with every resident visited by one of them most days. The home employed a range of staff including nursing staff, care staff, catering staff, domestic staff, laundry assistants and maintenance staff. Hairdressing and chiropody services were also funded by the home. On a day-to-day basis, these staff groups primarily worked separately reporting directly to the manager or deputy manager. An exception to this were the care assistants who were supervised by and reported to senior care assistants, who in turn liaised with the nurses or managers, although on occasions a care assistant would liaise directly with a nurse. However, this was not a rigid hierarchy, for example the manager was seen to provide formal one to one supervision sessions for care assistants. Care assistants were allocated to areas of the home for each shift and were based away from the office where the nurses based themselves. The nurses only shared the medication rounds by area of the home,

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[4] NHS Continuing Healthcare is care arranged and funded solely by the NHS for some people with long-term complex health needs who meet criteria to qualify for free social care (NHS Choices 2018).

[5] Based on the categorisation used by carehome.co.uk for their Care Home Awards where a small group has 2 to 9 member homes, a mid-size group has 10 to 19 member homes and a large group has 20+ member homes (carehome.co.uk 2021).

otherwise working across the entire home. Care assistants and other staff groups did not attend handovers with the nurses, except at the start of the night shift, with updates being shared more informally on the floor. There was minimal turnover of staff, with only one member of staff leaving and two new starters during the fieldwork. Indeed, there was a celebration event held for several staff who had worked at the home for more than twenty years.

Most residents were registered with one GP practice from a nearby town. The home had a contract for this medical provision, an arrangement which had been in place for seventeen years. The contracted service involved the residents being registered with two doctors from the practice who took complete responsibility for managing their medical needs. This was achieved through the provision of a weekly visit to the home by one of the two doctors and one of these doctors also dealt with issues that occurred in between the weekly visits in all but exceptional circumstances. One of the two GPs had been visiting the home for ten years; the other had only been involved at the home for a few months. The weekly GP round was usually for two to three hours, with the GP spending time discussing residents with the staff as well as holding a 'surgery' in a small lounge and visiting bedbound residents in their rooms.

At any one point between ten and fifteen percent of residents were registered with the GP practice geographically closest to the home. These residents had been patients with this practice prior to admission to the home and had decided to remain registered there. They were registered with individual GPs within the practice who undertook routine visits to their own residents, although generally only on request.

A range of professionals visited the home during the study. Local community and mental health NHS services were accessed through the GPs. Private arrangements were made by either relatives or the nursing staff for dentist and optician input. Other than dentists and opticians, professionals known to have visited during the fieldwork were a community psychiatric nurse (CPN), a continence nurse specialist, a Parkinson's disease nurse specialist and physiotherapists. Two residents were visited by social workers.

The local multidisciplinary specialist palliative care team were also involved in the care of three residents. Although there were one-off visits from other professionals from this team including a doctor, most contact was with one CNS who was linked to both GP practices providing care within the home. The local hospice-at-home team was also involved on a one-off occasion to provide some practical nursing support with one resident, although this was reported as unusual. As well as assistance with the care of individual residents, the home also received education from the local hospice. The home did not use the GSF but had completed the Six Steps to Success programme[6] immediately before the study commenced. Their certificate was framed on the wall in the main office and the manager commented that they displayed it with pride. As a consequence of this education programme, they had implemented some processes to support their provision of end-of-life care. These included an end-of-life care register, recorded on their handover form, although this was not updated formally or discussed at the GP round, and implementation of ACP.

Residents were given the opportunity to discuss their wishes and preferences for future care, although there did not appear to be a clear process for when and how this was offered. A majority had been offered a discussion, but this was not the case for all residents. The numbers who had discussed their wishes had increased significantly from an audit completed as part of the education programme a few months before the fieldwork which showed less than fifteen percent of residents had a written record of their wishes and preferences. The home used a commercially produced care planning documentation system and end-of-life care wishes were recorded on one page of the resident assessment sheet. There was also another ACP document completed for some residents; this was a local CCG initiative and the forms were completed by the GPs. These forms and DNACPR forms for all residents, where completed, were held together in a folder separate to the nursing notes. Resident care notes were not recorded electronically, all resident care records held within the nursing home being paper records.

4.3 Nursing Home B

Nursing home B was also a large home but was situated in a town location, being less than a mile from the town centre, with the facilities accessed independently by residents who used electric wheelchairs. Like nursing home A, it was located in a Local Authority ranking in the top twenty-five per cent in the Index of Multiple Deprivation (Ministry of Housing Communities & Local Government 2019). The home was purpose-built set over three floors, with resident rooms on each floor. The main communal areas including the dining room were on the ground floor, but each of the upper floors had a kitchen and communal space. Each floor also had an office where resident notes and the medication trolleys were stored, with the main office being on the middle floor.

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[6] Six Steps to Success Programme is an education programme based on the six steps of the end-of-life care pathway outlined in the End-of-Life Care Strategy (DH 2008), which aims to enhance end-of-life care through facilitating organisational change (The End-of-Life Care Partnership 2021).

The home, which had been rated as Good by CQC, accepted residents for both residential and nursing care, with no specific numbers of beds allocated to either care category. Occupancy varied between ninety one percent and one hundred per cent during the fieldwork. There was no waiting list and there were frequent respite or convalescence admissions, with at least thirteen such admissions over the six-month period. At most times, there were between one and three short stay residents in the home, increasing the turnover significantly when compared with nursing home A. The majority of residents were female, the ratio of men to women averaging around one to five and residents were predominately White British. More than half of the residents were aged in their eighties, with the youngest nursing care resident aged seventy-four and the oldest aged one hundred and four at the start of the fieldwork. The home had less than the national average number of residents in receipt of Local Authority funding (Competition and Markets Authority 2017), with many residents self-funding their stay in the nursing home. NHS Continuing Healthcare funding was discussed in relation to some residents.

The percentage of permanent residents in receipt of nursing care, rather than residential care, ranged from seventy-six to eighty-five percent. The residential and nursing residents were mixed across all three floors of the home. It was the senior care staff who took responsibility for the residential clients and responsibility for the nursing residents lay with the nurses, the senior care staff and nurses being named keyworkers for individual residents. However, the top floor was frequently referred to as the residential floor. The responsibility for medication on this floor was assigned to senior care staff and the staff to resident ratio was lower than on the other floors. Residents were moved from the top floor to the lower floors if their care needs increased.

The home was part of a large group of homes. All the home’s policies were corporate policies and processes were defined by the organisation, including the organisation having its own documentation system and training packages. Support was provided with all aspects of running the home by the head office team, with managers and advisers visiting regularly. One of the home managers took responsibility for all clinical matters, with the registered home manager overseeing the business and corporate aspects of running the home. Staff included nursing staff, care staff, activity staff, waiters/waitresses, catering staff and housekeepers. There were some leavers and some new staff during the fieldwork, but staff turnover was reported as being lower than for other homes in the local area. Staffing levels were flexible and could be increased if resident dependency changed, with a change in staff hours implemented due to resident reports of lack of staff availability at a specific time of the day.

With the exception of the nurses, care staff and activity staff, the staff groups primarily worked separately. Although care staff and nursing staff had distinct formal handovers at the start of each shift, the handover was provided to the care assistants by a nurse. The senior care assistants were responsible for supervising care staff, but day-to-day supervision and oversight of resident care was managed by the nurse for each floor, with frequent liaison between the nurses and the care staff. The senior care assistant was the supervisor in a more formal capacity, but with only one senior care assistant on duty at any time who had responsibilities across the whole home involving close liaison with the senior nurse on duty, supervision of resident care provision therefore was undertaken by the nurses. There was also overlap between the care staff and activity staff, although managed separately, for example assisting with meals.

Residents were registered with one of the three GP practices in the town. An initiative implemented a few months before commencement of the fieldwork had seen the GP practices ‘share out’ the care homes in the town with one practice taking lead responsibility for residents in nursing home B. However existing residents registered with one of the other GP practices were able to opt to stay with their previous GP practice and new residents from the local area who were already registered with one of the other practices were also given the choice to remain registered with that practice. At any one time, between seventy-five and eighty-five percent of residents were registered with the nominated main practice. An arrangement had been in place for a GP from this practice to attend the home weekly to review residents and improve proactive planning to support admission avoidance. However, the funding in place for this was withdrawn before the home was recruited to the study, with GPs therefore reverting to visiting on request.

During the fieldwork, other than GPs, the following health and social care disciplines were known to have visited residents in the home: diabetes specialist nurse, OT, optician, palliative care nurse specialist, physiotherapist and social worker. The nursing home had close working relationships with the local hospice. Both a GP and some of the nursing home nurses reported the home as being a place where many hospice patients were discharged for end-of-life care. Some concern was expressed by the GP about the increased workload this caused for residents who were only in the home for a few days or weeks. The hospice multidisciplinary team were also involved in the care of several residents. Contact was primarily with one CNS who was linked with the home. There was talk of other services being available from the hospice, but this was not observed during the fieldwork. The nursing home staff, in particular the nurses, attended many courses run by the hospice’s education team and there were frequently flyers advertising these on display in the main office.

The home did not use GSF but some organisational processes to support their delivery of end-of-life care were in place. Immediately after a resident had died this was communicated to all staff by putting a picture of a flower on the resident's room door. An 'After Death Analysis' form was also completed after every death, reflecting on what went well and what did not go so well. Residents were given the opportunity to record their wishes and preferences for future care with a structured approach to ACP that was commenced pre-admission and recorded on specific ACP documentation. The home followed an organisational approach to care planning and record keeping. Each resident had a folder with care plans, daily notes and assessments stored in an office on the floor where their room was and also a file containing charts such as food charts, turning charts and mattress pressure charts stored in their room. Similarly to nursing home A, all resident care notes were hand-written paper records.

4.4 Resident ACP trajectory maps and pen portraits

The trajectory maps do not represent an exact timeline, rather demonstrate the places where the resident had received care commencing from when they were last living at home in the community prior to their move into residential care. The trajectory maps identify the contribution staff working with people living in residential care settings make to the ACP process by the parts of the trajectories to the right of the black dotted line. The professional disciplines involved with each resident in each setting are identified, with those having less involvement in ACP or decision-making relating to future care identified by a smaller sphere. Known involvement in ACP is indicated by a solid outline to the sphere, with no involvement or unknown involvement indicated by a dashed outline. Where the specific roles or disciplines involved in a setting outside of the nursing home are not known, this is indicated more generically, for example 'hospital staff'. Involvement of relatives is also indicated, with family a consistent feature in all care settings. The range of topics discussed are categorised on the maps as choices relating to practical matters indicated by purple boxes, medical matters indicated by pink boxes, psychosocial or spiritual matters indicated by orange boxes and location of care provision indicated by blue boxes.

4.4.1 Barbara

Barbara was admitted to the nursing home about eight months before the start of the fieldwork, following an acute admission to hospital and diagnosis with a chronic illness impacting her ability to manage at home alone. She was ninety years old at the outset of the fieldwork, celebrating her ninety-first birthday a couple of months later. She had two children who had identified the nursing home as a suitable place for her to live during her hospital admission, the home being located a few miles from her home. Her family visited regularly and one of her children was appointed as Lasting Power of Attorney (LPA) for health and welfare midway through the fieldwork. Barbara's ACP trajectory is displayed in Figure 4.1.

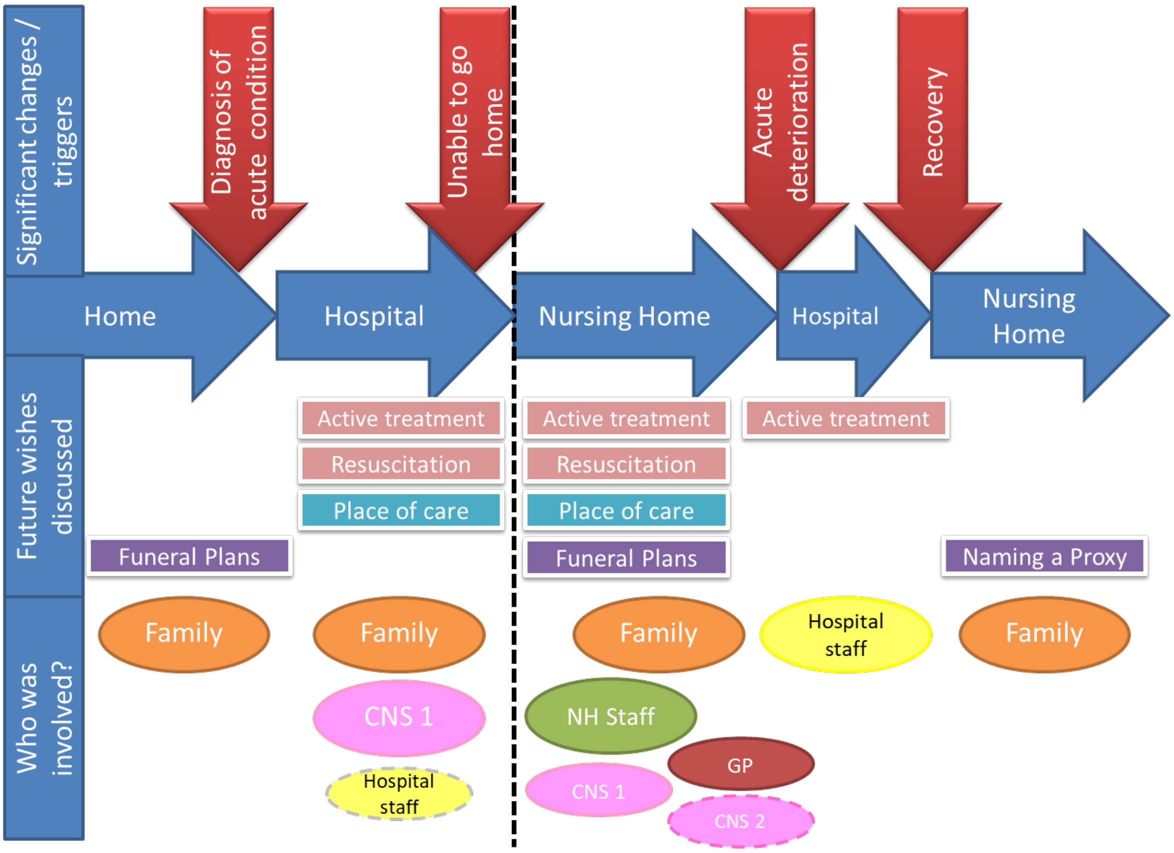

Figure 4.1: Map of Barbara's ACP trajectory

Barbara talked about future plans that had been in place for some time before the decline in her health that led to her admission to the nursing home. These were held by her solicitor and included detailed funeral plans and her will. The nursing home documentation also indicated that her solicitor held a living will but there was no copy in her notes, and this was not mentioned by Barbara or any specific wishes which may have formed part of a living will. Barbara appeared to have a long-standing relationship with her solicitor and appeared to prefer to discuss her future plans with her rather than her family, although she had informed her sons of her decisions. The decision to move into a nursing home was made by her children because her health status at the time the decision was made meant she could have limited involvement in this.

On admission to the nursing home, the nursing home's ACP documentation had been completed, but Barbara had no recollection of any discussions in relation to this or who was involved in completing the document. She had been quite unwell on admission and she had thought she was dying but she had gradually regained strength. She expressed conflicting views about future hospital admission. Her ACP document stated that she wished for medical attention and to get better, yet her verbally expressed views were that she did not wish for hospital admission which she said the staff were aware of. Following an admission to hospital during the fieldwork, her discharge back to the nursing home was expedited because she became distressed at being in hospital and did not want further intervention. Yet after the admission she struggled with balancing not wishing for hospital admission with knowing that treatment available in hospital was potentially lifesaving.

Barbara had GPs and disease-specific CNSs for two chronic illnesses involved in her care within the nursing home. Barbara saw a GP eight times over an eight-month period, all visits requested in response to acute symptoms except one which was post hospital discharge. These visits were made by four different doctors, with four visits from her named GP. There was minimal evidence of GP involvement in ACP, except the issue of a DNACPR form on two separate occasions. Discussion with one of the CNSs included options for treatment and future management of the condition. This confirmed previous discussions with a CNS for the specific chronic illness in hospital prior to nursing home admission. The CNS for the other chronic illness was known to have visited once but primarily discussed ongoing management with the nursing home nurses over the telephone; there was no known involvement in ACP.

4.4.2 Charles

Charles was an eighty-nine-year-old man resident in the nursing home for five months prior to the start of the fieldwork. He had a life-limiting diagnosis and had come to the nursing home from a hospice for end-of-life care. He was identified as likely to be in his last weeks of life at the start of the fieldwork and died during the fieldwork, a couple of months after consenting to participate. He had two children and had moved to the home from out of the area as it was near to his daughter. He appeared to have a close relationship with his daughter and his granddaughter who visited several times a week. Charles' ACP trajectory is displayed in Figure 4.2.

Charles had done a significant amount of ACP before admission to the nursing home. He had initially talked about his wishes with his family at home, focusing on practical concerns and considering options for place of care as his partner also had health problems. It had been his wish to stay at home and he had not wanted to go into a nursing home. It was not clear what involvement District Nurses or GPs may have had at this stage. Professionals became involved in his ACP during an admission to a hospice. He was transferred to the hospice from hospital following an acute admission. His daughter described the discussions that took place in the hospice about his wishes as "intense" with decisions needing to be made quickly, as it was expected his admission would be for terminal care. However, he started to pick up a little and following further discussion, the decision was made for him to be transferred to a nursing home and his partner moved to be closer to her family.

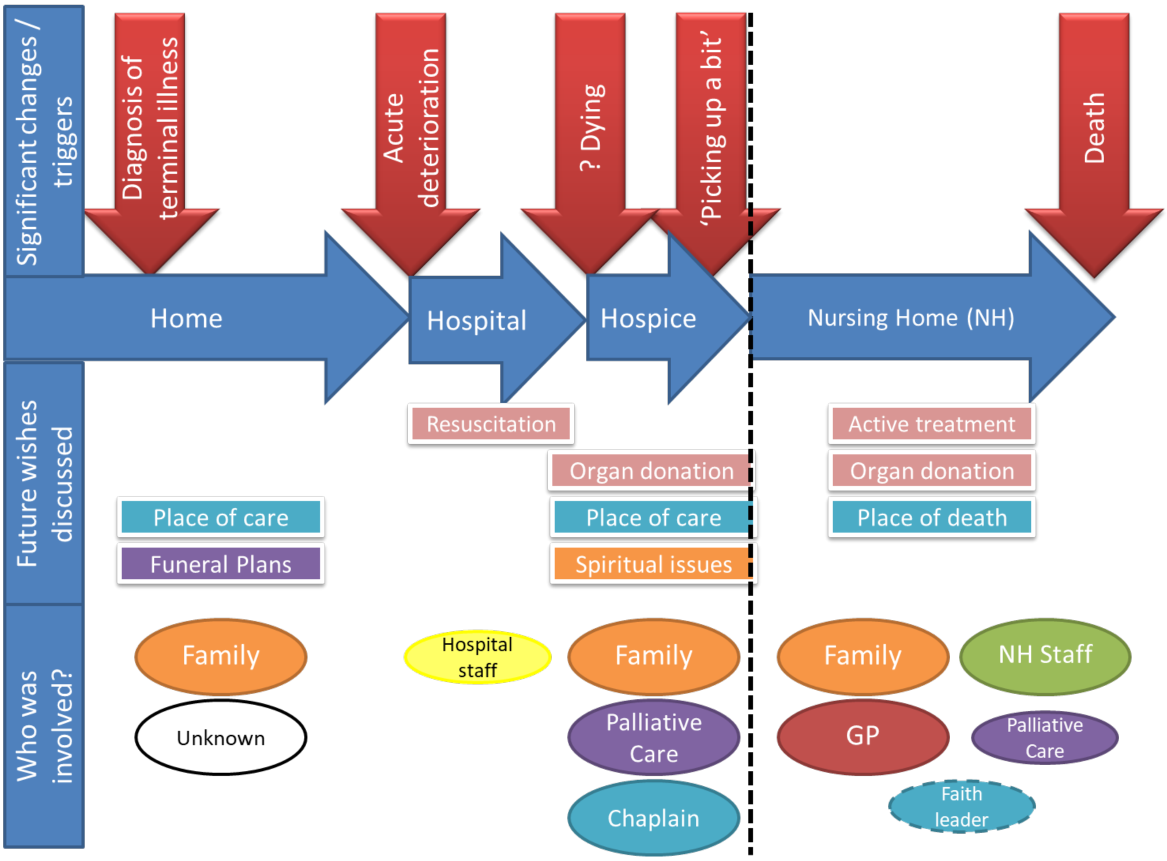

Figure 4.2: Map of Charles' ACP trajectory

No specific ACP discussions were easily identifiable from his time in the nursing home although his daughter said that they had met with the manager on several occasions to discuss his care more generally. There appeared to have been a clear handover of his wishes from the hospice, including those relating to tissue and organ donation. The nursing home manager worked with the family to ensure he was on the organ donation register and documented the process to be followed on his death. His wish was honoured as he donated his corneas after he died.

The professionals involved in his care in the nursing home were the GPs, a CNS in palliative care, a local church minister, a dentist, a continence adviser and the nursing home chiropodist. He met with the CNS once and the church minister on a couple of occasions. He was seen by a GP twenty times whilst resident in the home. Initially, this was approximately fortnightly and then was weekly for the last couple of weeks of his life, as his condition deteriorated. The focus of these consultations was very much on medical management of current problems, such as treatment of infections with antibiotics and changes to medication. There was limited evidence of any discussions about future wishes. This may have been because much of this had been documented already by the hospice, including medical aspects, such as completion of a DNACPR form and discussion of future wishes regarding medical treatment. During his last couple of months of life it was decided to no longer treat him with antibiotics; this was discussed with him by one of the GPs.

Initial telephone contact was made by the local specialist palliative care service shortly after his admission to the home; they requested that the nursing staff get in touch if they needed support. A referral was made to the service the following month at the request of a relative and a one-off visit was made. It appeared from his notes that his future wishes were discussed to some extent during this consultation. Reference was made to his open acknowledgement of dying and support for him staying at the nursing home and not being admitted to hospital.

There was no documentation of his interaction with the church minister, the dentist or the continence adviser. The documentation from the chiropodist did not indicate any conversations relating to future care wishes. His daughter advised that he had declined further contact from the church minister after a couple of visits. She had thought he would find this helpful as he previously appreciated visits from the chaplain at the hospice, but he was less enthusiastic about seeing the minister in the nursing home which, she suggested, may have been because he “just clicked with the lady in the hospice”.

His daughter advised that he was content in the nursing home during his final few months of life which had become his preferred place of death following admission there. It was reported he died peacefully in the nursing home.

4.4.3 Jack

Jack was a seventy-nine-year-old gentleman with two life-limiting illnesses and a long-term condition, admitted to the nursing home around three months prior to the start of the fieldwork in his nursing home. Jack was admitted with a terminal prognosis following recurrent admissions to hospital over a short period of time due to deterioration in his condition. His daughter had managed arrangements for transfer to the nursing home as Jack had been too unwell to facilitate this himself. Following his admission to the home, his condition improved and he was able to get out and about in the community. Jack's ACP trajectory is displayed in Figure 4.3.

Jack had three children. His daughter was the main contact for the nursing home and the member of the family he saw most. She visited him and attended hospital appointments with him as often as she could. She lived about an hour's drive from the nursing home. His wife had died many years prior to the study and his last remaining sibling died during the fieldwork.

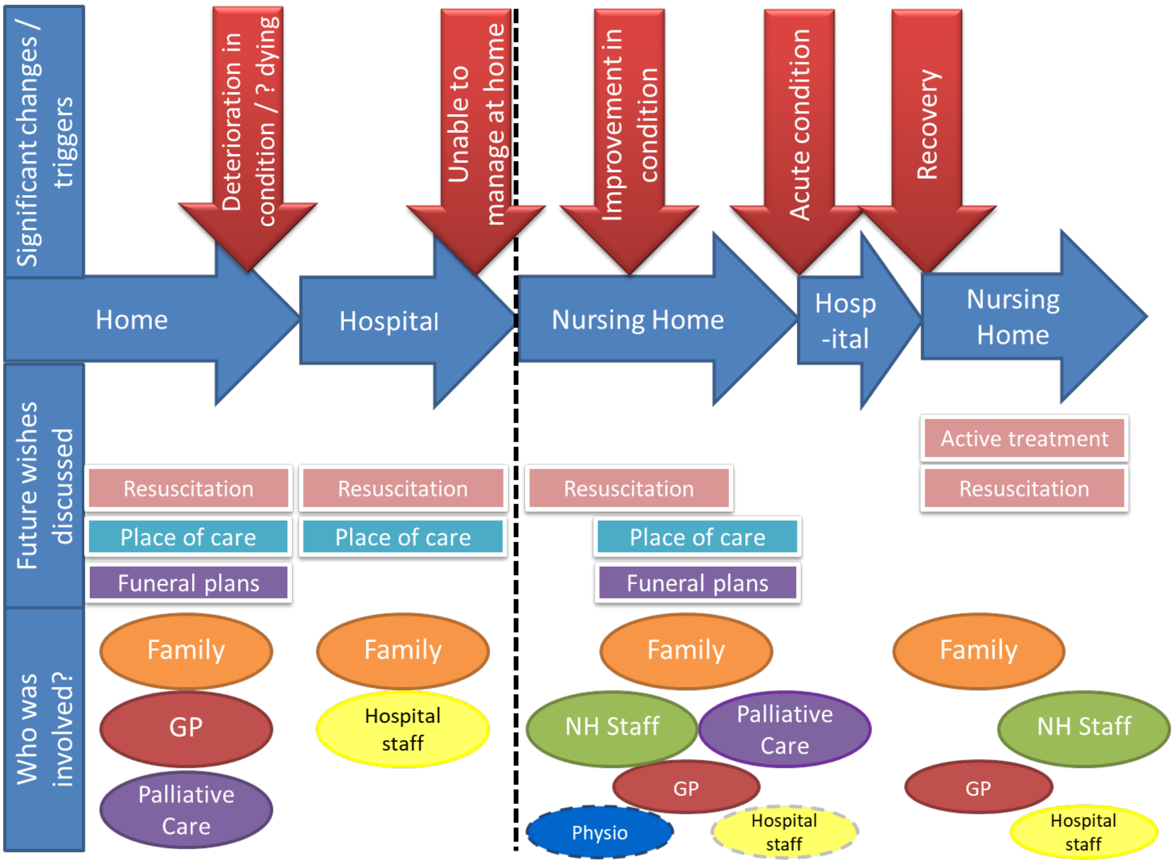

Figure 4.3: Map of Jack's ACP trajectory

Prior to his multiple admissions to hospital leading up to the transfer to the nursing home, he said he had never thought about a nursing home, although he had discussed possible options for future accommodation with his daughter about a year before he was admitted to the nursing home. This related to continuing to manage in his home as he got older; he was not ill at the time. Prior to moving into the nursing home, he had expressed wishes around his funeral arrangements with his family and this had been recorded in his will, which had "been made out for donkey's years". He considered family as important to ACP, believing they were the people who would need to know his wishes rather than professionals. A DNACPR form had also been completed prior to admission. An initial form was issued following a discussion with a hospital consultant soon after diagnosis with one of the life-limiting illnesses and a further form by a hospital consultant during his hospital admission immediately prior to moving into the nursing home.

It was not clear when Jack's ACP document was initially completed in the nursing home, as his notes stated "not done on admission". The form was given to him to complete with his daughter, which she reported happened shortly after admission. His expressed wishes included to die in the nursing home, to be cremated, to be treated respectfully and not to be resuscitated. Jack had an eight-night stay in the local hospital a month into the fieldwork for treatment of an infection, and subsequent to this, his ACP was reviewed with him by his named nurse. As part of this review his views on hospital admission were clarified as a wish for hospitalisation on his GP's advice for basic things such as infection. The review also added information relating to his current wishes rather than wishes to be implemented if he lost capacity, such as a wish to see his GP when he wants and to make his own health decisions.

Jack was seen by a GP twelve times over the nine-month period from admission to the end of the fieldwork, with two thirds of these visits being made by his named GP. With the exception of the first visit when he was a new patient with the GP practice and a visit to review him after a hospital admission, the visits focused on medical issues such as medication reviews and/or dealing with acute issues that had led to the visit being requested. Jack was also under the care of a specialist palliative care CNS in the nursing home and had previously had a palliative care CNS visit him in the community. He was visited by the palliative care CNS five times between admission to the nursing home and the end of the fieldwork. However, only four of these visits were recorded in the professional pages of his resident notes. I knew about the other visit because I saw the nurse in the home after her visit, so it is possible other visits also occurred. The records of these visits indicated that the main purpose for the visits was to review symptom management. The palliative care CNS perceived that he did not want to talk much about the future so had not had any specific ACP conversations but had talked to him about wishes for active treatment.

Jack also had a one-off visit from a physiotherapist soon after admission and was seen by someone from social services in relation to funding. He had multiple outpatient appointments during the study including with two hospital consultants in relation to his life-limiting conditions, a hospital consultant in relation to a planned routine operative procedure, specialist nurses and for long term condition screening. The reviews with the consultants overseeing the management of the life-limiting conditions did not appear to involve any ACP, with Jack referring to one of these as 'just a review' to find out how he was and how he was feeling.

4.4.4 Joyce

Joyce was a ninety-three-year-old lady with frailty due to functional deficits and co-morbidities who had been living in the nursing home for over three years. She had previously resided in a residential home for a few months, until the home closed. She made the decision to move into residential care when she knew that she could no longer manage living alone. Joyce's ACP trajectory is displayed in Figure 4.4.

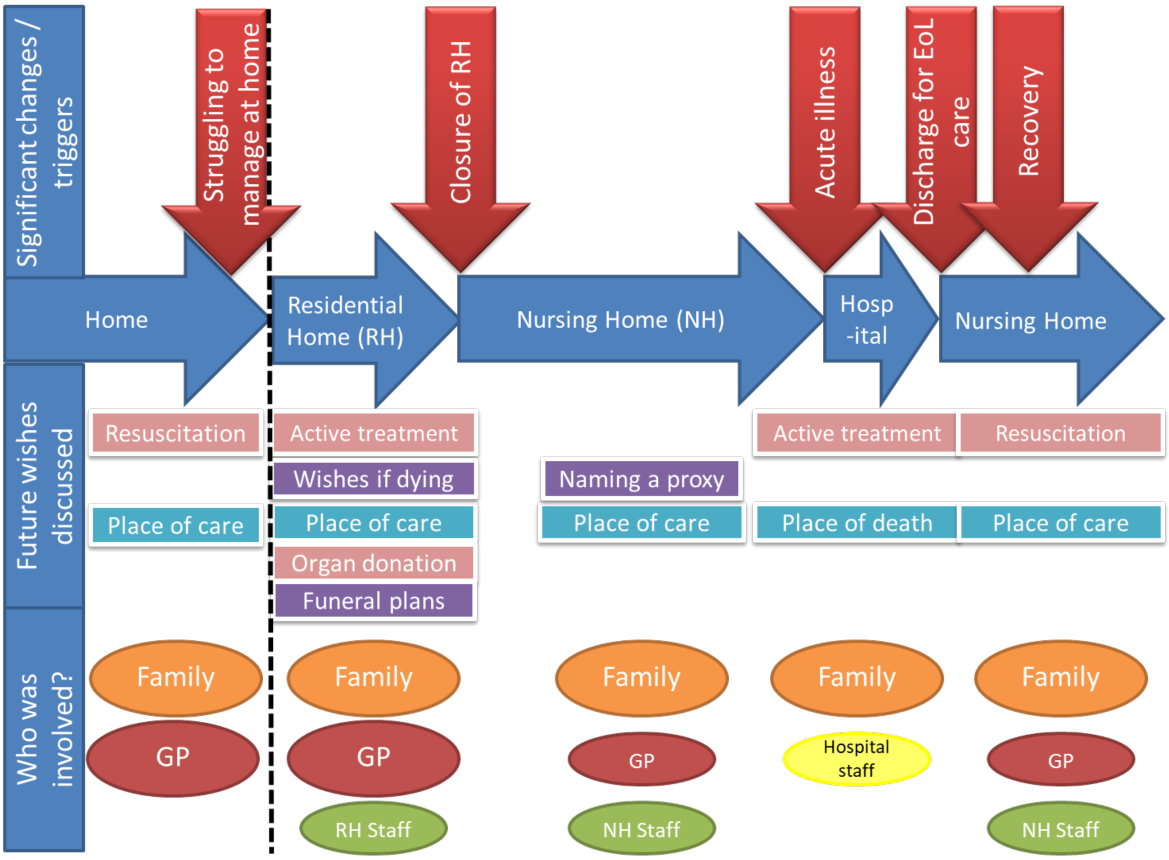

Figure 4.4: Map of Joyce's ACP trajectory

Prior to admission to residential care, she had expressed her future wishes both in relation to future place of care and about resuscitation, requesting a DNACPR form from her doctor the year before. However, her wishes and preferences were outlined in more detail when she was admitted to the residential home through the completion of an ACP document. This formed part of the home's documentation. She completed this with her son and could not recall the care staff being involved. This document was transferred with her when she moved to the nursing home. It included details of what she would and would not like to happen when she was dying, her wish to have all treatment considered necessary except cardiopulmonary resuscitation, her preferred place of death being the care home, her funeral wishes and her wish to donate her organs if possible.

Subsequent to her transfer to the nursing home, this form had been updated to indicate the nursing home rather than the residential home as her preferred place of death but was otherwise unchanged. She had also expressed a wish for her youngest son to be allowed to make decisions on her behalf and this was documented in her notes. She had discussed her wishes with her youngest son and he confirmed that he was aware of these. She had three sons with whom she spoke frequently. She was visited regularly by her two sons who lived closest and the nursing staff reported that they were involved in decisions about her care.

Following an admission to hospital a few months before the start of the fieldwork, she was subsequently discharged back to the nursing home for end-of-life care. However, her condition improved. Consequent to that admission she changed her wishes for future medical treatment and preferred place of death. She also expressed a wish to reduce the medication that she was taking. These changes were not documented in her nursing home advance care plan, although there was a record in her end-of-life care plan about her GP reviewing and reducing her medication following discharge from hospital. She expressed that she regretted having life-sustaining treatment during the hospital admission and said she would have refused it had she had the capacity to do so at the time. She expressed a reluctance to share this wish not to have further treatment with the nursing home staff but had discussed her preferences with her son. It appeared that she lacked trust in all but a few members of staff and said she did not think they would understand her views about not wanting to continue living.

The only visiting professional involved in her care in the nursing home was her GP. She had opted to stay with her existing doctor rather than change to the surgery linked with the nursing home. She rarely saw her GP with the last record of a GP visit being immediately prior to her admission to hospital. However, a new DNACPR form was issued which indicated that her doctor discussed this with her after the admission, suggesting that she had been visited on at least one other occasion. Her notes showed that her concerns since then had been dealt with by telephone communication between the nursing home nurses and GP, without the GP visiting. Her GP had completed a care plan relating to her future wishes for medical treatment when she was admitted to the nursing home. Although not documented in her nursing home notes, she thought her GP was aware of her amended decision regarding future treatment although she could not clearly remember discussing it with him.

4.4.5 Norman

Norman was an eighty-two-year-old gentleman, admitted to the nursing home several months before the start of the study. He was admitted from hospital following a month as an inpatient due to an acute episode causing mobility and memory problems. He had limited recollection of his hospital admission or how arrangements were made for his admission to the nursing home, except the knowledge that his son had overseen this. He was initially admitted for a short-term placement, but this was extended twice before becoming permanent when he realised he would not manage at home on his own. Norman's ACP trajectory is displayed in Figure 4.5.

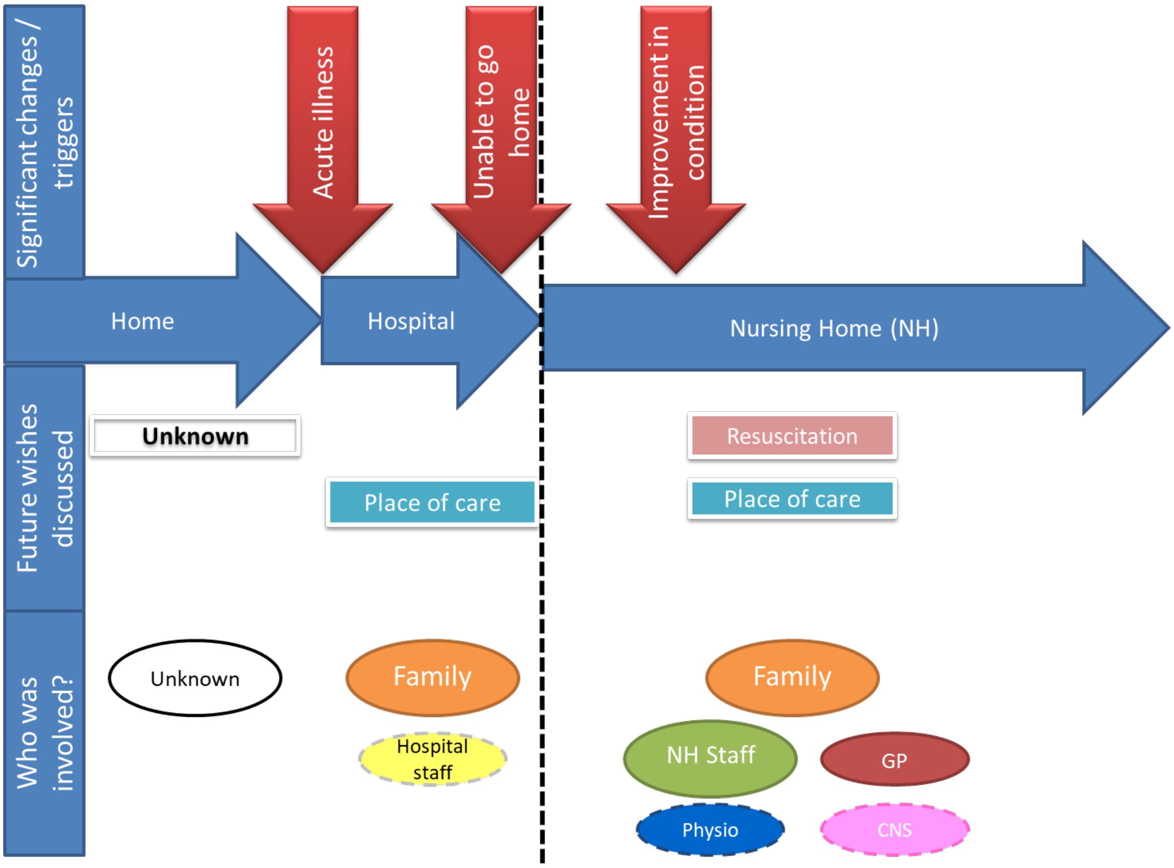

Figure 4.5: Map of Norman's ACP trajectory

Norman had been a widower for many years, having been the main carer for his wife prior to her death. He had a son and a daughter who both visited him in the nursing home, and he maintained involvement in family events which included a wedding during the fieldwork. The only aspect of ACP he said he had discussed with his family was his choice to remain in the nursing home until the end of his life as he was happy and settled living there. He said he had not previously considered nursing home care as he had not thought beyond living at home on his own. However, the changes to his health had led him to the realisation that he could no longer manage on his own. He said he had put his finances and paperwork in place prior to admission to the nursing home but did not share whether he had discussed this with his family.

There had been limited ACP with Norman in the nursing home. His notes identified that it had been raised with him on a couple of occasions several months apart, although primarily focused on his views on cardiopulmonary resuscitation. However, there were no recorded decisions as Norman did not wish to have this discussion. He talked about not wishing to go back to hospital, specifically to the ward he was on prior to transfer to the nursing home but said he did not think he had told the staff this. He said he hoped he could get all the care he needed at the nursing home. Despite not discussing his wishes for future care, Norman said he thought either the nursing home manager or nurses would be the best people to talk to about ACP.

Norman was registered with the GPs who visited the home weekly. He was seen by a GP twenty-one times over the fifteen months to the end of the fieldwork. These consultations were to deal with medical concerns such as hypertension and indigestion, to review medications and to monitor progress. There was no evidence that these included any ACP discussions. In the same time period, he was also visited multiple times by a dentist and a chiropodist, twice by an optician and a physiotherapist and once by a nurse specialist.

4.4.6 Peggy

Peggy was a ninety-two-year-old lady admitted to the nursing home mid-way through the fieldwork. She was transferred from hospital where she had been admitted as her health had rapidly deteriorated and the care she was receiving at home was not sufficient. Although admitted to the nursing home as a consequence of being too unwell to return home, the choice of home was based on a previously expressed wish. She had previously had a trial period in a residential home near to where her only son and his wife lived. However, this was in a different county and her preference was to be cared for near to her home where she had a network of friends.

Prior to her admission to the nursing home, she had written her will and had planned her funeral in detail. She had passed her plans to her son who had been asked to open the envelope after her death. Some discussion relating to future care and treatment had also been completed prior to her admission which included a choice not to have surgery. It was unclear from the information Peggy provided as to whether this occurred prior to her admission to hospital, whilst in hospital or immediately on arrival at the nursing home, as she spoke about involving her GP when making the decision. However, it was discussed with her son during the hospital admission. A DNACPR form was also completed whilst in hospital. Peggy's ACP trajectory is displayed in Figure 4.6.

ACP decisions were documented in Peggy's nursing home within the first few weeks after admission. These included the preference not to be readmitted to hospital and not to have surgical intervention, and the wish to be able to get back to Church. She suggested during her interview that she had some wishes relating to her spiritual care at the end of her life but did not open up about these. She said she had not been asked by staff whether she had any wishes relating to her religion.

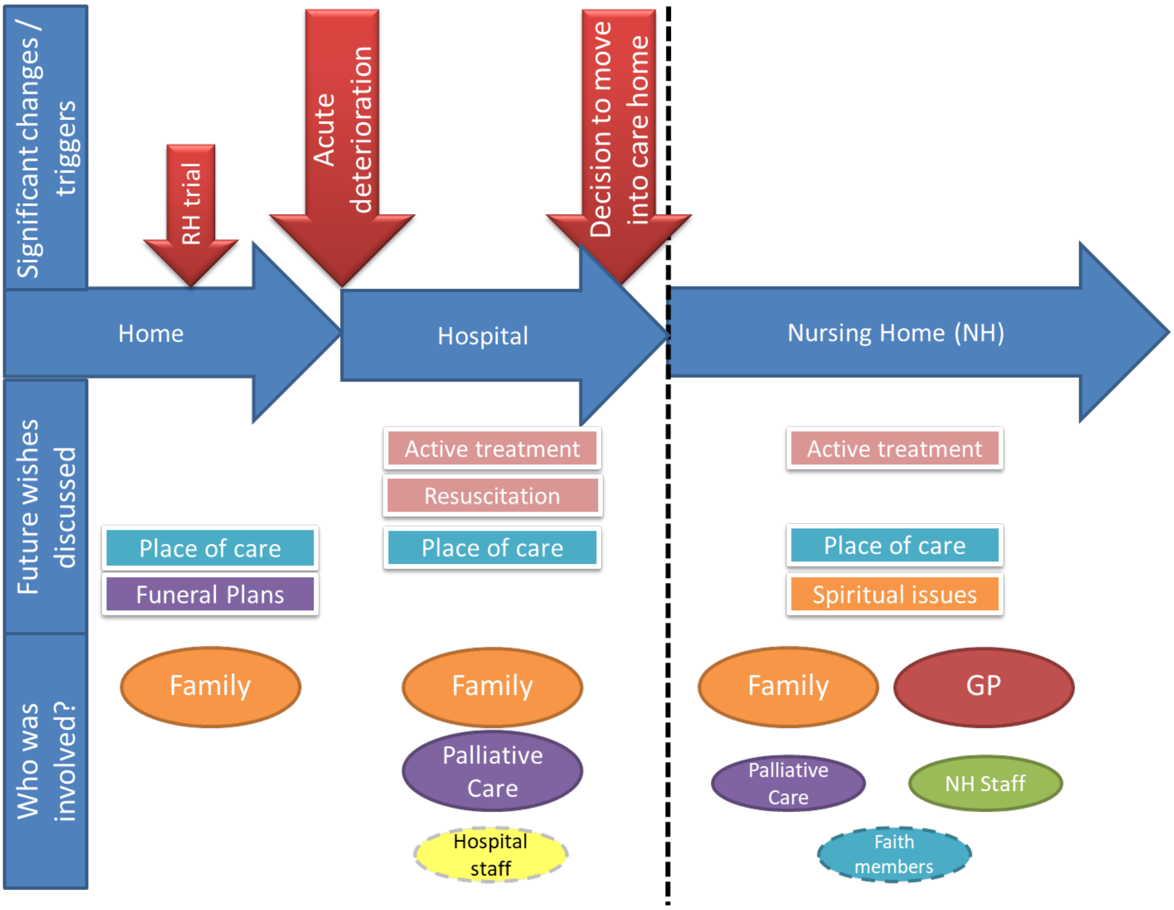

Figure 4.6: Map of Peggy's ACP trajectory

In the three months from Peggy's admission to the nursing home and the end of the fieldwork, she was visited by a GP six times and a nurse practitioner from her GP surgery once. Peggy had been registered with the GP practice and got to know her named GP over a long period of time. She was disappointed that it was not always her named GP who came to visit her in the nursing home. Her nursing notes indicated that aspects of ACP, including future escalation of care, were discussed during a visit by her named GP the day after her admission to the home. There was no written record of ACP discussions at subsequent visits.

Peggy had the palliative care team involved with her care during her hospital admission and she received a one-off follow-up visit once in the home, to reassess her eligibility for Continuing Healthcare funding. A professional involved in this visit indicated this had involved reviewing her wish not to be readmitted to hospital but that was not documented in her notes. Peggy was also seen by a rehabilitation assistant and a chiropodist, each on one occasion with no evidence of ACP discussion and also attended a hospital outpatient appointment. Her notes also indicated that she had been visited by a Vicar within the first few weeks of her nursing home stay and both Peggy and the nursing home staff also talked about involvement of her church friends. There was no written report from the Vicar following the visit.

4.4.7 Commonalities across resident trajectories

The trajectories and pen portraits demonstrate that a degree of ACP was initiated for all residents in the nursing home setting, and this was not determined by involvement of palliative care services or being admitted for end-of-life care. For all residents there was limited involvement of visiting professionals in ACP, with most professional visits being once only occurrences. This ad hoc visiting links to the theme of 'Disjointed System'. GPs had some involvement in ACP in the nursing home for all six residents. However, there was more involvement of GPs with ACP for the two residents admitted for end-of-life care than with the other residents, with the exception of one. She had been under the care of the palliative care team in hospital but was not considered to be approaching the end of her life when reassessed for Continuing Healthcare funding shortly after admission to the nursing home. Involvement of GPs in ACP therefore appeared more likely when a resident is or might be dying and informed the findings about timing of ACP within the theme 'Enacting ACP'. Likewise palliative care professionals were only involved with these same three residents.

Practical matters were the most common area of future planning completed by residents at home before changes in their condition led to care home admission. This also informed the theme of 'Enacting ACP', highlighting differences in the resident's approach to practical planning compared to healthcare related decisions. The main focus of ACP discussed and/or recorded within the nursing home for the six residents was resuscitation, place of care and treatment plans, although other areas were covered for some residents. The professionals identified in the resident trajectories were primarily involved for physical health concerns. Only two residents had professionals involved for psychosocial or spiritual matters, both being religious ministers. This links with other data showing that there was a dominance of a biomedical approach in both nursing homes. Both this and the prevalence of family involvement across the trajectories informed the theme of 'Professional Reach'.

4.5 Chapter summary

This chapter has provided contextual information about the nursing homes in which the study took place. It has also outlined details of the six participant residents whose ACP trajectories informed the study, thereby providing both micro and macro context to the findings. The nursing home context will assist the reader to understand the settings in which the findings are situated and also to assess transferability of the findings to other settings. The resident ACP trajectories illustrate the involvement of different professional groups and family from immediately prior to admission to the nursing home through to the end of the fieldwork. They highlight similarities and differences between each resident's ACP journey in terms of the settings where ACP was undertaken, the professionals involved in ACP and the ACP topics discussed. These trajectories informed the data analysis that generated the findings which are presented in the next three chapters.

Chapter 5 Disjointed System

5.1 Introduction

This chapter presents findings which show that ACP and multi-professional working in the nursing homes were situated in the context of a disjointed system. Continuity, both relationship and management as described by Freeman and Hughes (2010) in their study of General Practice, was found to be important for ACP. However, both were disrupted by the structure and organisation of care between nursing homes and visiting professionals. Power imbalance within hierarchical relationships, accessibility of services and an approach to visiting professional involvement explained using the theoretical framework of knotworking (Engeström et al. 1999; Engeström 2000, 2008), influenced relationships and enactment of ACP. This resulted in fragmentation of decision-making and marginalisation of the resident and nursing home nurse voice.

5.2 Relationship continuity

Relationship continuity is when care is provided by one or more individual professionals with whom the resident builds and maintains a consistent therapeutic relationship (Freeman and Hughes 2010). Relationships fostered by such continuity were valued by residents, relatives and professionals in both nursing homes. For example, one resident chose to remain with her existing GP on moving into the nursing home because she had built up a relationship with him over many years. The continuity achieved in nursing home A, where a weekly GP 'ward' round was led by one of two GPs, with these GPs also providing much of any reactive care required between the rounds, enabled relationships to develop between both the doctors and residents and the doctors and nursing staff. These were spoken about positively. The continuity of nursing home staff was also well evaluated, particularly by participants in nursing home A where many staff had worked for significant periods.

> [Relative] discussed that it was good that the two GPs knew the residents well. She identified that knowing the resident's history was important. She said that 'continuity is very important' … She spoke about the continuity amongst the care staff and that the staff remained constant here. (Field Notes – Visit 013)

Developing relationships with residents was talked about by professionals in terms of 'getting to know' residents. Staff in both nursing homes demonstrated that they knew residents well and used their knowledge of the things that were important to residents to reinforce resident identities. For example, a resident was dying and had loved gardening so strongly scented flowers were placed in his room each day. 'Knowing' a resident was considered important to facilitate ACP conversations by both nursing home staff and visiting professionals. They talked about how building a relationship through regular contact with a resident enabled involvement in ACP and laid the foundations for opening up full ACP discussions. Similarly, residents also suggested that they were more likely to share information about their preferences when they 'knew' a professional, such as a resident who spoke about not sharing her wish not to be readmitted to hospital with her GP because she had only met him twice. An informal interview with another resident revealed that she had not discussed her wishes for after her death with any staff member because of a lack of continuity with her direct care team because the staff allocated to residents often changed between shifts in both homes. The sensitivity of end-of-life care conversations underpinned the wish to have these with someone who residents knew and trusted.

> "I mean if you've got something wrong with your finger any doctor will help but for other things and the fact that they know you a bit makes all the difference." (Resident 5)

'Knowing' the resident was also considered important to inform end-of-life care decision-making.

> [Nursing home nurse] said … that the GP there the previous week had said she was not prepared to complete the DNACPR as she did not know the resident, so had advised them to request this from her former GP. (Field Notes – Visit 098)

Without knowing the resident over a period of time it was sometimes difficult for GPs to identify the changes in a resident's condition that might indicate deterioration in health, given the unpredictable nature of health decline in this group of elderly people (see Chapter 6). It was also noted by a manager that where the GP service provided was reactive, for those residents who required low levels of GP input in the nursing home, it was often only as they approached the end-of-life that they might start to see a GP regularly. Indeed, in nursing home A residents were reviewed regularly at the GP round, allowing GPs to get to know residents over time, which then informed decision-making when the resident became less well. A GP involved with the round commented that it allowed for routine discussions not just when deterioration in a resident's condition occurred.

> They then got to the list of residents who needed to be reviewed. [GP] said they try and review each resident every month 'just in case' even if 'just to say hello'. (Field notes – Visit 037)

Establishing and sustaining relationships between nursing home staff and visiting professionals were also considered important for provision of ACP and end-of-life care.

> "It's the key actually … if you have a good relationship with the multidisciplinary [team] and the GP. And if their involvement is actually good, well the end of life [care] will be much better." (Manager 2)

In nursing home A, one of the GPs had been providing the GP round service for more than ten years and a manager described how the relationship was continually developing saying "the longer we stick together the better we can improve the service that we provide" (Manager 2). This led to the GPs not only knowing the residents well but the GPs, the GP surgery staff and the nursing home staff also knowing each other, knowing how each organisation worked and having confidence in each other. Interactions were observed between the GPs and nursing home nurses that demonstrated sharing of information from both their perspectives and reaching shared agreement on the actions to be taken, including future planning when a resident's condition was thought to be deteriorating.

> One thing discussed [at the GP round] was the monthly weights, looking at those who had lost weight, and this was used as a source of information that informed discussions around future planning, in particular whether weight loss should be investigated or not. (Field notes – Visit 046)

Other professionals such as specialist nurses also built-up relationships with nursing home staff. By virtue of being the named professional from their service either linked to the home or linked to one of the GP practices that had residents in the home, these nurses usually visited regularly and worked with the home over a sustained period of time. Relationships developed through sharing care of residents and gaining confidence in the knowledge the other was able to contribute. However, despite involvement for more than a year, one professional remained sceptical of the skill levels of nursing home staff and their ability to manage end-of-life care.

Internally within the nursing homes the keyworker role offered potential for the organisation of work that enhanced relationships between nursing staff and residents, relatives and visiting professionals. Such a keyworker role was in place in nursing home B with each resident having a named nurse. This role was seen to support development of a relationship between a nurse and resident conducive to ACP, with a relative advising that she would wish her father's keyworker to be involved in ACP.

> "She's really good [be]cause I, when she comes in the room, I know that I can trust her with being professional and seems to know exactly what's going on. Some of them that

> come in don't know what Dad's on, what he's doing, what he needs but she's really good." (Relative 1)

Most professionals talked about the benefits of nursing home staff who knew the residents well, with a reliance by professionals on nursing home staff providing information to facilitate their interventions with residents, although this did not necessarily include sharing of ACP information. The keyworker role was suggested by some professionals as a good model to ensure they could be provided with informed insight into a resident's current condition. However, having senior staff members with oversight was well regarded by others. Within nursing home A, the manager had oversight of every aspect of resident care, often taking a lead on talking to relatives and to professionals. The knowledge imparted by the senior nurse in nursing home B who, although based in the first-floor office, had oversight responsibility for residents across the whole home was also commented upon.

> "So, there is something about some continuity and knowing the patients. Especially when we're going in cause obviously we're not going in as much." (Social Worker)

> "What could work better is if they subdivided may be some of the clients into smaller groups and staff knew them that little bit more intimately." (Specialist nurse 1)

> "I've got six people that are currently under my wing that are in [nursing home] and I went to see just the one nurse, who was the senior nurse who was on, and she was able to give me a very thorough, detailed handover about everybody and what's been going on. Even though there was three floors and she obviously doesn't cover everybody, she's obviously got an overview about everybody, and I think that's very good." (Specialist nurse 3)

However, the structural organisation of care between nursing homes and visiting professionals, and the organisation of staff within the nursing homes, made the relationship continuity necessary to build relationships to support end-of-life care provision difficult to achieve. Visiting professionals commonly attended on an ad hoc basis, limiting opportunities for relationships to develop. A GP acknowledged that continuity was not possible with reactive nursing home visits. In nursing home B, where almost all GP visits were in response to a request for a visit, nurses talked about not knowing which GP would visit until they arrived, and residents did not know who their named GP was because they saw many different doctors. Although the weekly GP round in nursing home A provided relationship continuity with residents, the hierarchical approach to the GP round led to relationship continuity with nursing staff being primarily limited to the managers. Both managers were involved with the GP round every week, with the involvement of just one manager being unusual. However, the division of work and unpredictable nature of other professional visits meant this relationship continuity was not replicated in all cases. Although managers were also involved with ad hoc professional visits, including from the GPs involved in the GP round, this happened to a lesser extent, and was usually dispersed across the nursing team.

> [Nursing home nurse] spoke about being more involved with the GPs who visited ad hoc rather than the big round …. She said that [the managers] … are only heavily involved in the round, yet she thought as these [ad hoc] visits were when a resident is poorly, they were more important and interesting. (Field notes – Visit 042)

Professional visits for dying residents were more likely to be reactive. However, the nature of nursing home staff rotas and these unpredictable visits made it difficult to ensure that the nursing home staff members with the most in-depth knowledge of the resident were present at the time of professional visits.

Similarly, the reality of implementing the policy that the named nurse in nursing home B would lead on all aspects of planning care, including liaison with professionals and ACP, for their named residents was challenging. Most multi-professional collaboration became the responsibility of the nurse on duty when the professional visited. As the nurse on duty did not necessarily know the resident as well as the named nurse, there were sometimes gaps in the information shared. This was seen to be overcome by a nurse involving a care assistant in one professional visit, but this did not work for multi-professional involvement in ACP as care assistants were not directly involved in the ACP process in either home. ACP was seen by both care assistants and nurses as a nursing role; care assistants might be told something by a resident relating to ACP, but the expectation was that this was shared with the nurses for the nurses to action.

> [Nursing home nurse] said … she would try to attend with the GP when [resident] being reviewed if she can and she said she did most of the liaison with the resident’s daughter. The resident is due a six-month review meeting early next month. (Field notes – Visit 073).

The way professionals worked within geographic boundaries also hindered relationship continuity between residents and professionals, with this frequently disrupted when a resident was admitted to the nursing home. This happened either because they were moving into a new area or across a service boundary. Four of the six participant residents had to register with a new GP practice, one swapped to a different specialist nurse’s caseload within the same palliative care service and one found that the vicar with responsibility for the home was from a different parish to the one she was previously involved with, despite the home being in the same locality as where she lived before. Such a change in professional provision did not just disrupt relationship continuity but could also disrupt management continuity unless adequate information was shared. A GP explained how residents registering with a new GP, particularly when they moved to the nursing home at the end of their life from another area, could create difficulties when there was not a proper handover of information, as the new GP did not have any knowledge of the resident.

The lack of relationship continuity inherent in the structural organisation of visiting professional services could have a negative impact on delivery of end-of-life care. This was recognised by the nursing home nurses who would try to influence relationship continuity of GP provision if they could. In both nursing homes, when requesting GP visits, they would ask for a visit from a GP that had seen the resident before where possible.

> [Nursing home nurse discussing a resident who died in hospital following recurrent admissions with chest infections] said that she thought with more continuity from GPs then perhaps proactive discussions about the recurrent infections might have occurred with the family to enable her to have died in the home, rather than the family pushing for active treatment. (Field notes – Visit 094)

> [Nursing home nurse] said she would usually discuss with the surgery who was available to visit and try to get either their own GP or flick back through the resident's notes to see who else has seen them recently and see if one of these doctors is available. She said when they come in the GP will see any of the surgery's residents, so it is not necessarily the residents' own GP who sees them. (Field notes – Visit 070)

Yet amongst visiting professionals to some extent the reactive approach and lack of relationship was accepted practice.

> "[The resident has] come from out of area so it's not like he's been with the same practice for years and years so like his regular GP wants to keep kind of an overview of what's going on. I think the home, the GPs are quite happy that they would just be contacted if, if we needed them for something". (Specialist nurse 3)

5.3 Management continuity

Management continuity relates to the communication, coordination and information sharing, both between professionals in a single organisation and between professionals from different organisations, which is needed to bridge the gaps in increasingly complex care systems (Freeman and Hughes 2010). Management continuity was important to ensure wishes and preferences for future care expressed by residents could be honoured, as relationship continuity was difficult to achieve. ACP needed to be shared between many professionals and decision-making coordinated across organisational boundaries. Formalised communication processes such as handovers and documentation were used to share information and support management continuity internally within both nursing homes. Sharing of information between nursing home staff and visiting professionals, including ACP information, most commonly happened verbally, either by telephone or before a professional left the home after their visit. Fax communication was also used frequently in nursing home B's communication with GPs.

> "Dieticians ring as well, they check up on some of our residents … by phone, yeah mostly yeah and if we've any concerns they sort them out." (Nursing home nurse 5)
>
> [Nursing home nurse] spoke to the receptionist and asked to speak to a GP who had called regarding this resident the day before. It was apparent by her response that she had been told that GP wasn't available and so she asked to speak to [name of GP]. She advised [me] that there had been faxes going back and forth regarding this lady and so she thought it would be easier to speak to someone directly. (Field notes – Visit 102)

Shift handovers were used in the nursing homes to share information, including that concerning ACP, and provide management continuity. However, these usually only reported information relating to what had occurred in the immediate past. These did not often cover longer than the previous twenty-four-hour period, although one nurse said she would vary her handover content dependent on when the nurse she was sharing information with had last been on duty. This meant that it could be challenging to ensure all changes were effectively communicated. It was common for staff to have a few days off, not just for holidays but because many staff worked part-time and also because the usual work rotas were primarily twelve-hour shifts meaning full-time hours were worked over just three or four days per week. Verbal handovers were supported in both homes by written handover sheets, although this was more detailed and included more ACP information in nursing home B than nursing home A.

> [Nursing home nurse] explained that [another nursing home nurse] had been frustrated because she had been unable to answer the questions of a continence nurse a few days before because the information hadn't been communicated to her and had thought she had looked stupid. (Field notes – Visit 049).

> “[Be]cause I notice if I’m in the office writing up people’s notes, … then there’s things that I pick up and I think ooh if I wasn’t sitting here, I would never have picked that up.” (Nursing home nurse 2)

> [Care assistant] said it was like that yesterday as she had returned from a week’s annual leave. She said she had asked the nurse for more information so when he said “no change”, she said “really, nothing in the last week?” She said he then gave more information. (Field notes – Visit 113)

The physical space of the nursing home buildings shaped interactions and information-sharing between nursing home staff and between nursing home staff and professionals. In nursing home B, day to day operational activity was organised from two nursing offices, one on the ground floor from which work for this floor was coordinated and one on the middle floor from where care delivery for the upper two floors was managed. In nursing home A, the central and co-located offices were a focal point for visitors and staff and care for all residents was coordinated from the main office, providing a hub for information-sharing. In both homes, the nursing and care staff were allocated to support residents in different areas of the home on a shift-by-shift basis, with value placed on all staff having some knowledge of all residents and residents becoming familiar with all members of staff. However, the layout of nursing home B, with separate offices for the different areas, could disrupt internal continuity and be a barrier to information-sharing. As care assistants working day shifts in nursing home B only received handover about the residents on the floor on which they would be working, the rotation of staff between areas and the limitations of these handovers made it difficult for staff to keep up to date on all residents. They reported feeling slowed down by a lack of knowledge when they moved to work on another floor.

> [Care assistant] was giving out the supplementary drinks. She said she was slowed down as she wasn’t as familiar with the residents as she had been working on the middle floor this morning. (Field notes – Visit 113)

Nurses talked about feeling isolated when working on the ground floor, being the sole nurse on the floor, whereas when working on the upper floors they were based in the main office on the first floor alongside the senior nurse on duty and the senior carer, with whom information could easily be discussed and shared.

> [Nursing home nurse] said as a nurse, the separation of the nurses across the two floors made it isolating as they work quite separately. She said when she had first started it

> had been good to share the ground floor work with [another nursing home nurse] as they could bounce ideas off each other. (Field notes – Visit 108)

Relatives of residents on the ground floor rarely interacted with the senior nurse based on the first floor, with one relative reporting a lack of confidence in her as she did not know her, after meeting her for the first and only time at a care review meeting. Visiting professionals would report to the office where the resident they were due to see was located, reducing interaction with and for opportunistic advice to be sought by members of the nursing home team working in the other area and therefore also opportunities for building relationships.

In nursing home A, management continuity was supported not only through having a single communication hub in the nursing home to facilitate interaction between professionals but was also enhanced through management oversight of everything that happened within the home. The managers' office was co-located with the nursing office and overlooked the entrance to the home. This enabled frequent involvement of the managers in discussions about residents in the nursing office and they would frequently make themselves available when a professional was seen arriving at the home. They were fully apprised of wishes and preferences that had been expressed by residents. The managers themselves therefore bridged the gap between the different strands of care provided to residents and they made themselves available whenever needed through weekend working and availability OOHs. However, as discussed in section 6.3, this oversight and control could lead to nurses lacking confidence to get involved in ACP themselves.

> Towards the end of giving out the medication a carer alerted [nursing home nurse] to the fact that a resident was not answering her as she was trying to find out what she wanted for supper. … [After reviewing the resident, the nurse] advised me that she was concerned about [the resident] and so she would ask [manager] to see her. … [The manager reviewed the resident] and advised [nursing home nurse] that [the resident] was not really responding but her BP was OK. … [Manager] advised that she was going to contact the family. Whilst [nursing home nurse] continued giving out medications, I could see [manager] in the office on the telephone. … [Manager] advised that she was waiting for the GP to call back regarding the poorly resident and that the family were going to come in around 11.30. … The family of the poorly resident were seen coming up the path ... [Manager] leapt to her feet as they came in the front door and accompanied them to the resident's room, returning a short while later. (Field notes – Visit 002).

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There was a reliance on the management oversight in nursing home A, but in both homes documentation was also a key strategy to ensure management continuity in relation to ACP and visiting professional involvement. ACP was recorded in each resident's notes, as were details of professional visits. Professional visits were also recorded in the office diaries, which one nurse said she would refer to after her holidays to highlight changes that had happened. She reported coming in early to do this. Staff were rarely seen reading resident notes to update themselves during their shift, reporting a lack of time to do this. The practice-based concept of temporal structuring in organisational life suggests that time is realised through recurrent practices that produce temporal structures, individuals thereby regulating and accounting for their activities through these structures (Orlikowski and Yates 2002). These structures regulated staff activity in both homes through routines by which staff accounted for their activity. These included medication rounds and working through the tasks listed in the diary for nurses and bathing schedules, mealtimes and daily checks such as mattress pressures for care assistants. However, these structures hindered enaction of strategies to bridge gaps in continuity through staff reading notes or updating themselves, except through handovers. This only happened if gaps occurred in the usual temporal routines.

> [Care assistant] said she was just taking the opportunity to learn more about the residents – she was reading a page of their notes called 'All about me'. She said she didn't often have time to do this, but she liked to know more about the residents. (Field notes – Visit 104)

However, having future wishes documented ensured it was available to be referred to when needed, with one nursing home nurse explaining that you 'can't know everyone's care plan'.

As such, recording in the nursing home notes was a strategy considered important for management continuity by nursing home staff. However, this was not done routinely by all professionals and was not given priority by some professionals as something they should do. The perception of the importance of using the nursing home notes to provide management continuity varied between nursing home staff and visiting professionals. Although most visiting professionals stated that they were happy to record in the nursing home notes if asked to, all professionals talked about keeping their own organisational records of their visits. The manager of nursing home A was regularly seen asking professionals to record their visits and reminding the nurses to ask professionals to do this. However, in nursing home B, in most cases, a summary of the visit was recorded by the nursing home nurse, a record of the visit considered important even if not written by the professional. There was no particular reason given for this approach in nursing home B or why professionals were not asked to record in their notes.

> [GP] said they are not good at writing in the nursing home notes either, acknowledging that this is something that perhaps they should be doing. [GP] said they have a flurry for a month or so when the nurses ask them to do this, he assumes because they have been told to do so, but this then tails off. (Field notes – Visit 092)

The importance of professionals recording in the nursing home notes, particularly when they visited residents on their own, was highlighted by one professional talking about having ACP discussions who said: "Our role is to make sure we've communicated that effectively. And not just been in, had them sort of conversations and gone again" (Social Worker). While GPs were always accompanied by a nursing home nurse when visiting residents, other professionals such as specialist nurses and physiotherapists were mostly observed visiting residents alone. Physiotherapists were sometimes accompanied by care assistants as they would be the staff who would need to continue any exercise regimen. There was an apparent expectation that the nurses would be on hand to provide history to the request for a visit and records such as medication charts and clinical observations when GPs visited which was not obvious with some other professional disciplines. Some professionals wished to visit the resident on their own to allow open conversations with residents, particularly palliative care staff.

> "I think most times they would go on their own and particularly if they know the resident, they'll go on their own. I mean we do say 'would you like us to come with you?' so, but most times I think they would go on their own. And then they would come back and feedback." (Nursing home nurse 2)

Even when professionals recorded in the nursing home notes, management continuity could be enhanced further by a nursing home nurse being present during a professional visit to a resident. Being present for the discussion could give the nursing home staff a greater understanding of a resident's needs and wishes, which might be difficult to report fully in documentation.

> "Especially if I'm giving guidance [to the resident] [be]cause it makes sense that they're there and listening to the conversation um with the resident. … I think it's, it's sometimes very useful to have a staff member there so that as well they, they know what's been said in this conversation, you know. Um, [be]cause although you can document a lot about what you're saying, … sometimes the undertones of what you're saying and implying and stuff can't necessarily be put into words." (Specialist nurse 3)

Visiting professionals did not record in the nursing home's ACP documentation in either home, recording their ACP discussions in their own documents. Local area specific ACP documents were in use by healthcare professionals in both localities. Professionals acknowledged that the different organisational documents did not always link together. This led to silo working and duplication, with some ACP decisions recorded in more than one place and others only recorded in one organisation's document thereby not available to all involved in the resident's care. In nursing home A, a GP reported completing the locality document as this was a local CCG requirement although considered it unnecessary for his nursing home residents, as he recorded in the nursing home notes and the nurses kept a record of ACP. There was a widely held belief that the different documents were shared between organisations but in practice this did not always take place. Each organisation's requirements to hold a record of professional consultations, recorded on different documents and IT systems, conflicted with the inter-organisational nature of ACP. Nursing homes, which sit external to the NHS, were excluded from unified record-keeping processes, reflecting an imbalance of power between health organisations and nursing homes. There was a reliance on individual professional actions to ensure information was shared.

> "Saying that [name of locality ACP document] doesn't routinely go to the home. At the bottom of the form there's the three people you send it to and the home, believe it or not, isn't one of them." (GP 3)
>
> "I would hope that if they're in a care home they would be sort of overseeing there, what was going on there and pulling it together. But people can end up, can't they, between lots of different things and nobody really knows what's going on with everybody else?" (Specialist nurse 2)
>
> [Manager] also took a phone call from the geriatric team at the local hospital. From hearing one side of the conversation and then her feedback to [senior care assistant] it was apparent that in a recent outpatient appointment they had made changes to a resident's medication and ACP and were asking if the letter outlining this had been received. It appeared it had not, so the information about the medication was relayed to her on the phone and she was now expecting the letter with the changes to ACP. Her feedback [to senior care assistant] was that this would need to be updated on their ACP once the letter was received. (Field notes – Visit 075)

The regular GP round in nursing home A was the only example of a formalised multi-professional process for information sharing and ensuring both relationship and management continuity. Nursing home nurses, visiting GPs and specialist nurses spoke about the model of having a named GP undertaking a regular GP round as being best practice, including professionals working with nursing home B where this was not in operation. Frustrations with the process of sharing information and maintaining management continuity were common where services were reactive and difficult to access. Significant work needed to be done behind the scenes, including chasing fax communication and trying to engage with professionals on the phone.

> When [nursing home nurse] came off the phone she sighed and said that it was becoming harder to communicate with the surgery. She said ‘so much money and resources are wasted just trying to communicate’. She then told me this issue had been going on for a few days trying to get the dose of antipsychotic and anti-depressive medications reviewed for a resident who is significantly more sleepy during the day.
> (Field notes – Visit 102)

> “The GP is very much involved and they’re very proactive, with that if we are we stuck with something they are there to help. And as you know they come every week which is actually much, much better. We don’t need to chase them for all these things, so everything that we have to discuss with them we actually have that when they come in so it’s all organised.” (Manager 2)

5.4 Power balance in professional working relationships

The weekly GP round, in nursing home A, was highly valued and given special status. This reflected the importance placed on medical care in both homes, with the input of GPs reported to “play a vital part” (Manager 2) and “can make or break a nursing home” (Nursing home nurse 3). The value of the GP round in terms of the continuity provided, meaning GPs knew residents well, meant that the nursing home staff adapted their daily schedule to accommodate it. Usual routines were changed, and staff resource allocated to manage the round. Two nurses, usually the managers, were directly involved and would spend time prior to the round preparing for it. Care assistants were allocated to escort residents due to see the doctor to the room where the round was held. Often no activities would take place in the activity room, on the opposite side of the corridor to the room where the doctor was located, and this space would be used as a waiting room. To some extent this normalised the process of ‘going to see’ the doctor. However, this organised work around the GPs and led to ‘social’ space being converted to ‘healthcare’ space, with priority use of the rooms given to the doctor’s round over other activities. The round also created an additional handover for the managers to update the nurses after the round and significant time was spent updating records, phoning relatives and arranging prescriptions. However, the timing of the round was wholly dependent on the GP’s schedule, with no predictable start time. One of the nurses told me there was a lot of hanging around on a Monday because of the doctor’s round. The round had a knock-on effect on other aspects of the daily nursing work, such as the evening medication round.

> [Manager] then got the doctors folder, which contains records of the doctor's visits to check these notes against the list, commenting that she needs to be up to speed on what has gone previously and what needs to be reviewed. … [Manager] then went back to preparing the room for the doctor. She took the folder and the book out of the office. I saw her a short while later carrying a plate of biscuits … in the direction of the room where the doctor sees the residents. (Field notes – Visit 006)

> [GP] arrived late, not until about 4 pm. [Manager] had been regularly for the previous hour coming back in to see if he had arrived. (Field notes – Visit 037)

> We returned to the office but the notes were still with the doctor so [nursing home nurse] was unable to record the blood sugar readings, writing them on her piece of paper with the resident names on it so she could record it later. … [Another nursing home nurse] advised me that they have a handover after the doctor's round, so as it was to be held shortly she would not start the medication round at 5 pm but wait until after the handover. (Field notes – Visit 001)

The use of time and space in this way was a source of control. Medicalisation of the environment reflected a dominance of biomedicine in most professional involvement, including in ACP (see Chapter 7). The acquiescence of the GP round falling into line with the GPs timeline reflected power relations between the GPs and nursing home staff. This can be understood in terms of monochronic and polychronic time, first described by Hall (1983) as ways that complex societies organise time and used by Allen (2002) to understand tensions in the time organisation of nursing work on hospital wards. GPs primarily worked to monochronic time, with their work generally compartmentalised completing one thing after another in a scheduled manner, even if the timings were not exact. The organisation of the nursing home work, however, was in polychronic time, involving doing many things at once with the focus on relational transactions rather than rigid schedules (Allen 2002), and thereby making the GP's work possible. Use of time is symbolic of social power with less demands made on the time of an important person and the flexing of usual routines reflecting that physician time is perceived as more important than the nurses' time (Tellis-Nayak and Tellis-Nayak 1984). Other visiting professionals similarly visited at times that suited their own schedule, with organisation of nursing home work adapting to accommodate this, inferring power on the visiting professionals. Work, including professional involvement in ACP, was organised on the terms of the professionals rather than the residents or the nursing home staff.

This hierarchical relationship between visiting professionals and nursing home staff was reflected in the behaviour of nursing home staff which demonstrated deference to these professionals and from observations it appeared that nurses worried about how they were perceived by visiting professionals. This was exhibited through the need to justify requesting input, not wanting to waste a professional's time, even when the resident was considered to be approaching the end of their life. Visits were not specifically requested for ACP, rather this was raised when the professional visited for another reason.

> [Nursing home nurse] said she struggled with this resident as to whether to call a GP or not as she said he reports symptoms such as diarrhoea or coughing up blood but there is never any evidence. … She said given his diagnoses and admission for end-of-life care she didn't want to not call the doctor and for him then to die. (Field notes – Visit 073)

Deference was also revealed through a reluctance to challenge professionals. Despite a policy in nursing home B specifying an expectation that the appropriateness of the treatment advocated by professionals would be determined by the professional judgement of the nursing home nurses and one professional expressing a wish to be challenged, a lack of confidence to question professionals was evident.

> "It works well because they will do what you suggest but that's not necessarily always a good thing is it? [Be]cause you kind of want, it's always nice to be challenged and actually theoretically they should know that client more than I do because they're there 24/7." (Specialist nurse 1)

Visiting professionals were viewed as 'experts' in both homes, one professional acknowledging that involvement of visiting professionals could be perceived as a threat by nursing home staff. A nursing home nurse talked about how easily a relationship with a professional can breakdown and that this can impact on the reputation of the nursing home.

> "You know, I don't, you don't want to be coming in and saying ooh that's not how you should do it. It should be more that you're working alongside but sometimes I've gone in, I've felt it's a little bit of a threat." (Social worker)

> [Nursing home nurse] said 'things can breakdown so easily'. … Reputation can be lost. Information about not following guidance can spread quickly. She said [most professionals] don't like being challenged. (Field notes – Visit 028)

Observations showed that nursing home nurses challenged when they had support from another professional, the balance of power tipping when the nurses were supported by a senior colleague or a visiting professional with perceived higher status. A GP suggested that his endorsement of

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ACP specifying hospital avoidance protected nursing home nurses from challenge by other professionals and supported the nurses to honour wishes expressed by residents in ACP.

Nursing home staff referred to their perception of the lower status of nursing homes within the health and social care system and the impact of this on residents, such as being a low priority for ambulance transfer to hospital. A manager's perception of their position in the professional hierarchy was illuminated by a discussion between the manager and a nurse about a professional visit during which the professional was perceived as raising unfounded criticism of a resident's care and therefore on the status of knowledge of nursing home staff.

> [Manager] told [nursing home nurse] that this is the general attitude of the NHS to nursing homes. … She said that generally the NHS treat nursing home staff as lay people and therefore that they know nothing. (Field notes – Visit 066)

Yet there were contradictions in views expressed by visiting professionals about the professional knowledge of nursing home staff which influenced their perceptions of the need for their involvement in nursing home care. It was suggested that professionals could be quick to question the actions of nursing home nurses if residents were sent to hospital when they had expressed a wish for this not to happen, yet the difficulties faced by the nurses trying to manage complex and sometimes worrying situations without additional on-site support were also acknowledged. It was suggested that there was less need for specialist palliative care support in nursing homes compared to other settings as resident needs were perceived as less complex, yet some professionals also considered that staff working in nursing homes were less skilled in this area of care than those working in other settings. Questions were also asked about the appropriateness of a request for support with managing an aspect of one resident's end-of-life care, something the nursing home nurses reported they had not dealt with in that setting before.

The rhetoric of nursing home nurses suggested that support from visiting professionals with resident care, including ACP, was generally not forthcoming and that they were "left to [their] own devices" (Nursing home nurse 1). Nurses in both homes reported issues with access, with one-off visits typical and support from some services being provided primarily over the phone. They also spoke about sometimes needing to repeatedly chase services for follow-up post initial visit. There was a widely held view amongst both professionals and nursing home staff that nursing home residents were given a lower priority for access to community services as they were 'less vulnerable' than other community residing older people. This included access to professional involvement in ACP.

> “And I think because of the assumption that when they are actually in the nursing home, they are alright, they are safe, so we can actually forget about them. So that’s what I feel with the multidisciplinary [team], you know, if they want us they let us know so then if we don’t hear from them, you will manage them OK.” (Manager 2)
>
> “You know when they’ve, someone’s in the, you know, in the community obviously we see them more vulnerable don’t we?” (Social worker)
>
> “Our residents are in a place of safety, they are getting looked after and therefore I think it’s right that we perhaps don’t have such a high priority. But I think it’s just down to the provision of community services.” (Manager 3)
>
> “The threshold for doing advance care plans in the community is slightly lower due to the fact that some of them are far, are a bit more vulnerable.” (GP 3)

However, sometimes the actions of nursing home nurses also reflected this expectation that they would manage without external support. There was a reticence to make referrals if they thought they should be able to manage.

> “I often think sometimes being called in to help with things, that the home see it as a bit of a failure, do you know what I mean? Or they feel like we, we should be able to do this.” (Social worker)
>
> [Nursing home nurse] said she thought there was reluctance on both sides. She said there have been times when she has asked to e.g. refer to the tissue viability nurse but has been told let’s just hang on another week or so. She wondered whether there was a sense of needing to be able to do things themselves. (Field notes – Visit 069)

Although policy in both nursing homes acknowledged and supported the involvement of a broad range of professionals in ACP and end-of-life care, this was not mandated. Rather, in nursing home A’s end-of-life-care policy it stated “where appropriate” and in nursing home B’s ACP policy “if the need requires”. Yet a decision to refer to another professional relied on the confidence of the nurse to assert their rationale, which was difficult for staff when challenged by a professional perceived to be in a more powerful position. A professional suggested this meant they might not get involved until there was a crisis.

> [Nursing home nurse] reported being questioned by the ambulance crew about the appropriateness of the transfer, as the resident was for ‘palliative care’. … She said it was the doctor who had advised that admission to hospital was required anyway. [She] also reported that the resident had wanted treatment and to be admitted to hospital.

> She appeared very frustrated that the transfer had been challenged. (Field notes – Visit 017)

Accessibility of services was controlled by external organisations, often imposing decisions that impacted the homes without consultation. For example, a change to the request process for GP visits implemented unilaterally by a GP practice during the fieldwork in nursing home B, caused disquiet amongst the nursing homes nurses, with a manager expressing annoyance that there had been no discussion about the plans. From the GP perspective, this was an attempt to reduce non-specific requests for visits and to make better use of the time allocated for visits but from the nursing home perspective it was seen as restricting access to medical care for their residents.

> [GP] said nursing homes are not 'special' and so the residents can't just have a home visit for 'a chat'. There needed to be a specific medical reason for the visit as there would be for a home visit for any of their other patients. He said too often they would visit and the resident would be in the dining room, so they were kept waiting whilst they were taken back to their rooms. So, they were now requesting if a GP visit has been requested that they have lunch in their room. (Field notes – Professional site visit 5)

An undercurrent of some professionals' talk about nursing homes was their being independent providers, raising strong feelings about the services being led with a business head and suggestive of a divide between private and public sector organisations. This related particularly to the expectations of residents and relatives as they were paying for a service and the funding of medical services to support nursing home provision. A GP expressed frustration about the building of new nursing homes without consideration as to the healthcare resources that will be required to support them. There was a consensus amongst participant GPs that the ideal model of a regular GP round would not happen without additional funding. However, there was a difference between the two nursing home organisations with respect to a willingness to fund such input. The GP round model had been possible in nursing home B when some NHS funding to support work in relation to frailty had been made available. However, when this ended the home reverted to the reactive model of GP provision. The advantages perceived by nursing home staff of saving routine matters for the round rather than calling a GP most days as had happened subsequent to the GP round being stopped, was not considered sufficient by GPs from either home to justify the costs of providing the proactive service. The choice not to fund provision by the nursing home organisation was perceived from both the GP perspective and nursing home staff perspective as a business decision based on enhanced GP provision not generating income or having a profit advantage. This influenced medical input to ACP. When GP involvement was funded, such as through national frailty funding, and where this funding had expectations of ACP work, GP involvement in ACP occurred. When funding was not available, GP involvement in ACP was minimal.

> [GP] said nursing homes were an issue in primary care as no-one wants to take them on as they create a significant workload. He said that although he thought doing a weekly round reduces the numbers of visits required to the home that occur with a more reactive approach, the weekly round and associated work is significant, which is why it doesn't work with other homes that do not pay for the service. (Field notes – Visit 056)

At the bottom of the hierarchy were the residents who had the least power to influence their care and which professionals became involved with their ACP. Residents' access to health and social care professionals was controlled by nursing staff who were responsible for organising access, and GPs who were responsible for making most referrals. Nursing home nurses often consulted with professionals without direct involvement of the resident, such as agreeing changes to medication. One resident expressed her concerns about this, wishing for greater control over access to professionals:

> She said she had requested an increase in the dose of her antidepressant a short while back, but this had all been sorted out by the nurses faxing [the GP] and [the GP] hadn't been to see her. She reported this as 'not satisfactory' and said she thought that a nurse can't really explain how someone else is feeling, especially as when she is depressed even she struggles to explain how she is feeling. (Field notes – Visit 102)

One resident did manage his own appointments with professionals, but this caused some issues to nursing home staff due to their lack of oversight of appointment times.

5.5 Coordinating multi-professional ACP

A multi-professional team approach to ACP and end-of-life care was promoted in the nursing homes' policies. Nursing home A's End of Life Care Policy stated that they would "work in partnership with the GP and other health care professionals involved" and nursing home B's Death and Dying Policy stated that "there is an expectation that staff looking after a resident nearing the end of their life cooperate with members of external multidisciplinary teams". However, achieving this aim was difficult due to the largely reactive, discontinuous approach of visiting professionals and the imbalance of power between nursing home staff and visiting professionals, which impacted the coordination of multi-professional involvement in ACP.

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A coordinated approach to end-of-life decision-making was demonstrated by the GP round in nursing home A where, despite these power imbalances, collegial relationships had developed between GPs and nursing home staff. The GP round offered space and time for communication, agreeing care plans and coordination of care. The start of each round included time to communicate about aspects of resident care, with these discussions assisting with coordination of care provision. For example, agreeing to stop repeated interventions such as routine blood tests when these were deemed inappropriate due to residents nearing the end-of-life and ensuring the GPs and nurses were working together. On one occasion, it was observed that a GP provided the nursing home managers with a copy of a letter from a resident's outpatient appointment informing the nursing team of the outcome of the appointment and enabling them to jointly manage the expectations of the resident's wife. The collegial relationship that developed as a consequence of the regular GP round also led to good communication outside this forum, with discussion to negotiate agreements on resident care occurring at other times as well.

> Shortly after [manager] came through to the office and updated [nursing home nurse] about a [medication] dose change. She reported that she had discussed this with the GP who had initially proposed a different medication, but she said she had told the GP that there was a chance the medication would not be received until tomorrow. The GP decided to double the dose of the current medication. (Field notes – Visit 004)

However, due to the silo approach to multi-professional working, joint working in the two nursing homes often did not extend beyond a binary relationship between two disciplines such as the GP round relationship. There were exceptions primarily involving specialist nurses and GPs, where all three disciplines were involved in decision-making in relation to the resident. However, these situations never involved all disciplines discussing the resident's care together or jointly with the resident and family. This led to fragmentation of decision-making. Discussions occurred between pairs of disciplines with separate decisions being made that were then shared. 'Knotworking' provides a theoretical framework for this approach to work organisation in which professionals tie, untie and re-tie otherwise separate threads of activity during their interactions (Engeström et al. 1999; Engeström 2000).

Knotworking describes collaborative work as situations involving constantly changing combinations of individuals distributed over time and space (Varpio et al. 2008). The concept of a knot refers to "rapidly pulsating, distributed, and partially improvised orchestration of collaborative performance between otherwise loosely connected actors and activity systems" (Engeström 2008, p. 194). This is illustrated in the resident trajectories, for example Barbara (section 4.4.1). Multi-professional input to her ACP trajectory involved a range of different professionals and in different settings, as outlined in Figure 5.1. A range of combinations of pairs of professionals interacted in the nursing home, each bringing a thread of activity into a collaborative knot which could contribute to building a picture of Barbara's wishes and preferences. Different professionals contributed to the ACP knot over time, collaborators joining and then withdrawing. Different collaborating professionals move the knot forward at different times, involving threads of activity from different inter-professional team members at different times (Varpio et al. 2008), such as the hospital team or the GP in collaboration with the community specialist nurse.

Knotworking Approach to Professional Involvement in Barbara's ACP

- Within the nursing home:
    - Most ACP involved her family and the nursing home staff.
    - There was some involvement of GPs in her ACP.
    - At least one of two community specialist nurses involved in her care was also known to have been involved with her ACP.
- ACP also occurred in the hospital setting, during a short admission due to acute illness.
- Some were professionals involved on a temporary basis. For example:
    - The community specialist nurse who visited in the nursing home for a short period discussed future treatment options.
    - The hospital team involved in her care when she was admitted discussed preference for place of care.
- There was interaction between the nursing home nurses and GPs during the visits, but this interaction was not between a constant pair of professionals. Barbara was visited by four different GPs and the nursing home nurse responsible for her care interchanged between all the nurses in the team due to shift changes and rota allocations.
- Both the nursing home nurses and the GPs interacted with the community specialist nurse, but separately.
- It was not necessarily the same nursing home nurse who was present when the CNS visited as was present when the GP visited.

Figure 5.1: Knotworking approach to professional involvement in Barbara's ACP

Barbara's ACP evolved as the different collaborators had conversations and contributed to understanding of her wishes and preferences. However, professionals contributed to ACP separately and this was not necessarily shared with all involved. At first glance it may seem that the GP or nursing home nurses had oversight of all activity, but that was not the case. For example, the hospital specialist nurses shared some information with the community specialist nurse but not the nursing home and the community specialist nurse shared some information with the GP but this was not recorded in the nursing home notes. ACP was therefore fragmented, discussions occurring between pairs of professionals at different times and in different places. It has been suggested that communication tools or documents are crucial to the success of knot-based teamwork, being important to coordinate actions (Engeström 2000; Varpio et al. 2008). This highlights the need for management continuity to bridge the gaps between the involvement of different professionals in ACP.

Collaboration between professionals is pivotal to knotworking but this takes shape without set rules or a fixed centre of control, either individual or organisation (Engeström 2000, 2008; Varpio et al. 2008). Amongst the study participants, although coordination of ACP was highlighted as necessary to ensure all agencies were aware of a resident's wishes and the information was available when needed, there were differences in opinion about who should be responsible for that coordination. The power imbalance between some visiting professionals and the nursing home team was demonstrated by their perception that they would take a lead role, although not necessarily visiting the home regularly.

> "I think the nursing home are key in the coordination … I mean I think it makes the most sense because [the resident is] actually under their roof of, um you know that I think they keep the kind of the overall." (Specialist nurse 3)
>
> "But ultimately the responsibility if you are, to answer the question, is with me as the GP, OK. That is always the bottom line. Any patient wherever they are, who's ultimately responsible in the community? It's me. OK that is, that's unquestionable." (GP 3)
>
> "I think if we're already known to the patient and the patient's families, there is an expectation that we would kind of lead, we would continue to lead the [ACP] conversations." (Specialist nurse 1)

However, in practice ACP was seen to be left to the nursing home staff, unless they actively sought involvement of other professionals. Indeed, a professional suggested that her approach to ACP was different for residents in care homes compared to those living in their own homes because the care homes were seen to manage it.

> "Doctor [name] hasn't said oh this is, this is my plan for the, this is how things will develop. No, not really. It's been left down to [nursing home] to deal with it." (Relative 3)

> “I don’t tend to do that as much when they’re in a care home, because the care homes normally manage that, but I do sometimes.” (Specialist nurse 2)

Even with the collaborative nature of the GP round model the relationship was not necessarily equal. Decision-making that extended beyond the binary relationship of nursing home team and GPs sometimes excluded the nursing home team from aspects of the decision-making meaning nursing home staff knowledge of residents’ medical conditions and end-of-life preferences were disregarded. Concerns of the nursing home nurses about the advice from professionals were not always heard, reflecting the power imbalance. As a consequence, care was fragmented and less than ideal.

For example, in one case a palliative care CNS was involved in the care of a resident discharged from hospital for end-of-life care. The nursing home nurses had concerns about the appropriateness of the advice from the CNS, as it conflicted with the information provided by the hospital on discharge. They received no information from the hospital about what, if anything, had been discussed with the resident regarding wishes and preferences at the hospital.

> [Manager] described the discharge as poor, ‘flimsy’, with a lack of information and incorrect information. She has been given advice by a [CNS] but concerned that this may not be best for resident in terms of comfort/enjoyment. [CNS] due to visit next Wednesday. [Manager and nurses] said they were unaware of any discussions that have been had at the hospital and the resident has commented "making me better". … They were continuing based on telephone advice from [CNS] even though [manager] was questioning this. (Field notes – Visit 021)

Discussions between the CNS and the GP away from the nursing home led to a change in the resident’s medication, which caused further unease within the nursing home team. The nursing home nurses were also aware that the CNS was speaking with the resident’s family and were worried that information provided by the relatives contradicted their experiences of caring for the resident.

> [Nursing home nurse] spoke about her concern about a resident … and her concerns re the appropriateness of the medications. She thought [specialist nurse] was listening to the family but not to the staff, with the family reporting agitation that she said the staff say is only present when the family are there. (Field notes – Visit 028)

The medication and management plan were not altered when the managers discussed their concerns with the GP at a GP round. The manager thought that the change in medication was hastening the resident's decline and the explanation given for the change did not appease her concerns. The nursing home nurses felt powerless to influence the care of the resident and were left struggling with the management of the resident's care.

> [Two nursing home nurses] spoke about the poor communication. In this case they said that they are not sure what [specialist nurse] is saying to the family. The family have also asked that end-of-life care is not discussed with the resident directly. This makes it difficult with end-of-life care decision-making and knowing what the resident and family know. (Field notes – Visit 023)

Cross-boundary working such as between nursing home nurses, GPs and hospital consultants could also create challenges, knotworking again causing fragmentation and disempowered nursing home nurses left struggling to plan care with the resident. For example, in nursing home B one resident had a scan at the hospital following deterioration in his health, organised by his hospital consultant. Binary interaction in the form of a hand-written letter from the consultant kept the nursing home informed that it was expected that the scan would confirm the resident had a short prognosis, something subsequently confirmed to the nurses by the GP. The nurses talked about needing to put plans into place to ensure the resident was managed appropriately and to review his ACP in light of the change in his condition. However, they felt powerless to act as the resident had not been informed of the scan result. The GP wished to discuss the scan results with the consultant before agreeing an ongoing plan. The resident was known to the palliative care CNS, but the nursing home team had not informed her because they did not think it was their place to do so as the GP and consultant were dealing with the situation. A lack of coordination between the actors involved led to the resident waiting more than a month before receiving the scan results, a time when the multi-professional team could have been putting plans, including ACP, in place with the resident.

> [Nursing home nurse] thinks they probably need the hospice involved. … She said she hasn't contacted her [specialist palliative care nurse] as the GP is currently trying to liaise with the consultant and so she doesn't want to contact [CNS] as the GP is dealing with it. She is concerned though that they don't have a plan and says the GP is too, as she says it would not be appropriate for him to be sent to A&E if he was to have a fit or something. (Field notes – Visit 109)

An approach for coordinating end-of-life care provision in the community setting is GSF meetings[7], which bring professionals together to make decisions. However, although nursing home residents would be discussed at these meetings, a GP admitted that nursing home nurses were not included in these meetings. A palliative care professional suggested that a meeting similar to the GSF meeting should be held in the nursing home, so all nursing home residents are reviewed by the multi-professional team regularly.

> “There’s representatives from [specialist palliative care service] and there’s representatives from the surgery and the district nurses actually. Because obviously lots of patients will be in a home but there isn’t a representative from the nursing homes, which is a little bit of a pity I suppose because we are discussing end-of-life patients in the nursing homes. And therefore they, they’re not represented which is a pity and that might be something to consider.” (GP 3)

5.6 Chapter summary

This chapter has presented findings that depict a disjointed system in which multi-professional working and ACP occurred. It has shown that relationships were considered important between residents and professionals for ACP and that relationships between professionals were important for sharing ACP information, but that the knotworking approach to multi-professional working was not conducive to relationship continuity. The structure and organisation of both nursing home and visiting professional care, and the accessibility of visiting professional services, disrupted management continuity, limiting information-sharing and coordination of ACP. Multi-professional working and enactment of ACP was influenced by an imbalance of power in the professional and system hierarchies. The findings suggest that this led to ACP and end-of-life care decision-making being fragmented.

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[7] GSF meetings are regular multi-professional case review meetings, when all patients on the GP practice’s palliative care register are discussed, to ensure each patient has a management plan (Free et al 2006).

Chapter 6 Enacting ACP

6.1 Introduction

This chapter presents findings that demonstrate how the enactment of ACP impacted on multi-professional involvement in the ACP process in the two nursing homes. The process of ACP, involving discussion of wishes and preferences for future care with residents on more than one occasion over time, documenting expressed wishes and reviewing these decisions over time, functioned as part of the organisational routine of care planning in both nursing homes. In nursing home B, ACP was an organisational routine in its own right as it was "repetitive, recognizable patterns of interdependent actions, carried out by multiple actors" (Feldman and Pentland 2003, p. 95). Findings show that operationalising ACP influenced both the level of involvement of nursing home staff and visiting professionals and how the different professionals worked together. There were differences between residents and professionals, and between professionals in how ACP was described and accounted for. There were a number of challenges encountered in enacting ACP including: finding the 'right' time to have discussions; the need for competent and confident staff with the time to have the conversations; and a lack of unified understanding as to what constitutes ACP shared by all involved. Findings are interpreted using the lens of the ostensive, performative and proxy aspects of ACP routines (Pentland and Feldman 2005), highlighting the differences between these aspects.

6.2 Timing of ACP conversations

Although some conversations were initiated by residents or relatives, health professionals needed to initiate discussions to understand resident wishes, particularly in relation to medical treatment and goals of care. There was a difference in residents' approach to planning for personally relevant matters, such as funerals and family, and their approach to health decisions. While they perceived things as going well, despite advancing age and in one case significant illness burden, most residents tended to focus on getting on with life. Residents talked about planning for their future health needs in terms of "[I] take it as it comes" and "[I] never ever thought about it, never ever entered my mind". Residents were therefore unlikely to instigate these discussions themselves.

> "I don't know because I feel so well … if I was really feeling ill I'd probably start making plans for, you know, what's going to happen to me, but it hasn't got to that stage. And we haven't discussed it or … I haven't thought about it even." (Resident 2)

Areas of future planning such as making funeral plans and writing a will were often commenced long before residents moved into residential care. Residents talked about this in terms of 'putting their paperwork in order', wanting to make sure this was organised and items considered to be heirlooms or of value were passed on within the family. These issues were therefore perceived as practical arrangements and something they had undertaken almost as a matter of course, as part of growing older. Five of the six participant residents were widowed and so dealing with funerals and finances after a death was something with which they were familiar. The personal nature and level of detail of some of these plans suggested that the importance placed on recording funeral and financial preferences reflected the value to residents of having these wishes respected. These plans demonstrated personal significance: one resident put in place arrangements to ensure that both her ashes and those of the family dog were placed with those of her husband and another had chosen which photograph of her to use on her funeral order of service.

> She said she had been quite detailed in some of her funeral plans, such as she had already chosen the picture to go on the order of service. She said she had been to a friend's funeral and the picture of her on the order of service had been awful. It had been chosen by her family, but all of her friends agreed that it wasn't a good photo. She therefore wanted to make sure she looked OK in the photo on her order of service.
> (Field notes - Visit 046)

The number of residents appointing a power of attorney to manage their finances also showed the value placed on financial matters, compared to health matters. More residents in both homes had appointed a power of attorney to manage their financial affairs compared with the number of residents who had appointed an attorney to make health decisions on their behalf. Of the six participant residents, only one had a power of attorney for health and welfare in place, whereas at least three were known to have appointed a finance attorney.

However, in one case something that appeared to have personal significance for a resident had not been discussed with family or professionals or recorded by the resident in relation to her funeral plan. The resident discussed with me on several occasions how she would like similar flowers to the flowers she carried on her wedding day at her funeral. She would point these out in her wedding photo that hung on her wall, commenting on how special they had been to her.

However, although she had written her will and quite detailed funeral plans, she said she had not told anyone about the flowers and wasn't inclined to do so. I was unable to gain any sense as to why this wish differed from others and why it had not been included with her other funeral plans.

Occasionally, residents did open the discussion with professionals in relation to health matters but again this reflected a particular importance being placed on the issue. One of the participant residents was keen to ensure that no attempt was made to resuscitate her and had seen her GP whilst still living at home in the community to have a DNACPR form put into place. However, these were exceptions. More often residents stated that they had 'not thought about it'.

> "I haven't discussed anything with anyone. I haven't found it necessary I suppose." (Resident 3)

This approach was particularly evident in the way residents talked about how the decision was made to admit them into residential care. Most moved to the nursing home from hospital or hospice, with the decision based on a more acute change to their health which had impacted on their ability to manage at home. Nursing home care was not something they had thought about or given serious consideration to previously. Being acutely unwell also led to many residents having limited involvement in the choice of care home. Only one resident had planned her move into residential care.

> I asked her [resident] if she had ever thought about admission to a nursing home prior to her hospital admission last summer and she said no. She said she had been well and managing, getting out to the shops so why would she have done. It was only since that admission that she has been much more limited by her mobility. (Field notes – Visit 091)

A lack of future planning was due, in part, to the unpredictable trajectories to the end of life of older nursing home residents. There were inherent difficulties in discussing wishes relating to care and treatment in advance when it was unclear what health concerns they might face. This was particularly problematic for residents living with frailty rather than a specific terminal condition. Unless residents had encountered a medical situation often they had not thought about choices relating to medical care. Two residents had refused surgical treatment options, having discussed this in hospital prior to admission to the nursing home but for other residents, options were not so specific at the time of discussing ACP. One resident described how she had changed her mind about the medical treatment she would want to consider in the future but only after she had received treatment that she regretted undergoing. Her decision to refuse further hospital treatment and request a reduction in oral medication was a consequence of life-prolonging treatment that she received during an acute admission which, had she been well enough at the time, she would have refused. She said until that admission she had not considered refusing treatment.

> "They gave me blood transfusions. I wish they'd never done it. But I didn't, I wasn't in a, in a fit state to refuse anything but I certainly would never want it again." (Resident 5)

Nursing home nurses also identified residents who refused to talk about their wishes until they were facing deterioration and struggled to identify with medical issues they might encounter. One nurse described this as "you sort of draw a blank" (Nursing home nurse 5). The following field note extract documents the thoughts of a nursing home nurse following an ACP discussion with a resident and their relatives:

> She told me she had been discussing the resident's advance wishes and she had found it hard and advised that she had not got much information. She said she thought the main issue was not knowing what might happen in the case of a resident such as this who didn't have a specific illness but was very elderly and frail. She said even asking broad questions to open up the discussion that she thinks discussions are easier for residents and relatives when there is something more concrete to think about in terms of a situation or condition they may face and thinks it is very difficult to think about what care you may or may not want when you don't know what you may or may not need. She said the response of the resident and family she had had the discussion with was to 'Take it as it comes', 'Deal with it when it happens'. (Field notes – Visit 058)

A relative of a resident with a known life-limiting illness also spoke about how changes in his mother's condition meant that ACP discussions could have been held too early.

> "There's been no discussion about what should happen towards the end situation ... I would hope that on a professional basis that if they felt the situation was deteriorating, they would contact me and [at] that point perhaps we would then discuss how things should go … My feelings are that that would happen at a point in the future … I mean I'd be quite happy with that and, and you know we could do it now, but the trouble is that the situation could change … I could have had this discussion with the hospital before Christmas and I would have thought I need to really, because you know something could occur. But then everything changed … things transpired that they were slightly different then the whole thing changed." (Relative 3)

His expectation appeared to be that the nursing staff or a GP would identify an appropriate time to have a discussion, an expectation shared by other relatives and residents. In this way, ACP was seen to be the responsibility of professionals by relatives and residents.

The belief that there was a right time to open discussions caused difficulties for professionals who found it a challenge to identify this time. One nurse, who took a lead on end-of-life care within nursing home A, stated that she still found it hard to know when was the right time ‘despite all the training I’ve had’. GPs also recognised that the timing of the discussion was difficult because it was not something that residents necessarily wanted to discuss on admission but as they could become unwell so quickly, it was easy to miss the opportunity.

> “I mean I have known a couple of incidences where I think GPs have thought oh may be somebody else has had that conversation or it’s something that … we can worry about later and then there’s been the sort of change that, so I, I think timings has got quite a lot to do with it.” (Specialist nurse 3)

It was impossible to predict when a resident might deteriorate. A GP suggested that no death in a nursing home was a surprise as people are old and frail, but sometimes death occurred when not expected. Some residents rapidly deteriorated and died within one to two days, with infection a common cause of rapid deterioration to death. Such as for a resident described as ‘a little wheezy’ one day, who died two days later following diagnosis with a chest infection. Equally, there were many times when a resident who was thought to be dying made a full recovery. One resident who was mobile and alert suddenly became uncommunicative and needed hoisting back to bed, yet the next day she was up and around again. There was inherent uncertainty about identifying a resident as dying.

> “But it changes so much though, doesn’t it? Once they can be really ill almost at death’s door and then they can come to life again. Like [resident] last week, I didn’t think I’d see her here when, the day when I came back. But low and behold she’s back to her normal self again.” (Nursing home nurse 5)

> “And ah being ninety in a nursing home, and you can’t predict what’s going to happen.” (GP 3)

Finding the right time was more of a concern to staff in nursing home A than in nursing home B where ACP formed part of the admission process and the regular care planning review process, so it was an accepted part of their care planning. Nursing home A’s ACP policy suggested discussions should happen as soon as possible after admission but also acknowledged that many discussions take place when deterioration is anticipated. Nursing home staff and some visiting professionals admitted that due to the sensitivity of the topic often it was easier to raise the issue when a resident’s condition had deteriorated in some way.

> “With our policy it says that as soon as possible we have to actually discuss that. But the timing should actually be right I think with that aspect.” (Manager 2)

> I also asked her [nursing home nurse] about discussions regarding avoiding hospital admissions and again she said it would be primarily the doctor. She said there was no set time for such discussions but usually if something indicated that something might happen. (Field notes – Visit 034)

> “I think he feels he’s the best he can be at the moment, you know he doesn’t want to talk about perhaps what happens if you were to deteriorate and in a, in a few weeks. But with my role is that I am around to have that conversation with him should he take another deterioration.” (Specialist nurse 3)

There was a tension in how ACP was operationalised by residents and by staff. On the one hand, residents did not want to think about treatment and care decisions until their condition deteriorated and they knew what they were facing. On the other hand, professionals waited for the ‘right’ time to discuss ACP, believing there would be time for this conversation when the resident’s condition deteriorated but before they were too unwell. They were more comfortable with opening discussions when there was an identified reason for this, perceiving that the discussions might otherwise upset or distress residents or relatives. Nursing home nurses and some visiting professionals talked about ACP discussions raising concerns with residents and relatives because of the association with dying, making them question when was the best time for such conversations. In both homes, having an ACP discussion immediately on admission to the home was considered a challenging time, due to the link between ACP and dying. It was thought that introducing ACP at this already stressful time could lead to negative perceptions of the home.

> “Often, it’s not, it’s not always easy to engage, is it? Because once you start having those sort of discussions … the client often puts that with that they’re deteriorating, for you to be having some of them conversations. So, I try and have it as early on as possible.” (Social worker)

> “I think we should be getting an idea from the resident perhaps when they come in but it’s not always appropriate. Because they’ve come in here because they’re not managing at home, and they’ve come in just to manage this stage of their life. And I suppose with some of them they might be taken aback with discussions around advance care planning.” (Nursing home nurse 2)

> "It's difficult when they've sort of moved from a hospital to a nursing home situation. You don't want to sort of frighten them off on initial by sort of asking them all of these questions about advance care planning and that. … I'm leaving it for another while because even his son, I think, doesn't want to even think about it at the moment. Cause he's got all these other things to deal with. … So, it's all too much I think when they're first admitted to a home." (Nursing home nurse 5)

Yet in nursing home B, the managers routinely raised the topic with all individuals that they assessed for admission. They admitted that for some of them it was a bit of a shock as they did not see themselves as ill or dying. This was particularly considered the case for those being admitted for respite or into a residential care bed. However, there was tacit agreement that having the conversation whilst a resident was well and as part of the admission process was the best approach.

> I asked her [nursing home nurse] whether residents were willing to engage in advance care planning and she said yes. It is done soon after admission. She said that residents admitted for respite don't understand why they are being asked the questions and think that if they become sick, they are not going to call an ambulance. She said it takes some explaining. (Field notes – Visit 074)

> "I think it's better that they do it when they are able to think about it rationally and not when they're feeling pretty poorly or if at a point you go and say 'can we do this?' It's like oh my goodness she thinks I look a bit dodgy and, and that makes them anxious. So, we do it as a kind of a normal part of the process." (Manager 3)

These worries about timing and about starting the discussions were visible in the way a discussion could be put off from one day to the next in nursing home A and by nurses seemingly hiding behind the paperwork in nursing home B. Often the ACP form would be passed to the resident to complete along with a range of other forms that required completion at the time of admission with the nurses, thereby ensuring they fulfilled the organisation's requirements to seek the views of residents. Instigating a specific face to face discussion did not appear to be the norm as suggested in how ACP was talked about and the home's policy. One relative reported that she and her father had completed the form between them and then handed it in to an administrator. There had not been any discussion with a member of the nursing team. The ostensive routine thereby varied from the performative routine. The ostensive aspect of a routine is characterised as the way participants account for and refer to specific performances of a routine and the performative aspect is considered to be the actual performance of the routine by participants, which create, maintain and modify the ostensive aspect (Feldman and Pentland 2003; Pentland and Feldman 2005). Artefacts, such as written procedures or work records, serve as a proxy for the ostensive or performative routines (Pentland and Feldman 2005), ACP policy thereby being a proxy routine.

> Discussing the end-of-life care conversations she needed to have with two residents, [nursing home nurse] said that the timing of the conversations was difficult and often they were ‘put off’. (Field notes – Visit 012)
>
> “I came in here one day, and he’d only been in a while, and he said you need to fill this form in. We need to do it together.” (Relative 1)

Despite these difficulties in identifying a time to have a discussion, a significant amount of ACP happened in the two nursing homes for the participant residents as depicted in the trajectory maps presented in Chapter 4. One resident had the majority of ACP completed in another setting, triggered by him appearing to be entering the dying phase, but this was reviewed by the nursing home in light of his transfer to their care and an improvement in his condition. For many residents, declining health status was a trigger for initiating or reviewing ACP, indeed the resident with whom the least ACP had been completed had been stable following a significant improvement in his health after admission to the home. However, in terms of these nursing home settings it was transfer into this setting per se rather than a change in health status that triggered discussions. For several residents, some ACP was done on or within a short period of their admission to residential care, which included gathering information about ACP completed prior to admission.

Difficulties with timing did not only apply to the initial discussion. In both nursing homes there was also a lack of clarity about reviewing ACP decisions. Policies of both homes, the proxy routine, outlined that ACP should be reviewed. However, the performative routine varied from this. In homes A and B, although all care plans were reviewed monthly, this did not appear to routinely involve a review of ACP. In nursing home B where all residents had an ACP/end-of-life care plan, the care plan was reviewed but this did not necessarily mean the ACP document itself was updated. Care plans were generally updated if there was a known change with the evaluation otherwise indicating ‘care to continue’, ‘no changes’ or something similar. There was a review date space on the ACP document but the guidance for completion of the document provided no direction as to how often a review should be completed. One participant resident’s ACP document did not appear to have been reviewed since her admission three years before the fieldwork and there did not appear to be any involvement of visiting professionals in reviewing

ACP. This was acknowledged by one professional who suggested that the palliative care team should be involved in checking with residents whether their views had changed.

> "I don't know whether there should be a review of it because some of the advance care plan if you see they're [in place for a] long time you know. So maybe at, I don't know whether there should be a review date." (Manager 1)

6.3 The work of ACP requires confidence, competence and time

Although ACP discussions with residents by nursing home nurses were observed in both homes, several nurses were reticent about having these conversations. This was linked to general disquiet about death and dying in both homes, but particularly in nursing home A. This unease in dealing with death and dying was described by nursing home A staff when discussing the number of deaths they had had in the home over a short period, implying that too much end-of-life care was depressing. Although end-of-life care was accepted as part of their work, they did not want this to be their main focus. In this home, living and keeping residents going took precedent, as highlighted by the comment of a nurse:

> [Nursing home nurse] then said to me that [another nursing home nurse] was making people iller [sic] than they were and that you need to keep people getting up otherwise they will just deteriorate. (Field notes – Visit 043)

A palliative care professional suggested that staff in nursing home A were hiding dying, yet there was some acknowledgement of death and dying. CQC reported that residents were offered the opportunity to raise a glass to a deceased resident and share memories during lunch in the dining room. There was also acknowledgement in nursing home B where a simple sign announcing the death of a resident was seen to be placed outside the dining room. However, the perception that death is a taboo subject pervaded. Staff felt restricted from engaging with ACP by concerns that raising the topic of end-of-life care would not be well received, the emphasis of care provision in the homes being on living.

> [Nursing home nurse] then discussed how death was so taboo and compared it with her home country, where she said they were much more open about death and dying. She said it was a big thing to just launch on someone out of the blue and suggested that it was easier if it came up in conversation when she was doing care for the resident. (Field notes – Visit 012)

> "They're like, you know, if you, even if you ask them have you got a [colour] form, DNAR form, no are you saying that, am I going to be OK in your place, you know? So, I think it

> is still, there is a stigma of talking about it. You know, what do you want to, have you planned? I don't think many people accept that." (Manager 1)

The emotional reaction of relatives, who were frequently involved in ACP discussions, particularly impacted on staff willingness to open discussions. A nurse suggested that the difficulties faced in having these conversations varied depending on the closeness of the relationship between the relative and the resident. The emotive and unpalatable nature of ACP was acknowledged in my conversations with relatives, whereas residents were often willing to speak quite openly about death and dying.

> "I just listened to what Dad said and because it's not a very nice topic is it? You tend to brush it under the carpet." (Relative 1)

Professionals also talked about reticence of nursing home staff and a fear of having ACP conversations, but linked this to staff competency. Whether the staff had the competence and confidence to have ACP conversations was talked about by specialist palliative care staff in particular. One spoke about the skills staff needed for such discussions and whether the nurses feel that they do not have the skills to initiate conversations. There was also a suggestion that it related more to confidence and that specialist palliative care practitioners could have a role in instilling that confidence.

> "What I've seen … is that there seems to be a reticence and er may be a fear of delving too deeply." (Specialist nurse 1)

> "I think sometimes they almost just want somebody to give them permission to have that conversation. So, I think sometimes my role is a bit about instilling a bit of confidence in some of the staff." (Specialist nurse 3)

Training to support staff with ACP had been made available at both homes, with the Six Steps to Success programme[8] in nursing home A and internal training in nursing home B. Both these training methods involved a cascade approach, with a manager in nursing home B stating it was not an expectation that everyone will be trained in ACP. A manager spoke about how her confidence in initiating ACP discussions had increased, initially finding this uncomfortable and difficult to do but over time becoming easier. A potential explanation for the observed differences between the ostensive and performative routines in relation to timing of ACP

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[8] Six Steps to Success Programme is an education programme based on the six steps of the end-of-life care pathway outlined in the End-of-Life Care Strategy (DH 2008), which aims to enhance end-of-life care through facilitating organisational change (The End-of-Life Care Partnership 2021).

conversations could therefore be related to staff competence and confidence. The ostensive action of always asking about ACP at pre-admission assessment became more embedded in the performative routine for this manager as her confidence increased, although this was also influenced by organisational expectations that ACP would be discussed pre-admission.

Competence and confidence to open ACP discussions was important because of the need for conversations about medical related matters to be initiated by professionals. One nurse lacked confidence exacerbated by hesitancy about whether it was her role to have these conversations. She had experience of being involved in ACP in a previous job but identified her manager as taking the lead in this area of care in the nursing home.

> “Well, I think so [be]cause I felt that I had to refer it back to [the manager] because she takes the lead in it.” (Nursing home nurse 2)

Within this home the manager had oversight of all resident care, and although the other nurses were involved care was directed by the manager. This management style influenced the division of labour between the nurses and the managers with regard to ACP, impacting on this nurse in particular who was torn between wanting to be involved in ACP and thinking it was not her role. The manager herself considered ACP to be something all her staff would be involved with, which was also reflected in the home’s policy. However, her frequent involvement in ACP discussions meant other staff did not often get involved unless there was a clear delegation of responsibility, as was the case for the nurse who was the nominated lead for end-of-life care.

The level of knowledge of the person engaging in ACP was also seen to have an impact on what was recorded. A resident in one home was advised that while she had documented it was her wish to donate her tissues or organs, this would not be possible because of her age. Yet in the other home, the same request from a resident of a similar age had led to the resident being put on the NHS Organ Donation Register and contact being made with the tissue donation service to discuss what it might be possible for the resident to donate. Organ and tissue donation did not appear to be routinely discussed, although tissue donation was mentioned on the ACP document given to residents in nursing home B. A script for ACP discussions formed part of the ostensive routine of ACP in both nursing homes, in the form of the list of topic areas included in the ACP documentation, the content of ACP being informed by the document. This script was more extensive in nursing home B, reflected in the inclusion of organ donation which was not specified on nursing home A’s script. However, as the performative routine of ACP in nursing home B was mostly dependent on residents completing the document themselves rather than it being a professional discussion, the topic was only raised if it was identified as an issue of importance to the resident. Likewise in nursing home A, given the absence of specific reference to organ donation on the script. Indeed, organ donation was recorded for these two residents because it was something they particularly wished to do but it was not mentioned on the ACP of any of the other residents. This suggests that if a resident has not articulated a particular issue, then ACP could be limited by extent of the discussion initiated by the professional, informed by their interpretation of the script, and dependent on their level of knowledge of each potential area of ACP.

Another barrier was time. It was acknowledged that to do ACP well, nursing home staff and professionals needed to have the time to do this. Visiting professionals were often focused on a specific task and time limited due to their specific temporal structuring. Temporal structuring, as described by Orlikowski and Yates (2002) and referred to in Chapter 5, suggests that time is realised through recurrent practices that produce temporal structures. For example, visits from GPs outside a GP round situation were dictated by the well-established temporal structure of a typical GP's day with home visits taking place between morning and afternoon surgery, something routine in General Practice beyond the specific practice involved. Visits were sometimes described by the nursing home staff as rushed and a resident commented that she did not think GPs had time to have ACP conversations, but time availability for ACP was understood and potentially limited by the temporal structures. The temporal structure of reactive GP visiting did not align easily with the temporal structure of day-to-day life in the nursing homes. This was highlighted by a request from a GP practice working with nursing home B for staff to ensure residents for whom visits had been requested were available when the doctor arrived. The GP practice had specifically requested that residents were in their rooms and not in the dining room, with a nurse available with the medication chart, for two hours over the lunchtime period during which the visit might occur. However, a specialist nurse also considered time available during a GP round could be limited.

> "But you know to do it and to do it well it takes time and that's, that's the one thing that none of us have a surplus of. Um we just don't. And, and you know GPs are very busy people." (Manager 3)
>
> "And therefore to, the time then to sit down and do advance care plans is … so time is a limiting factor, workload is a limiting factor." (GP 3)
>
> "Obviously, some homes have a kind of contract with a GP so they might be going once or twice for sort of ward rounds. I think sometimes in those instances they don't have, you know again they come into a home and need to see ten people and would be perhaps a little bit put off by sort of thinking they're going to need to have a, you know,

> a long conversation, especially if they're not that familiar with, um you know, that resident. I mean [be]cause obviously sometimes if it's a new resident they might have come from out of area, might be whole new GP practice." (Specialist nurse 3)

Sometimes the nursing home nurses appeared to avoid having ACP discussions but there are likely to have been many reasons for this including professional issues such as lack of confidence and organisational factors such as division of work and understanding of roles and responsibilities. Doctors were also perceived by the nursing home nurses as avoiding difficult conversations particularly with relatives and needing to be more proactive in having ACP discussions, which again might have been for many reasons.

> [Nursing home nurse] mentioned that [resident] often talks about death, saying things such as 'why doesn't he take me?' [Nursing home nurse] talked about trying to make the conversation go on a different track when she does this. (Field notes – Visit 005)

6.4 Lack of shared understanding of ACP

Nurses in both homes were involved in instigating ACP discussions with residents and/or relatives to a greater or lesser extent, so as to complete their paperwork relating to ACP, with such discussions forming part of what was required of them as outlined in organisational policy.

> "[Organisation] expects that all homes support residents and their loved ones to complete an advance care plan with a record of the resident's wishes and preferences." (Extract from Death and Dying Policy, Nursing home B)

These specifically arranged discussions were clearly understood as ACP by staff. Two residents in nursing home B also identified with their involvement in ACP due to being given an advance care plan form to complete on admission, although one participant was less sure.

> "Well I did [fill out forms] when I first came in but don't ask me about them now because I wasn't really in a good state of mind." (Resident 6)

As such, the ostensive and performative routines of ACP were constructed by the nursing home staff through the process of completing documentation. However, ACP was not just a nursing home organisational routine and there was not one unified ACP process for both visiting professionals and nursing home staff. ACP was seen to be documented separately to the nursing home record by visiting professionals and discrete ACP documents completed by GPs.

Enacting ACP

The process and products of ACP were owned by professionals rather than residents. Professionals worked to their own organisational procedures relating to ACP demonstrated, in particular, by the existence of ACP documents in use by healthcare professionals in each of the localities, as referred to in section 5.3. ACP documents were seen as organisational documents and held by the professionals in each organisation. Professional involvement in ACP was also determined primarily by nursing home staff and other professionals. Nursing home nurses would seek GP involvement in their ACP process if, for example, a DNACPR form was required and an example of involving a Speech and Language Therapist was shared by one of the managers, where their involvement was required to ensure the nurses were protected when implementing his decision as he wanted to continue to eat and drink as normal even if this was done at risk.

The nursing home process for ACP was controlled by the nursing home organisations through their documents. In nursing home B organisational control was particularly overt with a corporate approach, policies and procedures not being home specific. Detailed guidance was provided for completion of documentation, with a demonstration folder providing guidance notes cross-referenced to policy on how resident notes should be structured and giving examples of care plans. A manager stated that "we have standardised care throughout all of our care homes" (Manager 3), the corporate approach clearly demonstrated by a manager talking about not being able to use an ACP form completed prior to admission, with a need to re-write this. She suggested that there needed to be a national version of an ACP document, in a similar vein to the DNACPR form which was used across a large region in which the home was located, commenting that the organisation would not change the DNACPR form.

> "Sometimes we might need to, even though we cannot use that form because the company needs their own form to be used but it is there as a guidance and you've got information there and it's kept there, you know. Even though we use, we fill in, re-fill in a form um it's there." (Manager 1)

However, one of the nurses who worked between more than one of the organisation's homes advised that although the documentation was the same in all of the homes there were differences in how it was used. This suggested there was divergence between the proxy routine and the ostensive routine in each nursing home, through local variation in the application of policy and procedure.

There was a greater sense of autonomy in nursing home A. Although the same documentation and policy was in place across all the homes in the group, the nursing home had some discretion in how they were implemented locally. This suggested power was more distributed than in the organisation running nursing home B. The managers considered what would work best in their environment, with a discussion between the managers and the nurses about new audit processes that had been brought in by a regional manager, suggesting implementation was not controlled by head office decisions.

> There was a discussion between [manager and nursing home nurse] about new audits they were required to complete. … [Manager] advised [nursing home nurse] that the nurses were not to complete the new daily medication audit as she had raised some questions about it, but to continue with the weekly audits that they usually do. (Field notes – Visit 047)

On one occasion, this autonomy was threatened by head office intervention. The nursing home staff outwardly expressed their irritation at the attempt by the organisation to impose too much control over the local actions in the nursing home:

> [Manager] was in the office later when the list [care plan and medication sheet 'problems'] provided by the member of staff from head office was still being discussed. She was quite fired up and appeared frustrated that the list was ever written. (Field notes – Visit 012)

Not all future planning was dictated by the nursing home ACP documentation and explicit ACP processes, however. Some ACP for five out of the six participant residents was discussed as part of general care planning or the regular care plan reviews required of nursing homes by CQC. When ACP was amalgamated with care planning in this way, it was not always understood as ACP by all involved. When I discussed ACP with a resident's daughter, she could not identify any future planning undertaken by the home staff and saw the approach more as taking each day as it comes. However, her father's nursing home notes revealed that his views on whether he would wish to receive treatments only available in hospital were discussed with both of them as part of a general care plan review.

> "I had quite a few meetings … just about his general care and settling in and so on. But I don't think we've actually talked particularly about any planning as such." (Relative 2)

In nursing home B, reviews of ACP would take place as part of a care plan review, but residents did not necessarily understand this to mean they had had an ACP discussion. I talked with a nurse about amendments she had made to an advance care plan following a discussion with a resident, something she had undertaken as part of the monthly care plan review. She said she had reviewed the content of the ACP document with the resident, clarifying that what was recorded remained accurate and adding some further detail relating to choices about hospital admissions. However, when interviewed for the study this resident suggested that he had not been involved in any ACP discussions. He could not recall any conversations about his wishes for future care had taken place, either with the nursing home staff or visiting professionals. The following excerpt from my research diary reflects on this following my interview with him:

> During the interview his answers to the questions appeared to indicate that he hadn't had any ACP discussions, although there was ACP documented in the home. He commented in relation to his request for cremation in his will that it was mentioned in passing to his daughter. On reflection it appears that he didn't consider any of his conversations as "discussions" more just part of day-to-day conversations with the nurses. (Extract from research diary – Visit 095)

The ostensive routines in both nursing homes placed ACP as a discrete entity. Recognised ACP discussions in nursing home A were set up as standalone meetings and in nursing home B, the entire process, including documentation, marked it out as distinct from other aspects of care. However, the operationalisation of ACP was not always discrete. Although the proxy routine outlined in nursing home A's ACP policy promoted ACP as integrated with the wider care planning process, interestingly, when this happened in practice it was not always recognised as ACP by staff or residents. Likewise, when ACP occurred as part of general consultations or care planning discussions in nursing home B, it was not identified as such. The integration of ACP into more general care planning could also happen as a natural part of conversations between professionals and residents. A specialist palliative care nurse described how a referral she had received from a consultant had included ACP information which appeared to have come from a conversation between the doctor and the resident about diagnosis and prognosis, rather than a planned ACP discussion. One participant professional also initially suggested that she rarely became involved in ACP in nursing homes, with her understanding of her role with residents relating to symptom management. However, on talking about how she might manage symptoms, she spoke about how such conversations might naturally lead to decisions regarding whether treatment should be escalated to hospital. Through this discussion she developed an alternative interpretation of her involvement with nursing home residents and suggested that she probably did get involved in ACP more than she thought.

> "I'd say to them you know it's not safe to do this here and the safer place would be to do it in hospital, and they say no, no, no. Well then, well what would you prefer? Would you prefer just to leave things as they are and get worse or, and then you would

> go on and have that discussion with them again. So then yes I would I suppose get involved." (Specialist nurse 2)

This blurring of ACP with care planning could lead to a lack of shared understanding of ACP between professionals. The way this professional had initially interpreted her involvement with residents, was also the understanding of her role in ACP held by other professionals. One of the nursing home nurses did not think this professional would be involved in ACP, considering GPs and palliative care professionals as those who would be involved. Also discussing professionals who participated in ACP with a GP, his perception was that this specialist nurse did not have ACP discussions with her patients.

> "No. She will deal with [their illness] and their medication and liaise with the hospital consultants but she's not involved in advance care planning." (GP 3)

Although she would always discuss the outcome of her visits with the resident's GP, which by nature of her example could include providing information about future treatment wishes, this was not understood as ACP by the GP. This meant that it was possible that such resident decisions might not be recorded as ACP and in a place where they would be readily available to inform care decisions.

Many professionals also talked about 'informal' ACP appearing to differentiate this from a more formalised process. References made to informal ACP suggested that this was less comprehensive and perhaps not documented as fully.

> "So, I think it [ACP] goes on informally all the time but I'm not sure it always, some of the difficult conversations are not." (Social Worker)

However, a GP also referred to a documented advance care plan as informal:

> "That's not to say that we don't do informal care plans especially for end-of-life care, if somebody's going to, you know, is really poorly, I do a care plan and I'll send it to ambulance crews, district nurses um and the out of hours services." (GP 3)

There was no one way of understanding informal ACP. Residents also saw day to day 'conversations' as something different to 'discussions', with the latter perhaps being considered more formal than the former.

From interviews with participating residents, it was apparent that the term ACP was not one they were particularly familiar with but even when talking about ACP in terms of expressing wishes and preferences, many would still report this as something they had not done. Indeed, a manager who raised ACP with all potential new residents during pre-admission assessments said her impression was that people do not know what ACP is. She said she had never had anyone say they had an advance care plan and although some identified with specific aspects of ACP, such as DNACPR, they did not identify with these as a component of ACP.

> "I haven't honestly I haven't seen anyone who come [sic] in with advance care plan in my experience. I have never come across even in my pre-assessment that I have seen an advance care plan with anybody at all or anywhere. Yes, they have, they have had DNAR but if you say for about the advance care plan they don't know what they are."
> (Manager 1)

Yet one of the specialist nurses suggested that many residents who were admitted to that home had had ACP discussions prior to admission. So discussions may happen without residents recognising that they are participating in ACP.

> "I think also [nursing home] does have um, we [name of service] send quite a few residents to there so likely would already have had an advance care planning kind of experience either with us or from say like [name of hospital]. … So again a lot of those conversations would have been had and documented." (Specialist nurse 3)

Also, as already discussed, residents had made practical plans such as planning their funeral or writing their will prior to admission to the nursing home. Funeral plans, in particular, were understood to be part of ACP by most nursing home staff, referred to in policy in nursing home A and included in the ACP documentation in nursing home B. One of the nursing home nurses talked about how it was difficult to ask relatives about funeral directors on the day someone died so they would specifically seek information about funeral plans in advance so that they could get on with managing the death when it happened. A GP also identified these practical matters as a key part of ACP. However, both the ostensive and performative components of the routine of ACP in the two nursing homes therefore deviated from accepted ACP definitions (outlined in Chapter 1), with practical concerns such as funeral planning and writing wills understood as part of ACP in the nursing homes but not defined as components of ACP (NEOLCP 2011; Rietjens et al. 2017; Sudore et al. 2017). ACP definitions also refer to ACP as only involving individuals who have the mental capacity to make decisions about the future, yet completion of ACP in the two nursing homes was not restricted to those residents who had decision-making capacity but was offered to all residents, with ACP documents completed with relatives when the resident was unable to contribute to the discussion. This demonstrated a lack of collective understanding of ACP.

A lack of shared understanding of ACP had potential to lead to information not being available to professionals who would have responsibility to implement resident choices. Several residents had DNACPR forms issued prior to admission to the nursing home but this decision was not always understood to be part of ACP. On discussing DNACPR with one participating resident, he informed me that he had had a DNACPR form for some time in the community but said he had not thought to pass it to the nursing home staff on admission. However, he had indicated on his ACP document completed a short time after admission that he would not wish for resuscitation; this was a direct question on the form. Although, in his case, a new DNACPR form had been issued by the hospital which was passed on to the nursing home on discharge, given the fluctuating and frequent lack of mental capacity of many residents, this identified a need for professionals to ensure that decisions are shared between settings. The different meanings given to ACP by both professionals and residents adds to the complexity of ensuring information is shared.

6.5 Chapter summary

This chapter has presented findings that show how ACP was operationalised in the two nursing homes, the challenges encountered and the impact of enacting ACP on multi-professional working. ACP was identified as a professionally led activity by nursing home staff and visiting professionals. It was an organisational routine, constructed by the process of completing documentation. Professional involvement was constrained by a widely held perception amongst residents, relatives and professionals that there is a ‘right time’ to have an ACP discussion, creating tensions when trying to align these discussions with the unpredictable dying trajectories of a frail, elderly population. There was divergence between the ostensive, performative and proxy aspects of the ACP routine, with variance impacted by the competence and confidence of professional staff and limitations of temporal structures. How ACP was understood in the nursing homes varied from how it is described in national policy. ACP was accounted for in different ways by different people and there was no collective understanding as to what constitutes ACP and when, how and by whom it is undertaken. This has implications for recognising when future planning has taken place and for multi-professional work to ensure ACP information is appropriately shared so as to be accessible when needed. ACP should not be considered as just a nursing home organisational routine but needs to be an inter-organisational process.

Chapter 7 Professional Reach

7.1 Introduction

The findings presented in this chapter identify limitations in professional reach in the ACP process in the two nursing homes. Professional reach refers to the extent of professional involvement, with respect to the range of professionals and professional disciplines participating and the scope of their involvement. Professional reach was limited in two ways: the reach in respect of the care domains legitimised as components of ACP; and the reach in terms of the breadth of team membership formally recognised and supported to contribute to ACP. The findings show that ACP was medicalised, with psychosocial and spiritual care involvement marginalised in the two nursing homes. The biomedical approach to ACP limited recognition of the potential involvement of a broader range of professionals in the process. Yet, psychosocial or spiritual matters that might impact ACP were discussed by participant residents. The findings highlight the importance of relatives to the ACP process. Residents frequently wished for involvement of their relatives in ACP, sometimes solely discussing ACP with relatives. However, the role of relatives was not formally recognised, and they were not supported in this role, which could lead to difficulties in honouring resident wishes.

The term ‘relatives’ is used throughout the chapter to refer to any family member, friend or significant other who knows the resident outside a health or social care professional relationship and includes the solicitor of one participant resident who was considered a friend alongside the professional relationship.

7.2 Biomedical model dominated

Comprehensive holistic assessment is a national quality standard for end-of-life care for adults in England (National Institute for Health and Care Excellence 2011) and underpins the Comprehensive Geriatric Assessment process, which is promoted to improve the health and well-being of older people (British Geriatrics Society 2019). The biopsychosocial-spiritual model for elderly and palliative care put forward by Sulmasy (2002) proposes that the biological, the psychological, the social, and the spiritual are distinct but interrelated dimensions of each person and no one aspect can be separated from the whole, with illness and frailty disrupting all dimensions. Using this model as a lens, it was identified that a biomedical approach dominated in both nursing homes.

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Many nursing home staff talked about not having as much time as they would like to stop and talk with residents, although they tried to do this as much as possible, acknowledging residents often wanted companionship. Physical health tasks such as administering medication, taking blood samples and dressing wounds, alongside updating care plans and risk assessments filled the vast majority of available nursing time. These were described by some nurses as their 'nursing jobs' and they were observed completing these more frequently than they were observed talking with residents, providing social, psychological or spiritual support. Care assistants also said they had little time for talking to residents, their routines of personal care tasks, such as assisting residents to manage hygiene needs or to eat and drink, and other tasks such as equipment checking, forming a temporal structure which shaped the temporal rhythm and shape of their daily practice (Orlikowski and Yates 2002). They took opportunities to talk to residents whilst completing care tasks, such as when assisting with a bath, and when the temporal structure was less prescriptive. Residents also referred to staff time being limited, with one resident talking about episodes when she had needed to wait to get assistance from staff. Another resident talked to a specialist nurse about how he did not use a medication as often as might be helpful because he did not like asking for it, being aware that the nurses needed to go upstairs to get it which was time-consuming for them.

> [Care assistant] explained how this part of the day was one of the few times when they had time to chat to residents and spend time with them. In the morning everything was more pressured: getting residents washed and dressed, out to activities and then to the dining room. (Field notes – Visit 049)

> [Care assistant] said she had a resident who was due a bath at 3.30 pm and this was a time when they could talk more to residents. … [She] said otherwise there isn't often time to have longer discussions. She said the residents also sense that there isn't time to chat. (Field notes – Visit 093)

As well as the busyness of the service getting in the way, managing emotional or spiritual concerns was not prioritised in the same way as physical health needs. One nurse talked about a resident being less well at a handover. She said that she considered his decline to be primarily related to a change in his mood. This was not considered serious or cause for professional support.

> [Nursing home nurse] said [resident] was less well but she felt it was his "mood not something more serious". (Field notes – Visit 025)

GPs were involved in the nursing homes more than any other visiting professional discipline, with nursing home staff indicating that GPs have an important role and “play a vital part” (Manager 2). Medical care was considered a critical component of nursing home care without which the nursing home was not able to function effectively.

> “[Nursing home nurse] said the GPs are easy to work with and open to discuss things. She said this is good as she thinks the GP service “can make or break a nursing home”. (Field notes – Visit 070)

GPs were present in nursing home A for two to three hours every Monday at the GP round, as well as at other times, and GPs visited most weekdays in nursing home B. A significant proportion of the GP round time was taken up reviewing medicines and writing prescriptions, with limited discussion of psychological approaches to managing issues such as low mood. There was a sense that nursing homes were medicalised to some extent. Behaviour changes were often treated as medical problems. Specific arrangements that medicalised the environment were put in place when GPs visited, such as alterations to temporal structures to ensure it was possible to arrange timely dispensing of prescriptions from the pharmacy and social spaces becoming medical spaces as a consequence of the GP round in nursing home A (see section 5.4), and requirements put in place by GPs in nursing home B for GP visits. These stipulated that when a visit had been requested the resident would have to remain in their room between midday and 2 pm, so they were not in the dining room when the GP arrived, and that a nurse must be available with the medication chart when the GP visited. Aspects of daily life, that happen without medical interference when people are living in their own home in the community, required GP authorisation for people residing in the nursing homes. For example, residents required authorisation from the GP to enable them to continue to administer their medication themselves in the nursing homes, something considered absurd by one of the managers.

> [Nursing home nurse] explained that quite a lot of residents self-medicate and the forms for this have to be signed by a GP six monthly. [Manager] said ‘It’s a joke getting it signed by GP’. (Field notes – Visit 071).

The professional disciplines staff talked about when asked about professionals who visited and were involved in the home were professionals who assisted with managing physical health or function, with physiotherapists, OTs and disease or condition specific specialist nurses seen to visit. The visits from these professionals primarily focused on completion of specific tasks relating to physical needs or tasks required to support provision of medical care. For example, a specialist nurse talked about the main purpose of her visits being disease monitoring and provision of symptom management advice.

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> I asked [nursing home nurse] what professionals they had visiting the home. She listed a range of specialist nurses including continence, bowel and bladder, specialist palliative care and tissue viability. I asked her about physios and OTs, and she said they often have physios and also OTs. She stated dieticians didn't tend to visit. (Field notes – Visit 064)
>
> [Written by member of physiotherapy team.] "Referral from GP re. mobility – pt seen walking with zimmer. Height adjusted. Seen on/off bed. Able to walk short distance along corridor then reported feeling tired." (Extract from Resident 1's notes)

Indeed, psychosocial professionals visited infrequently but like physical health professionals there was a task focus to their visits, such as a social worker completing a mental capacity assessment. These were also often medical tasks such as CPN visits to complete a medication review or undertake a memory assessment. Social workers rarely visited the two nursing homes, this minimal involvement potentially a consequence of the funding stream of the majority of the residents, with most self-funding their placement. Involvement of local authority social work teams is often limited to care reviews of placements funded by social care, with broader aspects of the social worker role constrained by care system pressures (National Institute for Health and Care Excellence 2015). The role of social workers within the nursing home setting was generally seen by others, both nursing home staff and visiting professionals, as primarily related to financial assessment.

> When I arrived a CPN was present and had come to review two residents. She spoke to [nursing home nurse] about the residents and recorded in their notes. [Nursing home nurse] advised me that it was a review of medication for one resident and with the other resident they were questioning the appropriateness of her continued placement at the home as her mental health needs were causing issues for other residents. (Field notes – Visit 041)
>
> I asked about social worker involvement. [Nursing home nurse] said some have case managers but they do not get involved with their care. (Field notes – Visit 007)

Similarly, the involvement of visiting professionals in ACP was primarily task focused. Nursing home nurses would call on visiting professionals to assist them with ACP in relation to a specific issue. Asked whether professionals got involved in their ACP process, a manager said:

> "Only if there are specifics. So, for example if we've got um difficulties with the pain management um then they would get involved. Um speech and language, you know so

> swallowing, those sorts of issues, they would get involved in that particular aspect of the care. They don't get involved as a routine thing and it tends to be in that particular area." (Manager 3)

A further indication of medicalisation was how a resident's diagnosis influenced involvement of particular visiting professionals. Residents were more likely to have multi-professional involvement beyond the input of GPs if they had a specific diagnosis. This was not just limited to involvement of disease-specific specialist nurses but also palliative care services. The three participant residents with cancer had at least one visit from a specialist palliative professional, whereas the palliative care service was not involved or mentioned for the three participant residents living with other long-term conditions or frailty. Medicalisation of care was evident in the reason for provision of ongoing specialist palliative care support. Two residents received one-off visits. A referral for one resident was made by the nursing home at the request of a relative who, having previously experienced specialist palliative care involvement with their father, was seeking ongoing support. Another resident received a follow-up review shortly after admission to the nursing home primarily in relation to an assessment for NHS Continuing Healthcare[9] funding. One resident received ongoing involvement of specialist palliative care to assist with management of symptoms, although as the care had been ongoing prior to his admission to the home, the original reason for referral was unknown. A visiting professional talked about ongoing symptom needs determining the involvement of specialist palliative care nurses in nursing homes and nursing home nurses agreed with this talking about visits from specialist palliative care nurses being centred primarily on symptoms. Visiting palliative care nurses also defined their role in nursing homes in relation to symptom management, albeit that once involved they would include other concerns when supporting the resident. This was the focus of a brief update given to me by a specialist palliative care nurse about a participant resident when I met her in the nursing home office following an unscheduled visit to the resident:

> [Specialist palliative care nurse] said that [resident] had filled her in on the symptoms and that he was aware that the [medications] were a temporary fix. She thinks he is aware that his condition is likely to deteriorate further. (Field notes – Visit 110)

Wishes relating to the management of residents' physical health also dominated talk about ACP and resident ACP records, such as treatment decisions and resuscitation status (See Figure 7.1). Although what is recorded in resident records is highly selective and translated into professional

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[9] NHS Continuing Healthcare is care arranged and funded solely by the NHS for some people with long-term complex health needs who meet criteria to qualify for free social care (NHS Choices 2018).

language (Prior 2011) and cannot therefore be taken as true factual representation of ACP discussions, dominance of a biomedical approach was evidenced in the guidance provided by the nursing homes about ACP and by what was selected for recording. The guidance for completion of ACP documentation in nursing home B stated “Ensure you have planned for possible healthcare decisions: Preferred place of care, Anticipatory medications, Resuscitation decision.” There was little evidence that ostensive and performative routines diverged from the guidance, which was the proxy routine. All six resident trajectories show that the majority of ACP subjects discussed in the nursing home were medical matters. Discussion about residents’ preferences for resuscitation was considered something that should form a standard part of ACP by nursing home nurses and many visiting professionals. In nursing home A, resuscitation decisions were raised with residents even when other aspects of ACP were not and in nursing home B views on resuscitation was one of seven questions on the ACP document.

> “Um I mean there are some things that will be fairly standard, so for example you know they will make a decision on whether they want a DNAR in place or not.” (Manager 3)

> “If there isn’t documentation for end-of-life decision-making such as do not resuscitate obviously you need to engage with that.” (Specialist nurse 1)

End-of-life section of assessment –
Religion/Culture – “… hoping to get well enough to go back to Church. Vicar has been in to see her”.
Concerns – “… that she may need to go back to hospital – she is not keen to return there, they were nice to her but she did not have a positive experience.”
Symptom Control – “… has just in case medication prescribed if required for symptom management. Not required at present.”
Future wishes – “… did not wish to have any surgical intervention … and for the palliative approach. … did not wish to have a pleural tap for her pleural effusion. She is aware that she may need a chest drain in the future for symptom control.”
Final days – “DNACPR in place.”

Figure 7.1: Example of ACP component of resident notes showing dominance of biomedical aspects

Discussions related to place of care were also linked to medical treatment in terms of whether the resident would wish to be transferred to hospital to receive more intensive treatment not available in the nursing home. This was not specifically about choice in place of care, rather underpinned by a desired goal of avoiding hospital admissions.

> “But of course, in the present situation we’re encouraged as much as we can not to send anybody to hospital unless it’s a real dire emergency.” (Nursing home nurse 5)

The need to avoid hospital admission was clearly recorded by visiting professionals in the nursing home notes of two residents and the nursing home nurses had explicitly discussed escalation of care options with one resident, who although indicated a preference to die in the nursing home still wished to receive care in hospital if necessary.

> "If [resident] is sick, he is happy to go to hospital on GP's advice. Any hospital is fine."
> (Extract from Resident 2's advance care plan)

The nursing home was indicated as the preferred place of care in the ACP for two other residents, although one of these residents discussed with me that her preference would be to die in the local hospice which had been offered as an option during a hospital admission when she was thought to be imminently dying. There were limits to the choices available to residents, especially given for most the decision regarding admission to the nursing home had been made by relatives. The nursing homes were viewed by professionals, in particular, as a place of care where residents could receive most medical treatment that they would require, negating need for transfer to other healthcare environments. In this way, the residents' home environment was identified as a medical space.

> "The alternatives to the care home are usually hospice or hospital, however although this may be the client's wish, we need to make it clear that it is not always possible."
> (Extract from nursing home B's ACP guidance)

7.3 Psychosocial-spiritual care marginalised

Only two participant residents had psychosocial or spiritual professional involvement, one being visited by a social worker and both by religious ministers. These residents' nursing home records did not evidence any involvement in ACP, although absence from the records did not mean that these discussions did not happen at all (Prior 2011). However, there was no talk of psychosocial and spiritual professionals participating in ACP discussions with any residents.

> A CPN came to assess a resident; she then came back and spoke with [manager] and [nursing home nurse]. [Nursing home nurse] said nothing was mentioned about any discussion about wishes and preferences. (Field notes – Visit 016)

Psychosocial-spiritual matters only featured in the documented ACP of two of the six participant residents. One resident had expressed her wish to engage with her Church. Another resident had expressed her wish that social contact with friends and family should continue even when she was dying; this had been documented without involvement of a professional. The lack of psychosocial and spiritual content in ACP documents occurred despite policy and guidance, particularly in nursing home B, indicating that these matters should form part of ACP. It was also in the context of the existence of psychological, social or spiritual factors that had potential to impact ACP for all six participant residents, including bereavement, low mood and existential issues, such as questioning whether or not life-sustaining treatments would just add time to life or would add purposeful time to life.

One resident faced the death of a relative during the study and two residents openly communicated about grief in relation to loss of a spouse.

> He [resident] said he was having another bad day and advised me that his sister had died yesterday. … He said he was the last of the siblings now, as his other sister had died a few years ago. He said "it comes to all of us" although he said that he used to say that it wasn't going to happen to him. (Field notes – Visit 081)

One resident reduced oral intake, recognised by her son as a decision made to hasten death, who consequently sought input from his mother's church friends to address the issue from a spiritual perspective.

> "[Resident] stopped eating and started to, [resident] went, went down and what happened then was um certain people came in er from the Church etcetera and then talked to, talked over with her, her spiritual er you know um let's say philosophy and the way she thought. And that, and really, she realised that she was contradicting what she was, what she really believed." (Relative 3)

Another resident seemed conflicted about her expressed wish not to be admitted to hospital.

> She [resident] said the hospital "saved me". She doesn't want to go back to hospital and has told her son this. But mentioned she is aware that they can't do things here [in the nursing home] that they can in hospital so is a bit unsure. She said she wasn't sure if she wants to be saved, although is clear that she doesn't want to find herself "ga-ga" as she describes it. (Field notes – Visit 085)

The primary professionals providing social support were activity coordinators who were employed by both homes. They were seen chatting to residents in their rooms, accompanying individual residents on walks in the grounds and facilitating a small group of residents to spend time reflecting on the life of a resident who had died, their friend. In nursing home B, information gathered by the activity coordinators to inform the home's life history for each resident contributed to ACP by informing an understanding of residents' values and any future wishes outside of the biomedical sphere. Yet their involvement in ACP did not extend to documenting in the ACP record. The ACP documents were only completed by residents, relatives or a member of the nursing team. This suggested that psychosocial contributions to ACP were not as necessary or important as the information provided by the nursing team to guide treatment decisions and immediate management of the resident's body after death. Therefore, the ACP discussions that activity coordinators had were excluded from the primary ACP record. A discussion with an activity coordinator revealed that one participant resident had a "bucket list" which I would otherwise have been unaware of as this was not referred to in her ACP document.

The participant social worker thought that there was a role for social workers in ACP within nursing homes.

> "I think, you know, advance care plan you can all follow a document can't you, but we are going to approach it differently. And you take that for granted don't you until you hear somebody else doing it, do you know what I mean? So, I think we all try and do a holistic approach when we're looking at people's wishes but for social workers you know about the advocacy and the enabling them to do is just, it's just second nature to us isn't it?" (Social worker)

Yet, social workers rarely visited either home for any reason. Indeed, there was a widely held view that there was limited need for involvement of social workers in nursing home care, both by other visiting professionals and nursing home nurses.

> "No, not in, not for advance care plans. I think there would be some interactions with social workers for those clients with dementia, partly because they may have had some interaction with them before and I would imagine the transition then into the nursing home/rest home but actually even the rest homes don't need social workers attached to them because once they're resident that's then their home, isn't it?" (Specialist nurse 1)

Based on the views of the participant social worker, this suggested poor understanding of the potential scope of a social worker's role in nursing homes and the lack of any substantial involvement of social workers in the nursing homes thereby reduced the scope for them to be involved in ACP.

Spiritual care was identifiable as a distinct aspect of care both in how it was discussed by staff and how it was recorded in resident ACP records. It was almost exclusively aligned with religion in both homes. The nursing home nurses talked about the helpfulness of a spiritual component to ACP but referred to this in terms of religious preferences such as knowing that a resident would wish for last rites. Staff discussed spiritual support as being provided by religious ministers, with both home managers stating that they had links with church and faith groups who they could call on to visit individual residents when required. There was no identifiable professional to provide spiritual support except to those residents whose spiritual needs were defined within religious parameters.

> "Spiritual care, I mean the local churches and things they are very helpful. Um they do come in you know with um, if the resident wishes. I mean on the assessment we do ask what they like, some of them they're not religious, some of them yes they want to receive communion, they want to, and we do encourage them to meet up with their spiritual requirements." (Manager 1)

However, spiritual care provided by religious ministers was marginalised as these professionals were afforded a different status to that of other visiting health and social care professionals. Involvement of religious ministers was not recorded in resident notes in the same way as other professionals. Religious ministers were known to have visited two of the participant residents but there was no record of their visit in the professional section of the resident notes. A manager confirmed that religious ministers do not see or write in resident notes although there was an expectation that the staff would record that a visit had been made.

> "They don't really write it, but we do. Say for example before we have a resident who actually passed away and er she knows that she is, you know, on the very last days but luckily she is still you know very good and sensible so she actually asked for that. 'I would like to see a priest'. So that we write that on the notes and call the priest right away. And it was very good because the vicar and the priest that we have locally here, if you actually ring them or email them, they come right away. Yeah, so they don't actually see the notes and anything like that but yes, they give the service. Yeah, so we are the ones who actually put that in the notes that visited by priest today given the last rite or something and that's that." (Manager 2)

Any discussion of future wishes that a resident had with a religious minister was therefore not documented within the nursing home. There was no mention of any wishes in relation to spiritual or religious matters in the ACP records of a resident who spoke openly about her Christian beliefs, other than a desire to be able to attend her Church again, and she said that the nursing home staff had not asked her about her preferences regarding spiritual care at the end of her life. She was visited on a regular basis by church visitors but commenting on whether wishes for her end of life might have been discussed during these visits, a nursing home nurse said:

> "I should think they probably do yeah. Not that I've ever been in on any of their meetings. But I think it brings her, it gives her comfort. But she's always been very much involved in things like that. And, you know during her lifetime." (Nursing home nurse 5)

There was no professional specifically providing psychological support. This was despite policy and guidance recommending sources of such support were accessed. Nursing home A's End-of-Life Care Policy stated that the home would try to provide and procure all care and support available, including where appropriate the "provision of counselling and other forms of psychological support" and guidance provided on writing an ACP care plan in nursing home B, advised that psychological needs should be considered, with involvement of counsellors suggested to assist with meeting needs. Yet no evidence of the availability of such support was either observed or talked about by staff. This may have reflected the accessibility of professionals to provide such support. Indeed, one nursing home nurse stated that although she thought such support would be beneficial for residents, she was not aware of any such support:

> [Nursing home nurse] talked about her concerns re. [resident's] denial and I asked whether they have any services that assist with managing psychosocial or spiritual needs. She said she hadn't ever known any involvement of anyone who could assist with this and wouldn't know where to access such support. (Field notes – Visit 109)

In delivering end-of-life care in the nursing homes, nursing home staff and visiting professionals identified with the nursing home team, GPs and palliative care nurses as the key professionals in the multi-professional team. The involvement of these professional disciplines was valued highly compared to others who might be involved.

> "But with my experience [of palliative care provision in the nursing home] yes it's only the GP and the [specialist palliative care nurse] who is actually quite involved in our service." (Manager 2)

> "I think that's the tripod of care [GPs, nursing home staff and palliative care if involved] really with occasional individual fringe people going in but there's, there's not really anybody else." (GP 3)

With professionals who could provide psychological and spiritual support extending beyond a religious framework unavailable, provision of holistic end-of-life care was therefore primarily left to the nurses, both nursing home nurses and visiting specialist nurses. Nursing home nurses were seen to provide some psychological support to residents, offering opportunities for residents to open up about concerns. In one such case, the nurse spoke about how this approach offered an alternative to the biomedical approach to managing a resident's symptoms.

> [Nursing home nurse] advised that they [nurse and resident] had had a good chat. She said he had asked a couple of things and she was able to add to the ACP. She said he appeared to benefit from having the chat and felt better following it. She said when he reports feeling shivery she would most likely sit and talk to him now rather than immediately calling a GP, saying she recognised the psychological element which she had been taught about by the local hospice. (Field notes – Visit 074)

Information imparted at handovers about three participant residents included reference to encouraging socialisation as a management approach for low mood, however management of symptoms were more frequently addressed from a biological perspective and with GP involvement.

The dominance of the biomedical approach to care within the nursing homes and in care provided by specialist palliative care nurses therefore side-lined the psychological, social and spiritual dimensions that constitute the 'whole' human person (Sulmasy 2002). In one of the homes there was specific acknowledgement of a need for a greater level of psychosocial and spiritual support. The manager identified that this could be done better, and that psychosocial support did not routinely form part of the home's temporal structure. She expressed a wish to develop a service providing spiritual and well-being support for both residents and relatives.

> "Um, I think may be in terms of emotional wellbeing perhaps that's something we could do a bit better. A … That maybe you know having somebody that comes in that does a group, that's a wellbeing type group without having religious connotations. … So maybe that's something that would be good to have more of is you know just back to this spiritual wellbeing and, and maybe ways of, of facing that unknown and facing it in a way that they feel comfortable with and supported by. I don't think that's something that's really out there. I don't think it's something we give much, much time and attention to really." (Manager 3)

7.4 Relatives' involvement in ACP

Relatives were an integral part of both homes, with nursing home A's End of Life Care Policy referring to the relationship between staff and relatives as one of partnership. Frequent liaison was observed between the nursing home nurses and relatives with this being the expectation of nursing home B's Care Planning Policy. Staff in both homes endeavoured to keep relatives informed and updated, apprising them of any changes in the resident's health.

> The GP round was fairly quick today and completed in less than two hours. [Managers] did the usual routine afterwards of phoning relatives regarding antibiotics prescribed. (Field notes – Visit 034)

> "No change at this time, regular family visiting, [relative] is informed when he is in to see [resident]." (Extract from Resident 6's notes)

The significance of the nursing home in the lives of relatives was demonstrated by them being seen to return to the home after their loved one had died, with more than one visiting on multiple occasions in nursing home A.

The importance of relatives in the ACP process was evident from the six resident trajectories. Family involvement is a consistent feature of ACP in all care settings along these trajectories. Wishes and preferences discussed prior to admission to the nursing home, in particular funeral plans, had often been discussed solely with relatives. Once residents were living in the nursing home, relatives continued to play a key role and some residents valued discussions with their family about future wishes more than talking to professionals about these.

> Researcher: "So you would prefer to talk to your family rather than professionals about your wishes?"
> Resident 5: "Oh yes. I don't see any point in anything more. I rely entirely on him."

> "I think just the role that I'm in now, that as soon as somebody asks him a question, he talks to me about it." (Relative 1)

Residents often talked about their future wishes with their relatives either without involving professionals at all or only involving professionals subsequent to conversations with their family. In nursing home B, the ACP document was given to residents to complete, and two residents described how they completed this with a member of their family, without involvement of the nursing home staff. The topics covered by such ACP discussions with relatives included medical decisions, such as resuscitation, that could be considered the domain of professionals.

> [Manager] said that the request for the [DNACPR] form completed today had come from the daughter as she had discussed it with the resident. (Field notes – Visit 048)

> "I came in here one day and he'd only been in a while, and he said you need to fill this form in. We need to do it together and then we both went to reception together and he

> was joking about it and said this is my wishes. So, we were both, yeah we both went through it together." (Relative 1)

Many residents chose to formally nominate their relatives to speak on their behalf defining their role in decision-making on a legal basis. A sizable proportion of residents had appointed a proxy to speak on their behalf. This was most commonly a close relative. Between ten and twenty per cent of residents at any one time in both homes had a designated LPA for health and welfare, the person appointed to speak on their behalf if the resident lost the mental capacity to make their own health and care decisions. Even when the provision of legal powers to a relative were not established, residents often still wished their family members to be fully involved. One resident wished her son to speak on her behalf, although she still had capacity to make her own decisions.

Nursing home staff often included relatives in their ACP discussions with residents. Discussions that the nurses in nursing home A initiated with residents frequently involved one or more family member. Many residents lacked mental capacity to make decisions about their future, necessitating a best interest approach which included relatives, but the views of relatives were also sought for those who had capacity, through participation in care plan review meetings. Visiting professionals engaged relatives in their discussions less often, usually only when relatives happened to be present when they visited, although one specialist nurse actively sought their input. The GP round in nursing home A enabled relative involvement as relatives were able to arrange their visit at the regular time of the round so as to sit in on discussions with GPs.

> [GP] discussed how it [the GP round] also means that they get to know relatives as they will sometimes sit in on consultations on ward round day, something that doesn't happen when the service is reactive. (Field notes – Visit 056)

Nursing home staff and GPs perceived that involving relatives in ACP discussions mitigated risk of conflict at a later date when a resident was unable to make decisions or confirm previously expressed views. This was illustrated by a situation described by a nursing home nurse when the nursing home staff had to deal with a shocked family after a resident's death. The resident's ACP said she wished to be cremated, yet prior to admission to the nursing home she had always talked about burial with her family. The views expressed in her nursing home advance care plan therefore conflicted with the views that her family thought she held, which caused tensions within the family after she had died. This highlighted to the nursing home staff the need for greater involvement of relatives in their ACP process.

> "But I think the real big advantage is that the resident and their family are all in agreement because one of the worst things is when you've got family saying no, no he has to go to hospital, he has to go to hospital, and you know that's not what the resident wants. And if you've done really robust advance care planning you can be really clear about that and support that resident's decision." (Manager 3)

But for some nurses the timing of conversations with relatives was challenging, in a similar way to opening conversations with residents discussed in Chapter 6.

> "I suppose once they're settled in the home for a while though, yes we should really be able to broach the subject with the families. But I suppose it's getting, it's getting to know the families really well and being able to but, but what is the right time to er you know." (Nursing home nurse 5)

7.5 Roles of relatives

Although admission of a resident to a nursing home leads to change in the type of care provided by relatives (Hainstock et al. 2017), relatives were seen undertaking a variety of roles in the nursing homes, many of which could be conceptualised as 'carer' roles. Nolan et al. (1995) extended Bowers' (1987) model of carer roles, developing a typology of family care consisting of eight categories of care. This definition of the roles undertaken by relatives moves beyond the instrumental aspects of care-giving that predominate policy guidance. Two additional categories of care that relatives were seen to participate in relation to ACP were preservative care and (re)constructive care, which Nolan et al. (1995) considered to be closely related. Both role types centred on maintaining the self-esteem of the cared-for person, but with the relationships that give purpose to the resident and underpin their dignity altering over time. In undertaking preservative care relatives work to preserve the self-esteem of residents, by maintaining family connections and the sense of hope and control of the resident (ibid). One way that relatives regularly participated in preservative care was through sharing of biographical information about the resident and supporting residents to share this information with the nursing home team, to support ACP and inform decision-making. There was reliance by residents, nursing home staff and some visiting professionals that relatives would take on this role sharing their knowledge of the resident. Nolan et al. (1995) describe (re)constructive care as building on the past but developing new and valued roles. Over time, relatives would increasingly advocate for the resident and take a greater role in decision-making, as changes in the resident's condition increased their reliance on others. In this way relatives were part of the team. On one occasion, a relative's views were sought to inform the decision-making of a nurse about whether to request a GP visit or not. The resident had requested a visit, but the nurse wished to clarify the problem with her daughter, as this was an ongoing issue that she considered might not need involvement of the GP.

> [Nursing home nurse] advised [manager] that she was not going to request a GP visit for the resident with the lump on her leg as she wanted to speak to her daughter first. She said that previously they had been concerned about possible issues with the lump for the daughter to report that this was something that had happened before, so she wanted to see what her daughter thought first. (Field notes – Visit 098)

Relatives also continued to be involved in instrumental care, the ’doing for’ the resident. Although usually not involved in the ‘hands-on’ care typically associated with instrumental care, relatives would ‘do for’ the resident by dealing with finances or influencing care provision, for example. This included instigating involvement of visiting professionals. Relatives would ask nursing home nurses to arrange GP visits they thought were required and their direct contact with a GP could lead to a visit, such as a GP visit made to a participating resident the day after her relative discussed his concerns about her health with her doctor. A manager advised how involvement of the GP in ACP could be led by the relatives’ wishes on this.

> And shortly after my arrival [nursing home nurse] said she needed to let the surgery know that another resident needed to be seen. The resident is currently on antibiotics, but the family have requested a GP review as they are concerned she is not picking up. (Field notes – Visit 071)

> “Some families would like to have the GP because they would like to get the, his input on that.” (Manager 2)

Being present during visits or having direct communication with visiting professionals was desired by many relatives, although this was not always forthcoming. A relative talked about requesting involvement of the palliative care team in her father’s care and her disappointment that she had not been aware of their visit and had not received any communication from them directly after the visit:

> “The [palliative care] team from [local area] hospice visited once. At my request really, because I think as the team at the hospice [in another locality] were so good and they were so good with me and my brother, I kind of thought we wanted them to be a bit involved here, if not for Dad but for the family as well. Um, but um, I haven’t had a lot

> of support from the [palliative care] team here. They did come and see Dad once, but they didn't follow up with me at all." (Relative 2)

However, there was variation in the level of involvement that relatives wanted. Some relatives did not get involved in professional decision-making unless they were asked to, or they had concerns about the care being provided.

> "I didn't know he was on morphine. I thought he, he didn't really have any pain, but he probably hasn't got any pain because he is on morphine. So that side I've probably been a bit blasé, but I just look at him and think everything's working for him so why would I question." (Relative 1)

> "My first point of contact would be, be here obviously. But if I felt that there was some sort of problem, that something wasn't being dealt with properly then I would have to contact the surgery and then get doctor [name] to contact me later on." (Relative 3)

Interaction between relatives and professionals was seen to impact multi-professional working with the nursing home staff both positively and negatively. A relative spoke directly to a consultant to find out her father's test results and the plan for his care, which was helpful to the nursing home nurses who were keen to have a plan in place. In this way the care provided by the relative complemented the care provided by the nursing home.

> "So, when I saw Dad on Thursday, I said have you found out Dad about your brain scan and he said no. So, I said I'm gonna phone Dr [name] myself. So I phoned him, he called me back Friday and told me that Dad's scan wasn't good really." (Relative 1)

However, in another situation communication by relatives directly with a professional to plan care left the nursing home staff feeling that they were being excluded as they were unable to share their views. In this way the carer roles of the relative and of the nursing home staff obstructed each other, the role being fulfilled by the relative not conceptualised as a carer role by the nursing home staff.

> She [manager] appeared frustrated that the views of the family … were heard louder than the views of the nursing home staff. (Field notes – Visit 031)

Relatives could also influence whether expressed wishes were honoured. Highlighted in the nursing homes' policy as an expectation (see Figure 7.2), nursing home staff both wanted to and actively sought to respect resident wishes. The proxy routine was observed in both the ostensive and performative routine in this case. In nursing home A, a resident's daughter was involved in putting him on the organ donation register, providing all the information so the home could initiate the process for him to donate his corneas when he died. The home honoured this resident’s wish, through liaison with the resident’s daughter and the organ donation service, both before and after his death, and ensuring necessary information was passed on to the funeral directors.

> He had been transferred to the undertakers before I arrived. [Nursing home nurse] said that [manager] had spoken to the organ donation service about donation of his corneas so his wishes had been implemented. The funeral directors were aware of the plans and had the organ donation service details. [The nurse] discussed with me that [resident]’s wishes had been implemented as he had died in the home and the tissue donation process had been initiated. (Field notes – Visit 028)

“The home will take this wish into account if such a decision must be taken and the person is unable to make their wishes known as clearly at the time.” (Extract from Advance Care Planning Policy, nursing home A)

“To create an environment within which residents, and those acting on their behalf, are able to feel confident and trust that their wishes for their future care will be respected.” (Extract from Death and Dying Policy, nursing home B)

Figure 7.2: Policy extracts

However, honouring wishes expressed by residents in ACP could sometimes be challenged by the expectations of relatives. Staff in both homes often talked about what they perceived to be unrealistic expectations of relatives and how this could mean a resident was admitted inappropriately to hospital. This situation arose when the expectations of relatives in terms of health outcomes did not align with those of the professionals. In one case the nurses talked about a relative expecting too much, in relation to how much a resident was eating and her need for physiotherapy, questioning whether the relative was ‘on the same page’ in terms of the resident’s expected deterioration. On another occasion nurses spoke about a resident being treated for an infection whose relative wanted the resident to be admitted to hospital. They commented that they did not think anything could be gained from an admission, acknowledging that due to the resident’s frailty he might die from the infection, and that they wondered whether relatives expected residents to live forever.

> On returning to the office there was a discussion between [manager and two nursing home nurses] about relatives and them not wanting residents to die. This appeared to stem from the granddaughter's request for the resident to be reviewed by [GP] despite already being on antibiotics. Another couple of residents were also mentioned in terms

> of relatives continuously seeking active treatment. They discussed unrealistic expectations and how that could make it difficult for them to achieve what they considered a good death for residents. They expressed concern that these expectations could mean that the residents get admitted to and die in hospital. (Field notes – Visit 044)

> "Because some of them actually know the reality that you know this is the last chapter of the resident's life and you don't actually expect someone to get better and to walk away and go back to their home from here. And, but some thought that when their relatives come in that we do, we, you know, they can miraculously get better and get back to how they were ten years ago. Yeah, so the expectation is very different, it varies from relatives to relatives." (Manager 2)

Although relatives' views were sometimes considered unrealistic in relation to residents approaching the end of their life, this was not something that was actively managed. The nursing home nurses suggested this was the role of the GP. A GP recognised that sometimes it is the relatives that are more of a concern, talking about a resident's family that he thought were not coping with the resident's deterioration. One of the nurses also commented about how one member of this same family was struggling, apparent by his behaviour and his inability to stay with the resident for more than a short period. However, no specific support such as discussions about their expectations of care was offered. Yet, a situation with a resident who had deteriorated where an unrealistic expectation of one relative was discussed and dealt with by another relative, who was also a health care professional, demonstrated how managing expectations could prevent hospital admission.

> [Nursing home nurse] told me that the resident had died in hospital. She said she thought it was a shame as she was only in hospital since yesterday, such a short period. She said she had had recurrent chest infections and the family had wanted her admitted to hospital. She had been admitted to the nursing home from hospital following a chest infection three months ago and had been into hospital with a further chest infection two months ago. She said had she been treated palliatively in the nursing home, she would have died then but the family had pushed for hospital admission. She said that she thought with more continuity from GPs then perhaps proactive discussions about the recurrent infections might have occurred with the family to enable her to have died in the home, rather than the family pushing for active treatment. (Field notes – Visit 094)

Professional Reach

The burden of decision-making was something that was not explicitly acknowledged by nursing home staff or visiting professionals in either home. It was accepted practice to ask relatives to become involved in decision-making either jointly with the resident or as an advocate for the resident if the resident did not have mental capacity to make the decision, such as through involvement in care plan reviews. However, one participant relative openly acknowledged that talking about end-of-life care was emotionally difficult for him.

> [Relative] advised that his mother is very matter of fact about dying mentioning the recent death of [a resident] and his mother saying it was a relief. He said there is no emotion when she talks about her end of life but for families it is much more emotive. (Field notes – Visit 099)

Both nursing home staff and visiting professionals identified that relatives need support as well as the residents.

> "Do we support families as much as we should and could? Maybe not. Maybe not. I think, you know, it's very easy whether you work in a hospital setting or something like this, you know you concentrate on the patient or the resident and actually if you're looking at spiritual wellbeing it's got to be a whole family, whole family approach. So maybe that's something that perhaps we could work on a bit more." (Manager 3)

As discussed previously, access to psychosocial and spiritual professionals was not routinely available within the nursing homes, which may have been of benefit to relatives as well as residents. One relative talked about her brother who suffered with mental health issues having a tough time coping with the ill-health of their father:

> "Yeah, so maybe a wider view to encompass the whole family would be a bit better for the care plan in a way. I don't know if anything's, nothing particular has been offered for the family in the way of counselling or talking to somebody." (Relative 2)

A social care professional suggested that relatives may also need support with coming to terms with resident ACP decisions. The benefit of providing support was recognised but not provided.

7.6 Chapter summary

This chapter has outlined findings which show that psychological, social and spiritual care was not privileged and a biomedical approach to ACP dominated. This limited the range of professionals involved in ACP and the extent of professional involvement. Access to a broader range of professionals was also restricted by the availability of psychosocial and spiritual professionals within the health and social care context in which the nursing homes operated. The main professional groups recognised as having involvement in ACP were medical and nursing staff. The findings have also shown that relatives make a significant contribution to ACP, end-of-life care decision-making and multi-professional working, being both important and influential. However, they were not formally recognised as part of the team or supported with their involvement in ACP. The biomedical approach constrained ACP and multi-professional involvement in ACP, both in the extent of ACP achieved and in the formal recognition of the range of individuals potentially able to support residents with the process.

Chapter 8 Conceptual Framework and Discussion

8.1 Introduction

The primary focus of this exploratory study was to understand the factors which influence multi-professional involvement in ACP and how multi-professional working impacts on the ACP process in two nursing homes, to inform the development of pragmatic approaches to improve the effectiveness of ACP practice. This chapter presents a conceptual framework of multi-professional involvement in ACP in the nursing homes, a synthesis of the findings presented in the previous three chapters, and demonstrates the relationship between the three conceptual themes from which the framework is constructed. The conceptual framework proposes that multi-professional working and ACP were 'running side by side' in the two nursing homes, rather than multi-professional working being integrated with ACP through an inter-professional and inter-organisational approach to the process. The framework is critically examined, explained and situated within the wider literature. This leads to a consideration of how the conceptual framework can assist in understanding how both ACP and, in light of the study using ACP as an exemplar of end-of-life care practice, end-of-life care provision can be enhanced in nursing homes.

8.2 Running side by side – a conceptual framework

Three key findings were identified: the structure and organisation of care disrupted the continuity and coordination required to enact ACP; challenges were encountered in the enactment of ACP which impact multi-professional working; and both professional and relative involvement was constrained by the dominance of a biomedical approach to ACP. The findings highlight a reciprocal impact between ACP and multi-professional working. Multi-professional working was not an integrated component of the ACP process in either home, with multi-professional working and ACP better understood as running side by side with occasional interaction between each other.

The title for this thesis and the conceptual framework, 'Running Side by Side', is a verbatim (in vivo) quote captured in an interview with a professional participant. He described the ACP document in the nursing home and the ACP document in use within his organisation as "running side by side". These ACP documents were closely aligned in content, which was sometimes identical, and faced the same direction, the aims of documenting ACP being the same, yet these were separate documents which were not shared. As the analysis progressed these words became increasingly meaningful, illuminating not just how ACP documents were running side by side but how this phrase could be used to describe other aspects of multi-professional involvement in ACP in the two nursing homes.

The conceptual framework (Figure 8.1) represents multi-professional working and ACP as ill-defined objects with curvy edges, as these were not linear or standardised but had variation according to the actors and organisations involved. There was no one ACP routine which coordinated involvement of all professionals in either nursing home. The concepts of multi-professional working and ACP were impacted by the 'Professional Reach' of multi-professional working, by the 'Disjointed System' in which multi-professional working and ACP occur and by the complexities of 'Enacting ACP' in practice, as outlined in the findings presented in the previous three chapters. The framework depicts multi-professional working and ACP as running side by side but with some connections, reflecting that sometimes practice was more integrated than at other times.

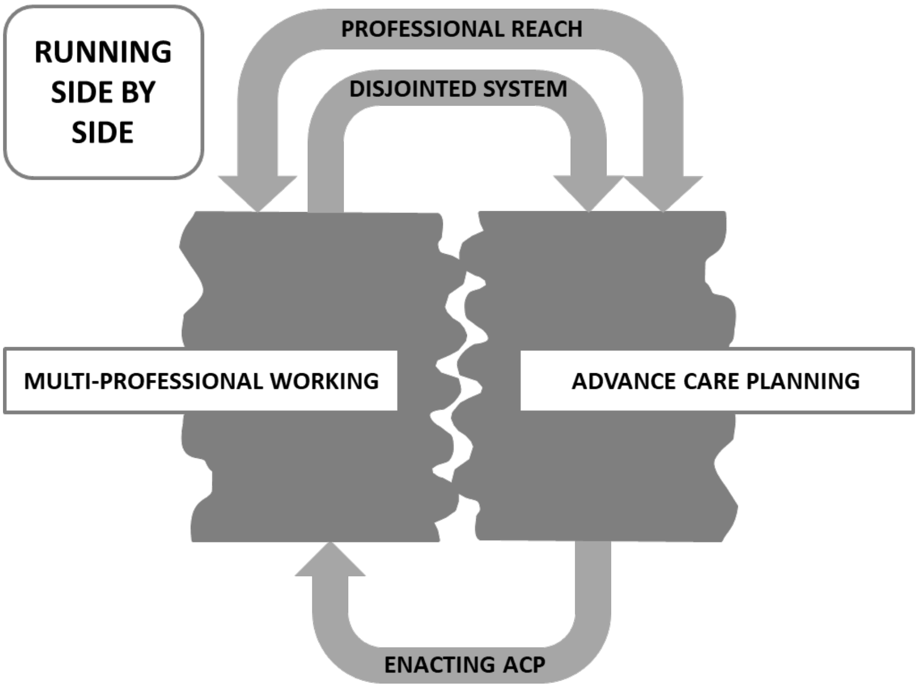

Figure 8.1: Conceptual framework - Running Side by Side

The thesis presented is, therefore, that both ACP and multi-professional practice in the two nursing homes were running side by side. Study findings revealed that the professional work structures of the disjointed system are misaligned with the relationship and management continuity required for the enactment of ACP, leading to ACP work happening in professional silos and running alongside each other. Conceptual confusion about what constitutes ACP and its construction as a professional process, primarily focused on biomedical planning, influences the professional reach of ACP in terms of what future planning is recognised as ACP and who is recognised as being involved in this. This can lead to professionally recognised aspects of ACP running side by side with both unrecognised components of ACP and areas of planning prioritised by residents. In this way multi-professional involvement rather than inter-professional involvement was observed and it is proposed that ACP practice could be enhanced through approaches to support more integrated and inter-professional working.

8.2.1 Misalignment between professional practices and ACP

The findings have shown that there was misalignment of professional practices both internal and external to the nursing homes in relation to the enactment of ACP. The disjointed system of professional work structures impacted integration of multi-professional working with ACP. This led to multi-professional working and ACP running side by side. Three key factors influenced relationship and management continuity, identified as necessary for ACP: misalignment of time and space; the knotworking approach to multi-professional work; and organisational control.

The need for sufficient time to build relationships to enable ACP and to facilitate ACP discussions was identified. A lack of time was considered a barrier to ACP. Time availability has previously been reported as a challenge to having ACP conversations (Barnes et al. 2007; Gilissen et al. 2017; Llewellyn et al. 2018; Sharp et al. 2018), with research primarily highlighting a need for sufficient time to facilitate ACP discussions (Detering et al. 2010; Seymour et al. 2010; Robinson et al. 2013; Stone et al. 2013; Lund et al. 2015; Gilissen et al. 2017). However, these studies did not explore time beyond the potential constraint on ACP in practice. Interpreting the challenges faced in relation to time availability for ACP through the lens of temporal structuring (Orlikowski and Yates 2002), has shown how time for ACP was understood and limited by embedded temporal structures that regulated activities of both nursing home staff and visiting professionals. Misalignment between the temporal structures of the nursing homes and those of visiting professionals impacted both multi-professional working and the perception of time availability to become involved in ACP. The only temporal structures that incorporated ACP to any extent were the GP round and the care planning process in each home.

Orlikowski and Yates (2002) suggested that some temporal structures become connected with particular social practices to the extent that those involved have little cognizance of the potential to enact alternative temporal structures by changing social practices. The temporal structures of the nursing home and of visiting professionals ran side by side and did not interrelate easily, such as the mealtime schedule, with three meals per day something deeply rooted in everyday practice more widely than just care homes, and the well-established temporal structure of a typical GP's day. This created difficulties for multi-professional involvement to integrate into nursing home processes and for sufficient time to be available for ACP discussions. However, highly institutionalised and widely recognised social practices are hard to change and are usually only altered as a result of considerable explicit effort (ibid). Findings from research into team effectiveness in primary health care in Canada identified that communication by other professionals with physicians was impeded by conflicts in schedules (Delva et al. 2008). The impact of time schedules on multi-professional working has been reported, with implementation of standardised scheduling of GP visits to nursing homes as a component of a work programme to improve inter-professional collaboration in German nursing homes (Muller et al. 2018). However, they did not discuss the specific timing of these visits and how they fitted with the usual temporal structure of the nursing home day.

Spatial segregation of visiting professionals from the nursing home also impacted integration of multi-professional working in nursing home ACP. The configuration of the current UK nursing home sector means cross-organisational working is unavoidable, creating complexities in management continuity of ACP across the different organisational boundaries. There was substantial reliance on asynchronous communication, where communication occurred between professionals who were not in the same physical or virtual space at the same time (Reeves et al. 2010), often leading to ACP and end-of-life care decision-making occuring in silos. Spatial segregation of disciplines working together has been identified as a barrier to effective teamwork (Pryor 2008). As previously reported in the literature spatial segregation limited the opportunities for interaction between members of the multi-professional team (Delva et al. 2008), although such interaction has been identified as necessary to nurture working relationships (Seymour et al. 2011) and agree joint processes (Lette et al. 2020).

Multi-professional working in the two homes was mostly characterised by knotworking (Engeström et al. 1999). This knotworking approach to multi-professional working meant that visiting professionals and nursing home staff were often working side by side rather than collectively on ACP. It has been suggested that because of the unstable nature of knotworking, instruments become important to coordinate actions (Engeström 2000; Varpio et al. 2008). The literature review also highlighted communication and coordination (see section 2.4.2) as necessary characteristics to ensure end-of-life wishes were implemented. This is reflected in guidelines for end-of-life care in nursing homes in Northern Ireland which state that effective communication between professionals is necessary to build strong working relationships and ensure good care for residents (Guidelines and Audit Implementation Network 2013). Lund et al. (2015) suggest that un-started, incomplete or failed interaction processes inhibit implementation of ACP. Additionally, there is evidence to suggest that collaboration and coordination between professionals is impacted by inter-professional and inter-personal relationships both in palliative care (Walshe et al. 2008) and in care homes (Badger et al. 2012). Using knotworking theory to understand multi-professional working in nursing homes may assist in developing approaches to improve interactions in relation to ACP and improve implementation of coordinated ACP processes.

Residents valued developing a relationship with professionals before feeling able to have open conversations relating to future care, but multi-professional involvement in the two nursing homes was not always conducive to the relationship continuity necessary for ACP. This supports previous research which identified that the development of relationships between professionals and residents are an enabling factor for sensitive ACP conversations (Furman et al. 2006; Jeong et al. 2010; Stewart et al. 2011; Pollock and Wilson 2015; Gilissen et al. 2017; Sharp et al. 2018). However, one study has cited a long-standing relationship as a potential barrier to GP involvement in ACP due to professional concerns about damaging that relationship (De Vleminck et al. 2013). Relationship continuity can help engender trust (von Bültzingslöwen et al. 2006; Dinç and Gastmans 2013). The literature suggests that trust is an important underpinning of both relationships between professionals and between residents and professionals (Seymour et al. 2011; Luckett et al. 2017; Wilson and Seymour 2017). Trust was explicitly mentioned by only one participant in the study but was an implied factor for several residents and relatives in deciding who to discuss their wishes with. Choosing to discuss wishes with a visiting professional rather than nursing home staff could add further to the silo working in ACP, with nursing home staff sometimes excluded from the discussions as a consequence of this. There was an absence of a forum for professionals to talk together with residents and/or relatives, with the exception of the GP round, although this was limited to nursing home nurses and GPs. Indeed, implementing ACP in practice has been acknowledged as challenging because the relational work and continuity of care required for the complex and unpredictable conversations is often not prioritised (Lund et al. 2015).

The ACP documents in use for residents in the two nursing homes did not assist with management continuity. There was no joint approach, and the documents were not usually shared and were held separately, therefore running side by side. ACP was often broken down into tasks, with professionals assimilated into the nursing home's ACP routine to complete a specific task, such as when GPs were asked to discuss DNACPR with a resident, but they were not fully integrated into the routine. This reflects the findings of a study by Tsakitzidis et al. (2017) investigating professional perceptions of inter-professional care in nursing homes in Belgium, which identified that professionals' work was described in terms of tasks, professional disciplines worked separately, collaboration was primarily limited to information exchange and there was minimal evidence that they were working towards the same goals. Shared goals and team processes have been identified as facilitative of inter-professional teamwork in primary and community care (Xyrichis and Lowton 2008). There is consensus in the literature that collaboration and cooperation should be underpinned by shared power and negotiated agreement (Gallant et al. 2002; Carnwell and Carson 2008; Le Riche and Taylor 2008; Nancarrow et al. 2013). However, the findings showed that there was a power imbalance between visiting professionals and nursing home staff. The traditional power differentials between nursing and medicine were evident, for example power exerted through a GP mandating whether and when they would get involved in ACP. Power imbalance between nursing and medicine has been found to be a barrier to the team discussion necessary for the implementation of ACP (Seymour et al. 2010). However, medical dominance was reduced with the relational working approach of the GP round, with collaborative power exercised (Nugus et al. 2010). Gair and Hartery (2001) suggest that where there is consensus on goals of care this can reduce medical dominance. Power imbalance was also manifested through the negative discourse of many visiting professionals about the situation of nursing homes in the private sector, with strong views expressed about what support should be provided as a consequence of this funding divide. Goodman et al. (2017) suggest that support from visiting professionals needs to be legitimised as part of their role and care homes recognised as partners at an organisational level.

ACP documents were organisational documents, with individual organisations and the local NHS systems having different documents. Organisations took ownership of ACP based on completion of their documents, with most organisations only accepting their own document as a legitimate record of ACP. In this way, organisations attempted to exert control over the ACP process through their documents, thereby exerting competitive power rather than collaborative power (Nugus et al. 2010). Organisational influence on the ACP process does not appear to feature in the literature but in the two nursing homes, power relations in the disjointed system impacted the enactment of ACP in a way that moved the process away from a resident-centred approach.

8.2.2 Conceptualisation and construction of ACP

The study findings have shown that there was conceptual confusion surrounding ACP. Differences existed in understanding of ACP, both between professionals and between residents and professionals. This has implications for the recognition of expressed wishes and preferences for future care as ACP. The findings showed that professionals might interpret some wishes and preferences as ACP, some as routine care planning, and by running side by side in this way these might not be integrated into a holistic representation of a resident's future wishes, shared across all teams and organisations involved. Professionals' narratives about ACP, such as use of the term 'informal ACP', indicated ways in which professionals made sense of what ACP is and what it is for. These understandings often deviated from national and international definitions. Figure 8.2 illustrates variance between how policy constitutes ACP and how ACP was found to be understood in the study. Artefacts, such as these ACP definitions and ACP strategy documents, including the guidance produced by the NEOLCP (2011), are proxy aspects of the ACP routine (Pentland and Feldman 2005). How ACP was understood by those doing the work of ACP and how ACP was enacted in the nursing homes differed from this proxy routine. However, this divergence between the proxy and the ostensive and performative aspects of the ACP routine (ibid) is not limited to these two nursing homes. Perceptions of ACP that vary from national definition are also held more widely, with ACP documents used in a range of settings, not just in nursing homes, including elements such as funeral planning (e.g. St Christopher's Hospice 2010; Sussex Community NHS Foundation Trust 2014; Milton Keynes Joint Palliative Care Group 2018). There was not just one ACP routine and there was variation in how ACP was constructed between the nursing homes and other organisations supporting residents with ACP.

Ambiguity about the meaning of ACP and of what it comprises has previously been discussed (Russell and Detering 2018). Previous research has shown that understanding of ACP varied between professionals and patients or residents (Stone et al. 2013; Russell 2016). Relatives of care home residents with dementia were uncertain as to what ACP was even after having an ACP discussion (Ashton et al. 2016). Perceptions of ACP have been found to vary amongst acute sector professionals (Llewellyn et al. 2018) and a lack of confidence in understanding of ACP reported by both nursing home nurses (Stone et al. 2013) and community nurses (Seymour et al. 2010). Pollock and Wilson (2015) found that there was an elusive nature to ACP making it hard to assess implementation and outcomes. Yet that ACP can be understood in different ways is generally not explicit in the literature, with Froggatt et al. (2008) suggesting that the term is often used without definition or explanation.

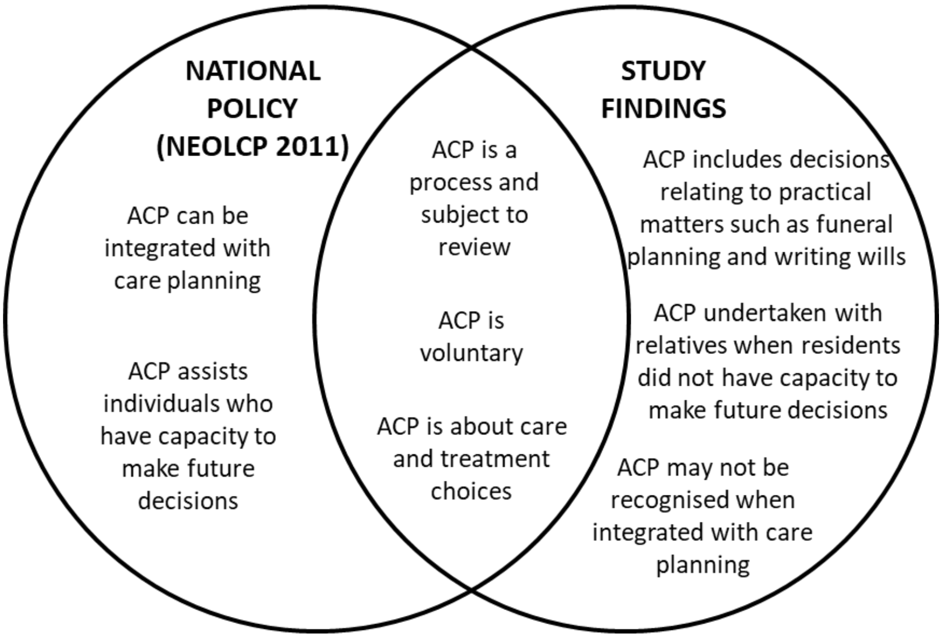

Figure 8.2: Difference between national definition of ACP and ACP in practice in the two nursing homes

ACP was constructed within the ostensive aspect of the routines of the two homes as something distinct from other aspects of care planning, with specific meetings to discuss ACP and specific documentation, separate from other care planning. Both homes also had specific policies for ACP, separate from care planning policy. Some visiting professionals also had specific documents for recording ACP. Yet the data showed that in practice ACP could be closely intertwined with other aspects of care planning. Similar findings have been reported elsewhere with community nurses expressing confusion about the differences between day-to-day care planning and ACP (Seymour et al. 2010). In addition, Pollock and Wilson (2015) found that community professionals rarely mentioned the term ACP, DNACPR and preferred place of death operationalised as tasks that were part of the general practice of end-of-life care rather than viewed as discussions about future care. They were associated more with aspects of end-of-life care planning such as placing the patient on the GSF register[10] and arranging anticipatory medication. They described this as professional planning, which was considered to not be directly orientated to ACP and mostly undertaken without involvement of patients or relatives.

In the nursing homes, ACP was not always separated from care planning in this way. However, the findings have shown that ACP that is integrated with day-to-day care planning might not be recognised as ACP and thus the wishes expressed not shared with other professionals, unless the

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[10] A GSF register or palliative care register includes patients/residents who are considered likely to be in their final stage of life (years, months, weeks or days). Most GP practices have a GSF register, as do some care homes (National GSF Centre 2021b).

care planning was a joint process such as happened at the GP round in nursing home A. National guidance proposes that ACP should be seen as part of the wider care planning process (NEOLCP 2011), with the finding of a study exploring GPs' perceptions of ACP suggesting the importance of making ACP part of ongoing discussions (Sharp et al. 2018). However, the inter-relationship between ACP and care planning is not explicit in ACP definitions, exacerbating the conceptual confusion of ACP as a separate process.

ACP was a professional construct, with ACP documents dominating ACP routines. Following the script provided by the document restricted discussions to the content of the form. ACP documents were devices of professional control, conferring primacy to the professional conceptualisation of ACP thereby subjecting death to medical control and giving precedence to the management of dying. Many of the residents in this study had prioritised planning for death and had not thought about choices relating to treatment. They framed future planning in terms of concerns of a practical or personal nature, thereby differing from professionals who concentrated primarily on medical matters such as wishes for future treatment and place of care.

Participant residents talked about not thinking about their future care but living day by day. There was some limited data from nursing home A to suggest that professionals struggled with opening ACP discussions as they did not want to intrude on this focus on getting on with living. All of the residents had completed some planning for after they had died, such as making funeral plans. Previous research has found older people focus on practical, personal, legal and financial planning; they plan for after death rather than future health needs and concentrate on living rather than dying (Carrese et al. 2002; Samsi and Manthorpe 2011; Dickinson et al. 2013; Fleming et al. 2016). Horne (2011), investigating ACP with community dwelling patients with advanced lung cancer and with a wider age range, also found that although some people talked about planning their funeral in a similar way to how they talked about a holiday, they did not speak about dying in the same way. Pollock and Wilson (2015) described this practical work that people undertake in preparation for their death as personal planning. They discussed this and professional planning, described above, as parallel strands of additional planning that intersected ACP as defined by policy, thereby identifying this aspect of future planning as primarily separate from ACP. Aspects of future planning prioritised by residents ran side by side with those prioritised by professionals.

However, the study findings identified some interaction between resident priorities and ACP undertaken by professionals. Personal and practical aspects of planning such as funeral planning and wills were a feature of professional narratives of ACP, although they prioritised medical matters. Indeed, components of what Pollock and Wilson (2015) describe as personal planning were incorporated into the ACP documents used by the nursing home professionals. The otherwise separate strands of resident-led ACP and professional-led ACP were also integrated through appointment of an LPA. This blurs the boundary between the two, being both a practical approach to managing finances and/or healthcare decision-making in the future but with appointment of an LPA for health and welfare formalised as part of ACP through the UK *Mental Capacity Act 2005* and relevant to professional-led medical planning. Appointment of a power of attorney has previously been found to be a common element of planning amongst elderly people, often linked to the uncertainty of getting older, although more frequently arranged just for managing finances (Dickinson et al. 2013).

The findings highlighted the difficulties encountered by residents when making decisions about future care and treatment, when they did not know what ill-health they might face in the future. Making plans for after death is making a decision about something tangible, with death a certainty even if the timing of death is unknown. Appointment of an LPA is making a decision in relation to the concrete situation of loss of capacity to decide. Residents indicated that knowing what might happen to their health and what decisions may need to be made is difficult. The dying process is rife with uncertainty (Carrese et al. 2002) and research suggests that this may reflect the difficulties faced by older people in planning for health needs. They are less concerned about planning for end-of-life situations outside their imagination (Piers et al. 2013) and consider decisions can only be made when it is clear what is being faced (Dickinson et al. 2013). However, the findings showed this may happen too late. The unpredictability inherent in end-of-life trajectories of frail, elderly people was demonstrated with residents often observed to have a rapid dying trajectory and no diagnosis of one specific terminal condition. The recovery of residents whose death was expected with near certainty was also observed, described as the phenomenon of ‘bounceback’, something which defies realistic planning for death and is reported as common in nursing homes (Johnson et al. 2014). Yet the professional perception that there was a ‘right time’ to have an ACP conversation raised in the study ran side by side with these difficulties. Finding the ‘right time’ is a barrier to ACP frequently cited in the literature, primarily associated with challenges in prognostication (Seymour et al. 2010; De Vleminck et al. 2013; Lund et al. 2015; Smeets et al. 2016; Elliott and Nicholson 2017). Professionals have suggested it is important to find a time when patients are ‘ready’ to consider ACP (Pollock and Wilson 2015) but research with older, frail adults suggests there may not be such a time due to the day-to-day existence of people living with frailty (Bramley 2016) and that models of ACP that focus on living well now are needed (Combes et al. 2019).

Running side by side with the resident conceptualisation of ACP dominated by personal and practical planning, professionals primarily conceptualised ACP in biomedical terms, working with a limited operationalisation of ACP in terms of medical decisions relating to end-of-life care such as resuscitation, place of care and treatment escalation. As a biomedical construct, ACP was impacted by the medicalisation of nursing home care limiting recognition of psychosocial and spiritual contributions. The biomedical dominance in ACP mirrored the approach to care more generally in the two homes. There was a focus primarily on residents' physical functioning, although other dimensions of care were not completely excluded. It also reflected the primary approach of visiting professionals. Although most nursing homes internationally report operating within a nurse-led or social-led model (Tolson et al. 2013), physical health tasks have been found to dominate (Murphy 2007; Kuo et al. 2019). This is shown in the finding that a typical resident with dementia in a care home spent only two minutes interacting with others outside care tasks over a six-hour daytime period (Alzheimer's Society 2007). The dominance within ACP of physical aspects of care also echoes palliative and end-of-life care provision more generally which has become underpinned by a hierarchy of care that prioritises biomedical management (McNamara 2004). Pastrana et al. (2008) found that definitions of palliative care tend to focus on the assessment and control of symptoms as the main task. This emphasis on physical symptoms at the expense of psychosocial and spiritual concerns has been associated with the medicalisation of palliative care (Clark and Seymour 1999; Clark 2002; Robinson et al. 2017). The Framework for Enhanced Health in Care Homes (NHS England 2020) is a national initiative that promotes delivery of holistic support to care home residents from visiting professionals, aiming to move away from a narrow medical care focus.

Reference to psychosocial and spiritual matters were largely absent from the ACP records of the participant residents. Availability of specific psychosocial or spiritual support from specialist professionals was limited, and exploration of these areas of care with residents was not prioritised by the nursing home nurses. Yet ACP has been envisioned more broadly than a focus on treatment choices or refusal of treatment. Alternative approaches emphasise the social process of ACP, understanding the context of the person's individual life and exploring their values and goals rather than specific treatment decisions (Singer et al. 1998; Winzelberg et al. 2005; Rodriguez and Young 2006; Séchaud et al. 2014; Russell 2016). Visits from social workers were infrequent in the two homes, yet Chaddock (2016) suggests that social workers have much to offer ACP, having skilled communication and extensive experience of relationship-based approaches to communicating about difficult and emotionally painful issues (Scanlan 2016). However, there is negligible reference to the involvement in ACP of psychosocial or spiritual professionals in nursing homes in the literature, although a role for social workers in undertaking work relating to grief and loss or dealing with psychological issues was identified in US nursing homes (Bern-Klug et al. 2004; Chapman and Toseland 2007). Research suggests that the limited incorporation of spiritual needs in the ACP completed in the two nursing homes reflects ACP practice more generally given the research finding that reference to spirituality is absent from much of the ACP literature (Lutz et al. 2018). However, research has also found that many religious leaders communicate with individuals about end-of-life matters and facilitate fulfilment of preferred spiritual care (Pereira-Salgado et al. 2017). Séchaud et al. (2014) suggest that the concept of quality of life and its dimensions form the basis of ACP and inform the need to de-emphasise the biomedical approach to consider the aspects prioritised by residents.

8.2.3 Recognising participation in ACP

Some professionals from organisations other than statutory health or social care organisations, such as religious ministers, were not afforded the same status by nursing homes as others, meaning their involvement in ACP could go unrecognised. Similarly, residents sometimes discussed ACP primarily with relatives[11], with the outcome of such discussions not necessarily integrated with the ACP undertaken by professionals. This could result in these strands of ACP running side by side with healthcare professional-led ACP. The construction of ACP as a professional process controlled by professionals, inferred power to healthcare professionals and prioritised their input. This impacted the professional reach of the team, in terms of who was identified as part of the team responsible for ACP, with this primarily limited to nursing home nurses, GPs and specialist nurses. However, the conceptual confusion about ACP also impacted professionals' understanding of who within NHS services might be involved, demonstrated clearly by the GP who considered that a specialist nurse would not be involved in ACP, whereas this nurse had completed some ACP with a resident. In this way, ACP completed by a healthcare professional might not be recognised as such by another healthcare professional, with these different strands of ACP therefore running side by side.

The findings demonstrated the involvement of spiritual care professionals in ACP was unknown. The only visiting professionals in either nursing home specifically providing spiritual support were religious ministers. Religious ministers providing spiritual care to residents were not recognised as members of the healthcare team and their potential involvement in ACP was not given consideration by the nursing home nurses. Not being afforded status as a member of the

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[11] The term relative is used to refer to any family member, friend or significant other who knows the resident outside a health or social care professional relationship and includes the solicitor of one participant resident who was considered a friend alongside the professional relationship.

healthcare team meant religious ministers did not record in the nursing home notes. There was potential that wishes were discussed but not recorded. Debates relating to the professionalization of hospital chaplaincy reveal challenges both internal and external to the profession in relation to their status in the healthcare team, whether they should have full access to health records and the relationship between spiritual expertise and religious pastoral ministry (Loewy and Loewy 2007; Merchant and Wilson 2010). The strict confidentiality of encounters with a religious minister means clergy rarely share information (Loewy and Loewy 2007). However, activity coordinators similarly did not record in the resident's ACP document, so their involvement in ACP was also unknown despite their role in ACP being recognised by managers in nursing home B. Absence of these psychosocial spiritual dimensions to ACP records reflected the biomedical construction of ACP, and the status of the professionals and their potential contribution to ACP records.

Although professionals identified with a role for relatives in the ACP process, this centred on informing ACP when a resident lacked capacity to be involved and ensuring relatives were aware of wishes expressed by residents, to avoid conflict when honouring these wishes. Although the nursing home staff involved relatives in the ACP process, the full extent of their involvement in ACP was not always recognised. The findings showed that residents had often discussed practical aspects of ACP with relatives prior to their admission to the nursing home and had sometimes engaged solely with relatives about future planning and decision-making within the nursing home, including medical aspects of ACP. Indeed, residents discussed ACP with their relatives more often than with professionals. The importance placed on involvement of relatives in future decision-making by residents was underlined by the number of residents in the two homes who had appointed relatives as a proxy, either informally or formally as LPA for health and welfare. ACP discussions happening solely between residents and relatives were not always shared with professionals and consequently this future planning was running side by side with professional ACP. This meant these expressed wishes were unknown by the professional team and therefore, might not be honoured, if the relative was unavailable at the time a decision needed to be made. That individuals look to relatives more than professionals to discuss their ACP, including treatment and medical care decisions, has been discussed in the literature (Singer et al. 1998; Mathie et al. 2012). A survey of people aged over sixty-five found that more than three times as many individuals had discussed ACP, including treatment decisions, with relatives than had discussed it with professionals (Musa et al. 2015). Horne (2011) found personal and practical matters were often discussed with relatives without involvement of professionals. Pollock and Wilson (2015) report similar findings and although they do not mention involvement of relatives in other aspects of ACP, they acknowledge that little is known about the extent or nature of discussions that happen within families, with this generally occurring outside professional awareness. Trust underpinned decisions residents made regarding with whom they discussed ACP. Relatives, and in one case the resident’s solicitor, were often chosen over staff. Trust has previously been identified as a reason for individuals involving relatives more than professionals (Singer et al. 1998; Bollig et al. 2016), which may not develop with professionals due to the lack of relationship continuity (Singer et al. 1998). As discussed in section 8.2.1, relationship continuity provides a foundation for development of trusting relationships with professionals, so poor relationship continuity may lead to more ACP happening solely within families and therefore running side by side with professional-led ACP.

In both nursing homes, staff involved relatives in the life of the residents and the home. They were often involved in ACP discussions, but a specific role in the ACP process was not formally identified such as in home policy. There was no overt recognition of their continued role as carers, although examining their involvement with residents using Nolan and colleagues’ (1995) typology of family care, they were fulfilling caring roles. They were a resource, both providing information to support ACP and also bridging the gap between organisations and professionals, such as by providing information from a hospital consultant to the nursing home. However, both nursing homes were primarily professional territories with the nurses in charge, and differences in the authority and knowledge bases between professionals and relatives inferring power on professionals (Twigg 1989). Holmgren et al. (2013) found that relatives were perceived as ‘visitors’ in Swedish nursing homes, with this concept pre-determining their level of involvement in care. This was not replicated in the two study homes, but professionals did maintain power over relatives. This power was particularly explicit in the way the nursing home nurses referred to the perceptions of some relatives about resident care and treatment options. They often expressed concerns that relatives’ expectations in terms of prognosis and recovery from episodes of acute illness were ‘unrealistic’ and this was perceived as problematic in achieving the best care for residents. There is minimal reference in the literature to mismatched expectations regarding care needs between nurses and relatives or the impact of such a mismatch on end-of-life decision-making. Gjerberg et al. (2011) found that relatives did not want to stop active treatment contrary to staff opinion. Majerovitz et al. (2009) found relatives’ unrealistic expectations of nursing home staff in terms of what is possible in an institutional setting were a barrier to communication between staff and relatives. It has been suggested that relatives lack knowledge about end-of-life care (Dreyer et al. 2009), which may be associated with unrealistic expectations (Hanratty et al. 2014). Australian GPs perceived relatives as posing significant challenge to providing palliative rather than active treatment, suggesting that this can be mitigated by meeting with relatives to agree goals of care (Phillips et al. 2009). Consensus building to ensure all involved in a resident’s care are working to the same goals was identified as a key characteristic of multi-professional working in the literature review (see section 2.4.2.4), with two studies including relatives amongst those with whom it was considered important to reach agreement (Forbes 2001; Bern-Klug et al. 2004). Promoting relatives’ understanding of the resident’s disease trajectory can help with a sensitive transition from curative to palliative care (Gonella et al. 2019).

Relatives’ views on resident needs were not given credence, assessed as unrealistic expectations using a professional lens. Limited opportunities were provided to discuss or understand relatives’ views by any professional or to agree shared goals for care. There was no clear strategy to provide support to relatives, either when their goals of care differed from those of the professionals or when relatives were struggling emotionally with deterioration of their family member, although these emotional difficulties were recognised by GPs and nursing home nurses. A systematic review of qualitative findings suggests that relatives identify good end-of-life care with the establishment of a partnership with professionals, including being recognised as the resident’s advocate and being involved in shared decision-making (Gonella et al. 2019). However, although not specifically raised by participants in this study, there is considerable research evidence to suggest that relatives also find involvement in end-of-life decision-making, with the associated decisional uncertainty, burdensome (Dreyer et al. 2009, 2011; Fosse et al. 2014; Ashton et al. 2016; Bollig et al. 2016; Sarabia-Cobo et al. 2016). One relative commented on the absence of specific psychosocial support for relatives and the benefits of providing this support was recognised by a manager. Nursing home nurses have an important role in supporting relatives (Dorell and Sundin 2019), with inadequate support from professionals causing relatives to experience additional burdens when involved in decision-making (Givens et al. 2009; Fosse et al. 2014). Consideration also needs to be given to relatives’ own needs which are influenced by loss and grief (Ashton et al. 2016). This suggests that using the conceptualisation of relationships between health and social care providers and informal carers outlined by Twigg (1989), relatives need to be recognised in the ACP process as both ‘carers as co-clients’ and either ‘carers as co-workers’ or ‘carers as resources’, dependent on the level of involvement wanted by both residents and relatives.

8.3 Applicability to end-of-life care beyond ACP

The study investigated ACP as an exemplar of end-of-life care practice and although the conceptual framework represents a cultural interpretation of multi-professional involvement in ACP, it also has resonance with other aspects of end-of-life care practice. The broadening of the definition of ACP used for this study, to include the processes by which a resident’s expressed wishes were implemented, intricately links the framework to end-of-life care provision more generally. Honouring wishes expressed in ACP takes place as an integral component of end-of-life care provision. The cultural underpinnings of the conceptual framework have implications beyond ACP in terms of how both nursing home staff and visiting professionals framed their work and how this impacted on integrated working between professionals and organisations. In the same way as ACP and multi-professional working were running side-by-side, it could be argued that much of end-of-life care and multi-professional working were also running side-by-side. The limited cross-organisational integration of processes and a multi-professional rather than inter-professional approach impacts other aspects of end-of-life care.

Misaligned professional practices impact end-of-life care similarly to ACP. The identified ‘disjointed system’ influences all care provision, with the power differentials between nursing home staff and visiting professionals, the misaligned temporal structures and the spatial segregation impacting beyond ACP. Given that at any one time most nursing home residents can be considered as approaching the end of their life (see section 1.2), the fragmented approach to care in the two homes influences end-of-life care provision. One resident was clear that relationship continuity is important for end-of-life care more generally, not just ACP, reflecting the sensitive and emotive nature of all care at the end-of-life which often invokes fear and anxiety (Chochinov 2006).

Conceptual confusion and construction of ACP are specific to ACP. However, the conceptual framing of end-of-life care can be equally applied so that the conceptual framework also informs end-of-life care practice. Hospice and palliative care was developed in response to cancer but there are subtle differences between the model of palliative care required for people dying of cancer and that required for frail, older people living in nursing homes, differences which are not always recognised (Hockley 2017). The challenges of unpredictable trajectories to death for a population of frail, older adults that have been discussed in relation to ACP work against the basis of the cancer palliative care model which predicates provision of high-quality end-of-life care on identifying dying (National Institute for Health and Care Excellence 2011). Assessment of symptoms requires a different approach, particularly when a resident has advanced dementia and is unable to communicate their experience (Brorson et al. 2014; Hockley 2017). Therefore, potential exists for professionals to work with different understandings of how to approach palliative care in a nursing home and for these to run side by side, so there is no one end-of-life care approach or routine, in a similar way to ACP. There is a need for information sharing and agreed systems of communication and coordination to support UK care homes not just in the area of ACP (National Institute for Health and Care Excellence 2015; British Geriatrics Society 2016).

In line with the espoused holistic model of palliative care (World Health Organization 2002; Butler et al. 2012), attention to psychosocial and spiritual aspects of care is important to all end-of-life care provision, including symptom management as advocated in Dame Cicely Saunders' theory of 'total pain' (Krawcyzk and Richards 2018). The dominance of a biomedical approach and marginalisation of psychosocial and spiritual care will therefore impact beyond ACP. The limited availability of psychosocial and spiritual services and focus on biomedicine by nursing home staff and visiting professionals mean these aspects of care can run side by side with biomedical aspects. Recognition of all those contributing to any aspect of end-of-life care, including relatives and professionals from non-statutory organisations, will ensure their contributions are integrated into holistic care provision rather than running side by side.

8.4 Enhancing ACP and end-of-life care practice

Although partnership working and cooperation in end-of-life care provision between the nursing home staff and visiting professionals was promoted in the study-site nursing home policies, the findings have shown that ACP and multi-professional working were running side by side. Exactly what 'partnership-working' and 'cooperation' should look like was not delineated in these policies. Although findings of two systematic reviews suggest that a system-wide approach is needed to achieve the best outcomes from ACP (Gilissen et al. 2017; Myers et al. 2018), there was limited integration of both the nursing homes in a wider local health and social care system approach to ACP and end-of-life care. Effective sharing of information is acknowledged as essential for professionals to be able to work together in ACP and to ensure wishes are honoured (Lund et al. 2015; Pollock and Wilson 2015; Sharp et al. 2018), yet the difficulties of sharing an individual's wishes across organisations and ensuring they are recorded in an accessible way has been identified as a barrier to implementing ACP in practice (Lund et al. 2015). The confusion caused by the array of documentation available for recording ACP has also been identified as a barrier (Robinson et al. 2013). This was demonstrated in this study by different ACP documents used by each of the nursing homes and the NHS in each area having its own document. The use of multiple ACP documents across organisations hindered a whole system coordinated approach to ACP for the residents in the two nursing homes. There is a literature reporting on whole system approaches to ACP in the UK such as 'Deciding Right', implemented in Northern England (Chaddock 2016), and electronic palliative care coordination systems (EPaCCS) (Leniz et al 2019). However, there is evidence to support that such approaches have limited benefits for nursing home residents (Whole Systems Partnership 2016; Chumbley 2021), with marginalisation of care homes reflecting the professional status afforded to this sector by other professionals in the system (Standing et al. 2020).

The finding in this study that there was a hierarchical approach to care and power imbalance between nursing home staff and their visiting professional colleagues, is also apparent in the literature as a barrier to effective inclusion of nursing homes in the whole-system approach to ACP of EPaCCS (Whole Systems Partnership 2016; Standing et al. 2020). Standing et al. (2020) found that care home staff felt their expertise was valued less than other professionals and variations in access and editing rights between professionals, with limited access to the system being provided to care home staff, was seen as reinforcing professional hierarchies and boundaries between care home staff and other professionals. The aim of ACP recording systems like EPaCCS is to enable a coordinated approach to ACP so people's wishes are achieved wherever possible (NHS Improving Quality 2013; Lindsey and Hayes 2014) and for all organisations in a local system, including nursing homes, to be able to access up-to-date information (Petrova et al. 2018). However, there are no mandatory requirements as to which professional groups should have access to the system (Lindsey and Hayes 2014) and the care home sector is missing from the organisations reported to have access to the system in some localities (Price 2016; Plenderleith 2017). Even where access is provided, IT challenges often prevent full access to care home staff meaning they are unable to enter data and unable to read live information, instead needing to rely on printed copies of the data which quickly become out of date (Whole Systems Partnership 2016). This compounds a sense of care homes being a peripheral rather than a core service and loss of professional jurisdiction (Standing et al. 2020; Chumbley 2021). Yet in this study the findings show that it is not just technical difficulties with electronic systems that mean care homes are marginalised from whole systems approaches, as with one of the locality ACP documents care homes were not included on the circulation list. Care homes are often not involved in development of system-wide approaches (Holdsworth 2016), the existence of multiple individual care homes and care home organisations making engaging with the sector challenging (Goodman et al. 2013a). 'Deciding Right' was reported as having been developed by doctors, nurses, social care professionals, patients and carers, but the level of involvement which nursing homes had in its development are not reported (St Oswald's Hospice 2018). In light of the study findings that cross-sector working is complicated by the lack of shared understanding of ACP, this suggests that involving all services and teams from across the system at the inception of a whole systems approach is important.

Chumbley (2021) found that having a locality ACP coordination system did not alleviate the perceived barrier to ACP of poor communication. The benefits of another method of communicating about ACP, namely a forum for discussion between multiple disciplines, was identified in the literature review, with research providing some evidence to support the use of case or care conferences and multidisciplinary meetings (King and Roberts 2001; Phillips et al. 2008; Seymour et al. 2011; Luckett et al. 2017; Wilson and Seymour 2017; Durepos et al. 2018). The literature on case or care conferencing reports on nursing homes outside of the UK and research to date has mainly focused on their use in dementia care (e.g. Phillips et al. 2013; Luckett et al. 2017; Nakrem et al. 2019). Nevertheless, the literature suggests that case conferences include residents and/or relatives and so this type of forum could therefore extend the team to formally include relatives in the planning process (Luckett et al. 2017; Durepos et al. 2018). The case conference approach would therefore fit with the findings from the two nursing homes highlighting the important role of relatives in ACP. However, time availability is likely to be a barrier to implementing such forums as the literature review identified time constraints as a barrier to professionals becoming involved in case conferences and multi-professional meetings, in particular GPs, and the study findings also showed that time was a barrier to enacting ACP.

Multi-professional GSF meetings have been identified as a key mechanism in the coordination of end-of-life care across a complex and sometimes fragmented system (Pollock and Wilson 2015). This echoes findings that suggest that regular team meetings can enhance inter-professional teamwork (Xyrichis and Lowton 2008) and sustain joint working between health and social care professionals (Kharicha et al. 2005). Yet, in this study it was found that neither nursing home was included in the end-of-life care planning discussions of the wider inter-professional team about residents at GSF meetings, which suggests that care homes are not considered a core service. This is despite multidisciplinary team meetings being a feature of national guidance to support an inter-organisational approach to provision of personalised care to people living with long-term conditions (NHS England 2014b). The only formalised structure to support discussion and sharing of information between professionals identified in either nursing home was the GP round in nursing home A. It provided space for communication between professionals, which had the benefits of providing opportunities for in-depth discussion, alongside building working relationships. However, this was only between two professional disciplines. One participant professional suggested that holding a similar meeting to the GSF meeting in the nursing home to discuss all residents would be beneficial, although as with case conferences this might not be achievable due to the additional time commitment. Greater coordination of care provision, including involvement in local system end-of-life care initiatives, such as GSF meetings, could lead to better end-of-life care planning and delivery for nursing home residents.

A focus on coordinating ACP from a professional perspective promotes it as primarily a professional construct, reflecting the findings of this study that professionals rather than the resident were in control. Yet, ACP is identified as an outworking of person-centred care (Exley et al. 2009; NHS England and Coalition for Collaborative Care 2016; Dixon 2017; Thomas 2018; Saevareid et al. 2021), fitting with policy promoting personalisation in adult social care services (Froggatt et al. 2008), and suggesting that any advance care plan should be owned by the resident, as outlined in a national framework for personalised care and support planning (Think Local Act Personal 2021). The professional documents framed ACP within policy rhetoric which depicts person-centred care as being promoted through choice and the opportunity to state preferences and wishes for care as a means of exerting control over decisions at the end of life (e.g. DH 2008; National Palliative and End of Life Care Partnership 2015). This approach reflects the application of consumerism to health and social care which emphasises the importance of promoting the independence and autonomy of older people (Nolan et al. 2004). However, research suggests that some people facing the end of their life place little importance on choice (Horne 2011), and it has been suggested that older people are disadvantaged because they are not in a position to negotiate their care (Parkinson 2004). Indeed, in this study the findings showed a power imbalance, muting the voice of the resident, with access to visiting professionals mediated through nursing home staff and GPs. How person-centred care has come to be represented in policy has been challenged, with the suggestion that there are more appropriate foundations than autonomy and individualism for enhancing the care of older people (Nolan et al. 2004). Rather than an individualistic view of autonomy an alternative approach is one based on interconnectedness and partnership, recognising the uniqueness of each individual, but also the interdependence that shapes our lives (McCormack, 2001). At the core of person-centred care is self, who we are, our values and beliefs, but personhood is also dependent on other people (Fazio et al. 2018).

Relationship-based care is fundamental to delivery of person-centred care (Nolan et al. 2004), in nursing homes meaning both developing close family-like relationships with residents and working collaboratively within the care team (Vassbø et al. 2019). This resonates with the study findings which highlight the importance of ‘knowing the resident’ and also that relationships play a key role in ACP. Given the uncertainty inherent in prognostication and end-of-life trajectories of nursing home residents, knowing residents well can assist end-of-life care decision-making. Research with care home residents living with dementia has shown that in situations where there is not a clear answer in any advance care plan to a decision encountered, everyday preferences and previous statements made by the resident can provide direction as to their wishes (Goodman et al. 2013b; Saevareid et al. 2021). However, the findings from the two nursing homes indicate that the professional construction of ACP did not situate the resident within their social world or seek to understand what is important to them beyond the primary focus on biomedicine, which has also been reported elsewhere (Russell 2016). Goodman et al. (2013b) found that the accounts of residents with dementia of their everyday experiences of care demonstrated what mattered to them both in the present and the future. They suggest that for residents with dementia agreeing an advance care plan prior to, or on admission to a care home, may unintentionally lead to their voice being excluded from ongoing discussions and decisions about their future care. In this study, the professional construction of ACP led to a biomedical focus which constrained the resident voice and identified that residents prioritised practical aspects of future planning rather than treatment planning. The approach to ACP observed in the two nursing homes reflects the dominant approach, with its focus on underlying disease and the medical model, and conflicts with person-centred care where the focus is on personhood (Kitwood 2019). Approaching ACP as a means to explore and record resident preoccupations and wishes about everyday care as proposed by Goodman et al (2013b) provides an alternative approach to ACP, which supports provision of person-centred care for all nursing home residents.

ACP is considered to be a device to reduce uncertainty in future decision-making (Lund et al. 2015) but there was considerable uncertainty encountered in the ACP processes in both homes. As well as relating to prognostication and unpredictable trajectories, uncertainty also existed about roles and responsibilities for ACP. Using structured tools, such as the ACP documents in use in each locality and nursing home, provided a script, which was a way to manage uncertainty in the professional-resident interactions (ibid) by limiting discussions to the topics identified by professionals to be needed. However, it was unclear in both nursing homes as to who had overall responsibility for coordinating and gathering information for ACP.

It has been reported in the literature that no one professional group is seen to have responsibility to initiate, lead or coordinate ACP, which creates challenges for its implementation (Robinson et al. 2013; Beck et al. 2017). Standing et al. (2020) suggest this could lead to health and social care professionals ‘passing the parcel’ of ACP and patients falling though the gaps. Given ACP is an iterative process (Levoy et al. 2020), with the resident trajectories demonstrating that this process happens both over time and in different settings, involving professionals from many organisations, alongside relatives, makes its coordination complex. Although GPs are frequently identified as being well-placed to coordinate ACP (Standing et al. 2020), they rely on the knowledge of care home staff to inform their decision-making (Goodman et al. 2015), which suggests nursing home staff may be better placed as coordinators. Nursing home staff consider acting as advocates for their residents to be part of their role in providing end-of-life care (Young et al. 2017) and leading and coordinating ACP would better enable them to do this.

The conceptual framework depicts the approach to ACP in the two nursing homes as multi-professional working not inter-professional working. The model of multi-professional input to the two nursing homes was generally not conducive to support the approach to ACP currently promoted in policy and practice. ACP needs to be an inter-professional process, but this is complex to implement (Lund et al. 2015) and potentially unachievable given the complex health and social care structures and resource implications at a system and organisational level. Except for the GP round in nursing home A, the arrangements for visiting professionals were not satisfactory, with NHS services favouring models of care that focus on treatment and episodic involvement, whilst care home providers prioritise relationships that promote ongoing review of care (Goodman et al. 2017). It meant decision-making was not necessarily informed by previous planning or made with someone, either professional or relative, who knew the resident well. Yet findings have shown that relationships are important both to ascertaining wishes and implementing wishes and to ensure ACP is person-centred.

The model of ACP enacted here did not incorporate the priorities of residents, thereby not delivering a person-centred approach to care. Enabling delivery of a relationship-centred approach to ACP would require a renegotiation of professional boundaries and a rebalancing of power, to put the nursing home staff in control of the ACP process and empower them to change how it is constructed, something that would be difficult to achieve given the embedded nature of multi-professional and ACP structures. Although coordination of the process is required to ensure information is available to inform decision-making, a whole systems approach to achieve this should not be prioritised over provision of relationship continuity. Relationships between staff, residents, relatives and visiting professionals remain the most common facilitators to ACP (Chumbley 2021). Reeves et al. (2010) suggested that approaches to professional teamwork are complex and nuanced, and that the structure and function of inter-professional working should be matched to the team's purpose and local needs. Aligning the structure and organisation of the multi-professional team to the purpose of ACP by ensuring relationship continuity with key professionals, facilitating shared documentation and shared understanding of ACP beyond a narrow biomedical definition, and broadening the conceptualisation of the team to include all those who can contribute to ACP including relatives, could offer ways to enhance end-of-life care practice in nursing homes.

8.5 Chapter summary

This chapter has presented a conceptual framework ‘Running Side by Side’, a synthesis of the study findings. This framework represents how multi-professional working and ACP within the two homes were running side by side. The framework has been explained and situated in relation to relevant literature in terms of the misalignment between professional practices and ACP, the conceptualisation and construction of ACP, and recognising participation in ACP. It is proposed that to enhance ACP and end-of-life care in nursing homes there needs to be greater integration between nursing home staff and visiting professional ACP practice. This could be supported through development of inter-professional and inter-organisational approaches, such as regular multi-professional meetings or case conferences, and development of a unified framework for ACP across the local system. However, to develop ACP and end-of-life care practice that aligns with resident priorities, developing relational continuity needs to be prioritised. ACP also needs to be constructed with a broader focus than biomedical matters and professional boundaries need to be renegotiated. Multi-professional working in ACP within nursing homes is a complex environment potentially involving many different organisations with a divergence of power between them, creating inherent difficulties in achieving the changes necessary to have a genuinely inter-professional and inter-agency approach. The contribution of this study to the knowledge base alongside its implications and the study’s strengths and limitations are outlined in the next chapter.

Chapter 9 Conclusions, Implications and Reflections

9.1 Introduction

This chapter presents the main conclusions and implications of the study for practice, education and policy. First, the study's contribution to the body of knowledge in the field of multi-professional working, ACP and nursing homes is presented. The implications of this work to practice and education, and to policy are then considered. The study's strengths and limitations are critiqued and recommendations for future research discussed. Lastly, a short reflection on my PhD journey is provided.

9.2 Contribution to knowledge

To my knowledge, this is the first UK study to explore multi-professional working through the vehicle of ACP in nursing home settings. Ethnography provided a novel methodological approach for the exploration of the structure and organisation of multi-professional working in ACP and end-of-life care in nursing homes. I suggest that the findings of the study make an original contribution to the expanding evidence base relating to ACP and end-of-life care provision in nursing homes, and to multi-professional working practice in nursing homes, through the exploration of both these topics and their impact on each other. The existing literature on multi-professional involvement in ACP within nursing homes is minimal, with research findings relating to multi-professional working reported secondary to the main study purpose. Much research relating to ACP has explored understanding of patient and professional experiences of and the challenges faced in implementing ACP, whereas this study specifically examined the impact of multi-professional working on ACP. The study also focused on nursing homes, an under-researched setting, particularly in the UK (National Institute for Health Research 2019). The conceptual framework developed from the study findings is not a predictive model but depicts an initial understanding of this complex area of practice and the reciprocal impact of ACP and multi-professional working, underpinned by robust analysis and interpretation of the data. It identifies that how ACP is enacted influences multi-professional working, which, to my knowledge, has not been identified in previous research. It also identifies how the disjointed system of multi-professional working impacted ACP, and the professional reach of ACP and multi-professional involvement impacted the integration of multi-professional working in ACP. The conceptual framework expands existing knowledge of the impact of multi-professional working on ACP as the framework has implications for ascertaining of wishes, whereas existing knowledge is limited to the implementation of wishes.

I have identified no previous research that recognises the interrelationship between how ACP is conceptualised and the approach to multi-professional working or the control exerted on the ACP process by professionals in the nursing home setting. Use of ethnography enabled an understanding that illuminates aspects of both the nursing home culture and healthcare system culture that shaped ACP as a professional construct and the composition of the team understood to be involved in ACP, such as the dominance of the biomedical model and power differentials between visiting professionals, nursing home staff and residents. The biomedical framing of ACP by professionals and the documents they use to record ACP have previously been recognised as misaligned with study participants' experience of living with or planning for dying (Horne 2011; Russell 2016). This study extends this knowledge with ownership and control of ACP seen to be situated with professionals rather than residents. This contradicts the finding from the one paper in the literature review that referred to the impact of multi-professional working on ascertaining wishes, which suggested that this led to a more person-centred approach to care, although this only related to ACP discussions with relatives in case conferences (Luckett et al. 2017). This study highlights that the impact of multi-professional working on ACP and shared decision-making depends on the structure and organisation of multi-professional working.

The conceptual framework running side by side depicts how aspects of ACP were sometimes separated and not recognised as ACP, with the understanding of ACP not universally shared. This adds to a body of literature acknowledging that ACP is not universally understood or interpreted, with ACP conceptualised differently by individual professionals (Seymour et al. 2010; Stone et al. 2013; Pollock and Wilson 2015; Llewellyn et al. 2018; Russell and Detering 2018). It extends this to include understanding that ACP may not be recognised as ACP when it is not undertaken as a distinct activity. This builds on the work of Pollock and Wilson (2015) who recognised that ACP in practice can be integrated with other end-of-life care planning meaning that ACP is not necessarily a discrete entity. This study demonstrated how ACP was usually identified as a distinct activity, but could be intertwined with care planning more generally, not just end-of-life care planning. When ACP was completed as an integral component of wider care planning it was not always recognised as such. This offers new insight into the complexity of ACP and ensuring resident wishes are shared with all professionals involved in their care, so they are available when they are needed.

9.3 Implications and recommendations

9.3.1 For practice and education

Aspects of ACP undertaken by different professionals running side by side has implications for professionals’ ability to honour residents’ wishes. If ACP discussions are not recognised as ACP this information may not be shared. If ACP is documented in separate places within an organisation’s records or in different ACP documents for each organisation, the information may not be readily available to the professional making the decision at the time a decision needs to be made. Education of professionals needs to raise awareness of the overlap between ACP and care planning. Although this was outlined in the national guidance published on ACP (NEOLCP 2011) subsequent to the End-of-Life Care Strategy (DH 2008), it was not explicit in national guidelines published by the Royal College of Physicians (Royal College of Physicians 2009) and the rhetoric and practice observed in this study showed that this knowledge is not generally held by professionals and did not inform their practice. Inclusion of ACP in all education relating to care and support planning in health and social care, rather than specifically as a component of end-of-life care education, would assist in achieving this.

To achieve more integrated ACP between nursing home staff and visiting professionals, strategies should be put in place to limit the opportunities for ACP information to go unrecognised and undocumented. At individual practitioner level, nursing home nurses need to incorporate into routine practice the seeking of clarification from every professional that visits a resident as to whether the content of their discussions with the resident included anything relating to future care, so this can be recorded in the resident’s ACP documentation. Nursing home organisations may also be able to work with one or more organisations to agree processes for multi-professional visits such as: shared ACP documents; shared expectations in relation to professionals recording in nursing home notes; and shared expectations regarding handover of information if the professional visits the resident without a member of the nursing home staff present.

Integration of multi-professional working and ACP could be enhanced at a local system level through greater inclusion of nursing homes within existing system processes, thereby reducing fragmentation. Nursing home organisations should be involved in GSF meetings or other opportunities to provide a face-to-face forum for multi-professional discussion should be explored. Given the resource requirement from all organisations to enable face-to-face discussions, and the increasing use of video-conferencing software, these could be established as virtual meetings. At the local health and social care system level, local CCGs need to develop ways to engage nursing homes as valued partners when developing inter-agency strategies for ACP and end-of-life care, something previously recognised through the work of Goodman et al. (2017).

The conceptual framework depicts ACP undertaken with relatives as running side by side with professional-led ACP, suggesting a need for more formal recognition of family members as part of the team who contribute to ACP, alongside acknowledgement of relatives as co-clients. At an organisational level, nursing home staff and visiting professionals need to acknowledge that relatives may have different views, expectations and wishes to professionals and work may need to be undertaken to reach agreement on goals of care that are in line with the resident’s wishes and considered in the best interests of the resident by all involved. This will help ensure resident wishes are honoured. In order for these differences to be considered, nursing home staff and visiting professionals should look at strategies for providing support to relatives as well as providing opportunities to hear relatives’ views. Offering opportunities for joint conversations between visiting professionals, residents and relatives when planning for the future may also be beneficial. At local system level, support is likely to be needed by nursing homes to agree strategies with other organisations on joint approaches to consensus building on appropriate care for residents that include relatives.

9.3.2 For policy

The conceptual framework shows how conceptual confusion about ACP impacted on the integration of multi-professional working with the ACP process. Conceptual confusion was highlighted by the lack of resonance with practice of current national ACP policy, demonstrating a divergence between what is prescribed in policy and how ACP is enacted. National ACP policy does not reflect how residents prioritise future planning or easily align with policy on person-centred approaches to care. Residents’ conceptualisation of ACP went beyond medical matters, with practical and family concerns of higher priority. Current policy promotes ACP as giving control to the individual but in practice, ACP for nursing home residents in the two homes was controlled by organisations and by professionals. Concurring with existing research, national policy needs to extend its definition of ACP away from solely being viewed in terms of physical dying understood in terms of prognostics, decisions and documents (Horne 2011; Bramley 2016; Russell 2016). At national, local system and organisational levels, policies need to reflect a broader understanding of ACP. National guidance is now dated and revision in light of the international consensus definitions and recent research evidence is indicated. CCG and local system end-of-life care groups should ensure involvement of the care home sector to inform development of system-wide policy that reflects all client groups including older, frail nursing home residents.

The conceptual framework also shows how the disjointed approach to multi-professional working impacted on involvement of visiting professionals in ACP in the nursing homes. National policy on multi-professional and inter-agency working for those with long-term conditions and frailty (NHS England 2014b) and commissioning guidance for healthcare for older people living in care homes (British Geriatrics Society 2016) is not reflected fully in practice. At nursing home level, they need to look toward ensuring their policies are congruent with other local organisations such as NHS providers and hospices. Nursing home organisations need to prioritise integration within local systems over their own organisational approaches. They need to achieve a balance between working with strategies and documentation from the home's local health and social care system and having a unified approach across all homes within a nursing home organisation, to enable integrated multi-professional approaches that best support ACP. At local system level, policy that ensures care within nursing homes is provided by professionals who know residents well may be more beneficial than policy to ensure implementation of one approach to ACP.

9.3.3 For future research

The conceptual framework developed is not a predictive model but offers a novel understanding of the structure and organisation of multi-professional working in ACP and end-of-life care in nursing homes. As such further research is required to test and evaluate the framework. Further research is also required to investigate which models of integrated working between the NHS, hospices and nursing homes best support ACP. Study participants identified the GP round as the ideal model of medical care for nursing homes and multidisciplinary team meetings are a component of the Enhanced Health in Care Homes Framework (NHS England and NHS Improvement 2020). However, this model has been implemented in different ways and although there has been research reporting its outcomes from individual locations (e.g. Cook et al. 2017), there is limited evidence to identify which model might best support ACP and end-of-life care. To my knowledge, there is no research into use of case conferencing in nursing homes from the UK although there is international research supporting use of this approach to multi-professional working, which also involves residents and relatives as well as professionals. Research to understand resident, relative and professional experiences of using locality wide ACP models, such as has been implemented in the north of England, would also be helpful in understanding whether this approach meets their needs and leads to resident-centred ACP.

This study has also identified a need to move beyond a biomedical model of ACP, with biomedical aspects of ACP currently running side by side with psychosocial and spiritual aspects of ACP in the nursing homes and not integrated into a holistic representation of the resident's wishes. There is a need for research that investigates ACP and end-of-life care interventions in nursing homes based on a biopsychosocial spiritual approach to end-of-life care (Sulmasy 2002). Research is needed to increase understanding of the contribution professionals such as social workers, spiritual advisers and psychologists make to ACP in UK nursing homes and the benefits psychological, social and spiritual professional involvement brings to the care experiences of nursing home residents, relatives and professionals.

9.4 Strengths and limitations of the study

A strength of this study lies in methodological approach using ethnography to enable an in-depth investigation in the study setting, with more than two hundred hours of observation in each home and the multiple voices, including nursing home residents, relatives, staff and visiting professionals, included in the data. The use of multiple methods of data collection extended the depth and breadth of insight possible. Use of ethnography strengthened the study outcomes by providing a unique, cultural perspective on multi-professional working in ACP in the natural settings of two UK nursing homes. The sites chosen were not intended to be representative of nursing homes more generally. Rather, the findings provide a rich, detailed account of the two homes to enhance understanding of the topic and with the context provided in the pen portraits of each nursing home in Chapter 4, allowing the reader to assess the transferability of the findings to other nursing homes and settings.

Another strength of the study was that it was not constrained solely by the accepted national definition of ACP in use at the outset of the study, instead being broadened to include consideration of end-of-life care decision-making more generally. This allowed a focus on ACP as well as exploring how future planning and decision-making was described more broadly, thereby permitting investigation of how these were understood by professionals. This broader approach assisted in gaining awareness of the conceptual confusion that existed, although the decision to broaden the definition of ACP was disputed by a senior medical professional at an early stage of the study. However, the inclusion of an explicit link between end-of-life care and ACP in the participant information sheets may have limited the depth of understanding gained from participants about the meaning they might attach to ACP, especially amongst the residents given recent research which suggests that the end-of-life orientation of ACP conflicts with the dynamic nature of frailty (Bramley 2016).

A limitation of this study was the recruitment only of residents who had mental capacity to both complete ACP as currently defined and consent to the study. No participant residents had a diagnosis of dementia, yet a substantial majority of care home residents in the UK have some cognitive impairment (Gordon et al. 2014). Data regarding residents with dementia was therefore only obtained indirectly as part of discussions with nursing home staff members. Situating the findings of the study within a literature relating to end-of-life care in care homes has involved relating the findings with literature specifically focusing on end-of-life care in dementia. Given the findings relate primarily to residents who had neither mental capacity nor communication difficulties impacting their ability to engage in ACP, it was not always easy to align these with studies involving residents with dementia. It also limits the transferability of the findings to other settings, specifically those nursing homes working solely with residents with cognitive impairment.

Another limitation was in relation to me as an inexperienced researcher. During data collection and analysis I often applied a nursing lens, particularly early on, rather than a researcher lens and was also an amateur ethnographer with limited knowledge of sociological concepts at the outset of the study. I may therefore have missed social constructs in the data early in the study that could have been explored in more depth if identified sooner. Through reading and discussion with my supervisors, I have been able to reflect on my use of taken for granted nursing knowledge and opened up my thinking to consider alternative interpretations and explanations of findings. The study is underpinned by a constructivist epistemology and it has therefore been made explicit that the findings and conceptual framework represents one interpretation of the data, informed by my knowledge and experience.

9.5 Reflections on my PhD journey

Completion of this PhD study has been an academic, professional and personal journey. I have developed my abilities in both research design and conduct. I have also significantly increased my knowledge of philosophical and sociological concepts that both underpin qualitative research, particularly ethnographic research, and have informed interpretation of the study findings. As an experienced nurse it has been challenging to balance two different identities and appreciate what each of these brings to my research. A reflexive approach as well as guidance from my supervisors has assisted me. As well as learning about academic practice during the study, the opportunity to learn directly from the residents, relatives and professionals who generously agreed to participate in the study, has increased my understanding of the nursing home setting and this has had an impact on my professional practice. Viewing ACP and multi-professional practice from a research perspective and with a cultural lens, has challenged some of my previously held views. These have been re-examined through critical reflection and discussion with my supervisors. In the future, I am interested in working to improve partnership working between the NHS and care homes, being transparent about the power differences and developing approaches to break down the barriers that prevent integrated working.

9.6 Conclusion

This study set out to explore the factors that influence multi-professional involvement in ACP and the impact of multi-professional involvement on ACP within two nursing homes. My interest in this topic originated from an observed divergence between the level of multi-professional working seen in nursing homes and the espoused multi-professional model of palliative care given nursing homes are essential providers of end-of-life care. What the findings from observations, interviews and documentary analysis show is that multi-professional working impacts ACP but ACP also impacts multi-professional working. A misalignment between professional working practices and what is wanted and/or needed by residents, relatives and nursing home staff impacts on how ACP is operationalised and conceptualised. The conceptualisation of ACP, which is not always shared by everyone involved in ACP, and its construction as a professional process defined in biomedical terms and controlled by professionals, impacts on ACP as a multi-agency activity and the team involved in ACP. In this way, multi-professional working was not integrated into the ACP routine in either nursing home, with ACP and multi-professional working ‘running side by side’. The implications for practice have been highlighted as a need for awareness of different understandings of ACP, with strategies put in place for professionals to clarify with each other whether future planning has occurred and for this information to be shared. Policy needs to be aligned with the priorities of residents and to be developed across systems with all organisations, including nursing homes, working in partnership. Further research is required to inform development of models of integrated, multi-professional involvement that support ACP defined more broadly than in biomedical terms.

Appendix A. Database Search Terms

A.1 CINAHL search strategy

Key term from research topic	**Search terms**	**#**
Nursing Home	MH “Nursing Homes+” OR MH “Nursing Home Patients” OR MH “Nursing Home Personnel” Date of publication 01/01/1990 – 30/09/2020	1
Nursing Home	AB “Nursing Home*” (keyword) Date of publication 01/01/1990 – 30/09/2020	2
	S1 OR S2	3
Advance Care Planning	MH “Advance care planning” OR MH “Advance directives+” OR “Anticipatory Care Plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	4
Advance Care Planning	AB “Advance* Care Plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	5
End-of-life	MH “Palliative care” OR MH “Terminal care” OR MH “Hospice care” Date of publication 01/01/1990 – 30/09/2020	6
End-of-life	AB “Palliative Care” (keyword) OR AB “End-of-life care” (keyword) OR AB “End of life Care” (keyword) Date of publication 01/01/1990 – 30/09/2020	7
	S4 OR S5 OR S6 OR S7	8
Multi Professional	MM “Multidisciplinary care team” OR MH “Teamwork” OR MH “Interprofessional relations+” OR MH “Collaboration” Date of publication 01/01/1990 – 30/09/2020	9
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword) Date of publication 01/01/1990 – 30/09/2020	10
	S9 OR S10	11
	S3 AND S8 AND S11	12
	S12 Limiters – English Language	13

MH = Mapped to MeSH terms; MM = Mapped to MeSH terms major heading; + = MeSH heading exploded; AB = Abstract search.

* = truncation mark

A.2 MEDLINE search strategy

Key term from research topic	**Search terms**	**#**
Nursing Homes	MH “Nursing Homes” OR MH “Skilled Nursing Facilities” Date of publication 01/01/1990 – 30/09/2020	1
Nursing Homes	AB “Nursing Home*” (keyword) Date of publication 01/01/1990 – 30/09/2020	2
	S1 OR S2	3
Advance Care Planning	MH “Advance care planning” OR MH “Advance directives+” OR “Anticipatory Care Plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	4
Advance Care Planning	AB “Advance Care Plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	5
End-of-life	MH “Palliative care” OR MH “Terminal care” OR MH “Hospice care” Date of publication 01/01/1990 – 30/09/2020	6
End-of-life	AB “Palliative Care” (keyword) OR AB “End-of-life care” (keyword) OR AB “End of life Care” (keyword) Date of publication 01/01/1990 – 30/09/2020	7
	S4 OR S5 OR S6 OR S7	8
Multi Professional	MH “Patient care team” OR MM “Interprofessional relations+” Date of publication 01/01/1990 – 30/09/2020	9
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword) Date of publication 01/01/1990 – 30/09/2020	10
	S9 or S10	11
	S3 AND S8 AND S11	12
	S12 Limiters – English Language	13

MH = Mapped to MeSH terms; MM = Mapped to MeSH terms major heading; + = MeSH heading exploded; AB = Abstract search.

* = truncation mark

A.3 PsycINFO search strategy

Key term from research topic	**Search terms**	**#**
Nursing Homes	DE “Nursing Homes” Date of publication 01/01/1990 – 30/09/2020	1
Nursing Homes	AB “Nursing Home*” (keyword) Date of publication 01/01/1990 – 30/09/2020	2
	S1 OR S2	3
Advance Care Planning	DE “Advance directives” OR “advance* care plan*” (keyword) OR “anticipatory care plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	4
End-of-life	DE “Palliative Care” OR DE “Terminally Ill Patients” Date of publication 01/01/1990 – 30/09/2020	5
End-of-life	AB “Palliative Care” (keyword) OR AB “End-of-life Care” (keyword) OR AB “End of life Care” (keyword) Date of publication 01/01/1990 – 30/09/2020	6
	S4 OR S5 OR S6	7
Multi Professional	DE “Interdisciplinary Treatment Approach” OR DE “Collaboration” Date of publication 01/01/1990 – 30/09/2020	8
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword) Date of publication 01/01/1990 – 30/09/2020	9
	S8 OR S9	10
	S3 AND S7 AND S10	11
	S11 Limiters – English Language	12

DE = subjects [exact] search; AB = abstract search.

* = truncation mark

A.4 AMED search strategy

Key term from research topic	**Search terms**	**#**
Nursing Homes	TX “nursing W1 home*” (keyword) OR TX ““care home*” N1 nursing” (keyword) OR TX “skilled nursing facilit*” (keyword) OR TX “residential aged care facilit*” (keyword) Date of publication 01/01/1990 – 30/09/2020	1
Advance Care Planning	TX “advance* W0 care W0 plan*” (keyword) OR TX ““care W0 plan*” N5 advance*” (keyword) OR TX “advance* W0 directive*” (keyword) OR TX “living W0 will*” (keyword) OR TX “anticipatory W0 care W0 plan*” (keyword) Date of publication 01/01/1990 – 30/09/2020	2
End-of-life	TX “palliative” (keyword) OR TX “hospice” (keyword) OR TX “terminal” (keyword) OR TX “end W0 of W0 life” (keyword) OR TX “end-of-life” (keyword) Date of publication 01/01/1990 – 30/09/2020	3
	S2 OR S3	4
Multi Professional	TX “Multidisciplinary” (keyword) OR TX “Multi-disciplinary” (keyword) OR TX “Multiprofessional” (keyword) OR TX “Multi-professional” (keyword) OR TX “Interprofessional” (keyword) OR TX “Inter-professional” (keyword) OR TX “Team*” (keyword) OR TX “Collaborat*” (keyword) Date of publication 01/01/1990 – 30/09/2020	5
	S1 AND S4 AND S5	6
	S6 Limiters – English Language	7

TX = All Text search; W = Within Operator (words within n words of each other in the order in which entered); N = Near Operator (words within n words of each other regardless of the order they appear).

* = truncation mark

A.5 EMBASE search strategy

Database used: EMBASE 1980 to current

Key term from research topic	**Search terms**	**#**
Nursing Home	SH Nursing Home OR SH Nursing Home Patient OR SH Nursing Home Personnel	1
Nursing Home	AB “Nursing Home*” (keyword)	2
	S1 OR S2	3
Advance care planning	SH Living Will OR SH “Patient Care” OR “Anticipatory care plan*” (keyword)	4
Advance care planning	AB “advance* care plan*” (keyword)	5
End-of-life	SH Hospice care OR SH Terminal care	6
End-of-life	AB “Palliative Care” (keyword) OR AB “End-of-life Care” (keyword) OR AB “End of life Care” (keyword)	7
	S4 OR S5 OR S6 OR S7	8
Multi Professional	SH Teamwork	9
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword)	10
	S9 OR S10	11
	S3 AND S8 AND S11	12
	S12 Limiters – English Language; Date of publication 01/01/1990 – 30/09/2020	13

SH = Mapped to subject heading; AB = abstract search

* = truncation mark

A.6 IBSS search strategy

Key term from research topic	**Search terms**	**#**
Nursing Home	SU.EXACT “Nursing Homes”	1
Nursing Home	AB “Nursing Home*” (keyword)	2
	S1 OR S2	3
Advance Care Planning	SU.EXACT “Advance Directives” OR SU.EXACT “Living Wills”	4
Advance Care Planning	AB “Advance* care plan*” OR AB “Anticipatory care plan*”	5
End-of-life	SU.EXACT “Palliative Care” OR SU.EXACT “Hospice Care”	6
End-of-life	AB “Palliative Care” (keyword) OR AB “End of life care” (keyword) OR AB “End-of-life Care” (keyword)	7
	S4 OR S5 OR S6 OR S7	8
Multi Professional	SU.EXACT “Interprofessional Cooperation” OR SU.EXACT “Collaboration” OR SU.EXACT “Teamwork”	9
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword)	10
	S9 OR S10	11
	S3 AND S8 AND S11	12
	S12 Limiters – English Language; Date of publication 01/01/1990 – 30/09/2020	13

SU.EXACT = mapped to subject heading thesaurus; AB = abstract search

* = truncation mark

A.7 BNI search strategy

Key term from research topic	**Subject terms**	**#**
Nursing homes	SH “Nursing Homes”	1
Nursing Home	AB “Nursing Home*” (keyword)	2
	S1 OR S2	3
Advance care planning	“Advance* care plan*” (keyword) OR “Anticipatory care plan*” (keyword) OR “Advance* directive*” (keyword) OR “Living will*” (keyword)	4
End-of-life	SH Palliative care OR SH Hospice care	5
End-of-life	AB “Palliative Care” (keyword) OR AB “End of life Care” (keyword) OR AB “End-of-life Care” (keyword)	6
	S4 OR S5 OR S6	7
Multi Professional	SH Interprofessional cooperation OR SH Collaboration	8
Multi Professional	AB “Multidisciplinary” (keyword) OR AB “Multi-disciplinary” (keyword) OR AB “Multiprofessional” (keyword) OR AB “Multi-professional” (keyword) OR AB “Interprofessional” (keyword) OR AB “Inter-professional” (keyword) OR AB “Team*” (keyword)	9
	S8 OR S9	10
	S3 AND S7 AND S10	11
	S11 Limiters –Date of publication 1992 – September 2020 (database only covers from 1992). Unable to limit by language.	12

SH = mapped to subject headings thesaurus; AB = abstract search.

* = truncation mark

A.8 Web of Science Core Collection search strategy

Key term from research topic	**Search terms**	**#**
Nursing Home	TS = (“Nursing Home*” OR “Skilled Nursing Facilit*” OR “Residential Aged Care Facilit*”) Date of publication 1990 – 2020	1
Advance Care Planning	TS = (“Advance* care plan*” OR “Advance* directive*” OR “Living will*” OR “Anticipatory care plan*”) Date of publication 1990 – 2020	2
End-of-life	TS = (“palliative” OR “hospice” OR “terminal” OR “end-of-life” OR “end of life”) Date of publication 1990 – 2020	3
	S2 OR S3	4
Multi Professional	TS = (“Multidisciplinary” OR “Multi-disciplinary” OR “Multiprofessional” OR “Multi-professional” OR “Interprofessional” OR “Inter-professional” OR “Team*” OR “Collaborat*”) Date of publication 1990 – 2020	5
	S1 AND S4 AND S5	6
	S6 Limiters – English Language and Date of publication 1990 – September 2020	7

TS = Topic field tag: searches for topic terms in title, abstract, author keywords and keywords plus.

* = truncation mark

Appendix B. Assessment of Relevance Form

Author	**Year**
Abbreviated title	
Nursing home setting	
	Focus or major part of study
	Minor part of study
	Mentioned in discussion / findings
End-of-life care and / or advance care planning	
	Focus or major part of study
	Minor part of study
	Mentioned in discussion / findings
Multi-professional working	
	Focus or major part of study
	Minor part of study
	Mentioned in discussion / findings
Relevance to questions to be asked of literature	
	Concept of multi-professional working in NHs
	Professional expertise and/or disciplines required for provision of EoLC or ACP in NHs
	Experiences of multi-professional working in EoLC or ACP
	Factors impacting effectiveness of multi-professional working in EoLC in NHs
	Characteristics of multi-professional working that enhance end-of-life care or ACP
	Impact of multi-professional working or lack of multi-professional working on EoLC in NHs
Source of data	
	Professionals
	Nursing home residents
	Family members
	Documents e.g. nursing home records
	Secondary data – e.g. secondary research data, published statistical data
	Literature
Study type	
	Empirical study – peer reviewed
	Theoretical paper – peer reviewed
	Research paper – non-peer reviewed
	Theoretical paper – non-peer reviewed
	Professional document
	Case study
	Other
Comments	
ACCEPT / REJECT	

Appendix C. Methodological Rigour Assessment Tool

Tool adapted from Hawker et al. (2002).

Author and Date:	**Good**	**Fair**	**Poor**	**Very Poor**	**Comments**
1. Abstract and title: Did they provide a clear description of the study? Good: Structured abstract with full information and clear title. Fair: Abstract with most of the information. Poor: Inadequate abstract. Very Poor: No abstract.					
2. Introduction and aims: Was there a good background and clear statement of the aims of the research? Good: Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions. Fair: Some background and literature review. Research questions outlined. Poor: Some background but no aim/objectives/questions OR aim/objectives but inadequate background. Very Poor: No mention of aim/objectives. No background or literature review.					
3. Method and data: Is the method appropriate and clearly explained? Good: Method is appropriate and described clearly (e.g. questionnaires included). Clear details of data collection and recording. Fair: Method appropriate, description could be better. Data described. Poor: Questionable whether method is appropriate. Method described inadequately. Little description of data. Very Poor: No mention of method AND/OR method inappropriate AND/OR no details of data.					

	Good	Fair	Poor	Very Poor	Comments
4. Sampling: Was the sampling strategy appropriate to address the aims? Good: Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained. Fair: Sample size justified. Most information given, but some missing. Poor: Sampling mentioned but few descriptive details. Very Poor: No details of sample.					
5. Data analysis: Was the description of the data analysis sufficiently rigorous? Good: Clear description of how analysis was done. Qualitative studies: Description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed. Fair: Qualitative: Descriptive discussion of analysis. Quantitative: Two out of the three above. Poor: Minimal details about analysis. Very Poor: No discussion of analysis.					
6. Ethics and bias: Have ethical issues been addressed and was necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered? Good: Ethics: Where necessary issues of confidentiality, sensitivity and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias. Fair: Lip service was paid to above (i.e. these issues were acknowledged). Poor: Brief mention of issues. Very Poor: No mention of issues.					

	Good	Fair	Poor	Very Poor	Comment
7. Results: Is there a clear statement of the findings? Good: Findings explicit, easy to understand and in logical progression. Tables, if present, are explained in text. Results relate directly to aim. Sufficient data are presented to support findings. Fair: Findings mentioned but more explanation could be given. Data presented relate directly to results. Poor: Findings presented haphazardly, not explained, and do not progress logically from results. Very Poor: Findings not mentioned or do not relate to aim.					
8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population? Good: Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling). Fair: Some context and setting described, but more needed to replicate or compare the study with others PLUS fair score or higher in Question 4. Poor: Minimal description of context/setting. Very Poor: No description of context/setting.					
9. Implications and usefulness: How important are these findings to policy and practice? Good: Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice. Fair: Two of the above (state what is missing in comments). Poor: Only one of the above. Very Poor: None of the above.					
TOTAL					

Appendix D. Table of Papers

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Addicott, R (2011) Supporting Care Home Residents at the End of Life *International Journal of Palliative Nursing* 17(4): 183-187	To understand factors that enable and inhibit residents in terms of remaining in care homes as they approach death.	UK 2 Nursing Homes & 2 Residential Homes	Case study	Interviews were conducted with 19 participants from the 4 case study homes and 20 external stakeholders.	Three core features fundamental to the delivery of high-quality end of life care in care homes: advance care planning; multidisciplinary communication; and working, and provision of dignified and compassionate care.	Critical appraisal score = 27 Choice of interviews as sole method not explained. Details of homes provided but not how identified. Sampling of participants outlined. Comparing homes considered by external stakeholders to provide high quality end of life care with those perceived to provide a lower level of care could have enhanced findings. Analysis included coded data being sorted into examples of good practice, but this was not defined. Findings presented relate to both nursing and residential homes with minimal reference to differences between the settings.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Badger, F; Plumridge, G; Hewison, A; Shaw, K L; Thomas K and Clifford C (2012) An Evaluation of the Impact of the Gold Standards Framework on Collaboration in End-of-life care in Nursing Homes. A Qualitative and Quantitative Evaluation. *International Journal of Nursing Studies* 49(5): 586-595	1) To identify key outcomes in relation to the three GSF in Care Homes (GSFCH) aims: a) Improve quality of end-of-life care for residents b) Improve coordination and collaboration between nursing home staff and other practitioners. c) Reduce resident transfers to hospital at end-of-life. 2) To identify features that supported or prevented programme implementation.	UK Nursing Homes	Pre and post survey. Case study. Interview data analysed in line with the template approach.	All 95 homes in the first national GSFCH programme were invited to participate in the survey. Case studies were conducted in a sub-sample of 10 homes. This involved 14 interviews with managers plus 9 individual interviews and 13 group interviews involving 26 nurses, 30 care assistants, 4 domestic staff and 1 primary care liaison nurse.	Improved collaborations between care home staff and health service practitioners were identified by 33% of managers as one of the main programme outcomes. The GSFCH programme increased the knowledge and confidence of nursing home staff which improved relationships with other services.	Critical appraisal score = 29 Criteria for selection of case study nursing homes not clearly outlined; may be potential for bias. Only method reported from the case studies is individual interviews and focus groups but unclear if other methods were also used. No information about quantitative data analysis other than that it was analysed using SPSS. Findings clearly explained. Qualitative data supports survey findings by providing more in-depth, contextual data.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Bern-Klug, M; Gessert, C E; Crenner, CW; Buenaver, M and Skirchak, D (2004) "Getting Everyone on the Same Page": Nursing Home Physicians' Perspectives on End-of-Life Care. *Journal of Palliative Medicine* 7(4): 533-544	To improve understanding of nursing home physicians' perspectives regarding end-of-life care and to suggest directions for further research.	US	Qualitative interview study. Qualitative concept analysis.	A purposeful sample of 12 nursing home physicians with more than 4 years' experience working in a nursing home setting.	Four themes: extensive familiarity with dying; consensus is integral to good end-of-life-care; obstacles can interfere with consensus and advance directives set the stage for conversations about end-of-life care.	Critical appraisal score = 31 Small sample; decision about sample size was not provided. Useful insight into the perspectives of experienced nursing home doctors. No reference to any potential impact of medical students undertaking interviews on response of the participants. Ethical issues not discussed.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Brodtkorb, K; Valen-Senstad Skisland, A; Slettebø, A and Skaar, R (2017) Preserving dignity in end-of-life nursing home care: Some ethical challenges. *Nordic Journal of Nursing Research* 37(2): 78-84	To investigate how healthcare workers are influenced by and deal with ethical challenges in end-of-life care in nursing homes.	Norway Two nursing homes in a medium sized municipality	Qualitative clinical application research design based on hermeneutic research understanding. Involved 4 research groups.	Each research group consisted of 6 to 8 clinical co-researchers with different health backgrounds – 23 nurses (17 RNs and 6 Enrolled Nurses), 2 physiotherapists and 1 sociologist.	Main theme of ‘Dignity in end-of-life nursing home care’ with two sub-categories ‘Challenges regarding life-prolonging treatment’ and ‘Uncertainty regarding clarification conversations’.	Critical appraisal score = 31 No information provided regarding recruitment strategy. Data interpreted from a care ethics perspective. Findings highlighted multi-professional working as important in dealing with ethical concerns in end-of-life decision-making. Focus primarily on relationships between RNs and Enrolled Nurses, with no specific mention of other internal disciplines, although challenges relating to multi-professional working with external physicians raised.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Burgess, M; Cha, S and Tung EE (2011) Advance Care Planning in the Skilled Nursing Facility: What do we need for Success? *Hospital Practice* 39(1): 85-90	To identify important barriers to ACP among Skilled Nursing Facility providers and to identify ACP practice-based differences between Skilled Nursing Facility physicians and midlevel practitioners.	US 9 Skilled Nursing Facilities in one county	Online survey	27 physician providers and 12 midlevel providers (nurse practitioners).	Location of ACP documentation is variable, and the 2 groups of providers possessed key differences in their own documentation habits. Most respondents thought physicians or midlevel providers are responsible for ACP documentation. Largest barriers to ACP are patient's impaired cognition, lack of time and lack of family involvement.	Critical appraisal score = 29 Research appeared to have been a quantitative survey although this was not clearly described. No information was provided as to how the survey tool was created or validated. Including a qualitative approach may have elucidated additional responses not considered by the authors. However, statistical testing did allow for a useful comparison of responses between the two professional disciplines. Ethical issues such as anonymity of the survey response are not described.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Chapman, D G and Toseland, R W (2007) Effectiveness of Advanced Illness Care Teams for Nursing Home Residents with Dementia. *Social Work* 52(4): 321-329	To evaluate the effectiveness of advanced illness care teams for nursing home residents with advanced dementia.	US Two Nursing Homes	Randomised, partial cross-over trial	118 residents, 60 from one nursing home and 58 from the other.	Advanced Illness Care Teams were effective in reducing agitated behaviour when compared with usual care. They also reduced pain, although this was not statistically significant.	Critical appraisal score = 28 Research questions and aims not reported. An identified flaw in design meant potential for spill-over of treatment effect to control group. No blinding was possible. Statistical analysis not clearly outlined - parametric assumption testing not stated. ACP was excluded from specific role of team intervention but mentioned in discussion.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Cornally, N; McGlade C; Weathers, E; Fitzgerald, C; O'Caoimh, R; Coffey, A and Molloy, D W (2015) Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives. *BMC Palliative Care* 14: 55	To examine the effect of systematically implementing an ACP and palliative care education intervention.	Ireland Three nursing homes	Qualitative design using focus groups. Analysed using content analysis.	3 focus groups with samples of two, seven and eight staff members, who were staff involved in delivering or overseeing the implementation of the programme at senior management level.	Five main categories presented: 1) Issues relating to Implementing ACP; 2) Benefits of ACP programme; 3) Challenges to Implementing ACP; 4) Disadvantages to using the programme; and 5) Programme recommendations.	Critical appraisal score = 29 Qualitative part of a larger mixed methods study. Multi-professional involvement not explored in detail, but a recommendation was that the programme should have a multi-professional approach. The sample included only those in senior management posts and was small. There was no explanation for this or any details as to which levels of staff were involved in the education programme and delivery of ACP. Highlights multi-professional working as an important component of ACP although does not explore this is detail.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Cronfalk, B S; Terestedt, B-M; Larsson, L-L F; Henriksen, E; Norberg, A and Österland, J (2015) Utilization of palliative care principles in nursing home care: Educational interventions *Palliative and Supportive Care* 13(6): 1745-1753	To describe nursing home staff attitudes to competence-building programs in palliative care.	Sweden Seven nursing homes	Focus group study. Analysed with descriptive content analysis.	RNs, Enrolled Nurses and care assistants participated in 11 focus groups.	Staff reported positive experiences as they gained new knowledge and insight into palliative care. The experiences seemed to be similar independent of the educational programme design. Staff experienced difficulties in talking about death. There was insufficient collaboration and lack of a common language between different professions.	Critical appraisal score = 26 No details of the participants or the number of participants in the focus groups and no details on sampling strategy were provided. Multi-professional teamwork issues focus primarily on internal nursing team and professional differences between RNs and Enrolled Nurses; although, there was some limited but useful reference to work with physicians. No mention of ethical issues. Minimal context for the seven nursing homes provided limiting transferability.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Dreyer, A; Førde, R and Nortvedt, P (2011) Ethical Decision-making in Nursing Homes: Influence of Organizational Factors. *Nursing Ethics* 18(4): 514-525	To explore how doctors and nurses in nursing homes describe professional collaboration around dying patients.	Norway Ten Nursing Homes	Qualitative interview study	10 doctors and 9 nurses from 10 nursing homes.	The frameworks for the professional collaboration and organisation of physicians and nurses prevent patient treatment and care complying with ethical considerations and the law.	Critical appraisal score = 30 The reason for recruitment of only one nurse and one doctor from each nursing home was not specified. However, it was stated that data saturation was obtained. No specific approach to analysis was outlined and there was no mention of the influence of the researcher.
Forbes, S (2001) This is Heaven's Waiting Room: End of Life Care in One Nursing Home. *Journal of Gerontological Nursing* 27(11): 37-45	To describe the end of life in one nursing home from the perspective of residents who are chronically ill and declining, their family caregivers and staff.	US One Nursing home	Qualitative methods, including formal and informal interviews, participant observation and document analysis. Qualitative content analysis used.	13 chronically ill residents whose health was declining, and 3 family caregivers participated in interviews. 30 staff members participated in either interviews or focus groups.	One dominating pattern: conflict and five themes: communication, quality of life, staff education, teamwork and work environment emerged as factors that influenced end-of-life care.	Critical appraisal score = 29 Methods matched aims. However, findings supported by only health professional quotes. Impact of researchers (as participant observers) on data was not explored. Dominance of issues specific to the regulatory climate of US nursing homes at the time of the study limit the relevance of study findings to UK nursing homes.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Froggatt, K A and Hoult, L (2002) Developing palliative care practice in nursing and residential care homes: role of the clinical nurse specialist. *Journal of Clinical Nursing* 11(6): 802-808	To explore the involvement of community CNSs in palliative care with nursing homes and residential homes by identifying the extent and nature of work they undertake with residents and staff in this care sector.	UK	Postal survey.	730 community palliative care CNSs	Much of the focus of CNS involvement was reactive work, meeting the direct clinical needs of residents, primarily those with cancer. Although the CNSs perceived that there were some educational and care deficits in these care settings, the amount of proactive work undertaken was limited. The development work undertaken was focused on educational initiatives and establishing link nurse systems.	Critical appraisal score = 30 Presents findings from both quantitative and qualitative survey data. The paper provides limited description of the analysis of qualitative data, only stating that it was coded. No description of the quantitative data analysis was provided. However, quantitative data analysis was outlined in the other paper from this study (Froggatt et al, 2002). Ethical issues were not addressed in this paper but outlined in the other paper. Paper highlighted education as a characteristic of multi-professional working between specialist palliative care and nursing homes.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Froggatt, K A; Poole, K and Hoult, L (2002) The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work. *Palliative Medicine* 16(6): 481–487	To explore the involvement of community CNSs in palliative care with nursing homes and residential care homes.	UK	Postal survey	730 community palliative care CNSs	Although 92% of the CNSs surveyed had worked with nursing homes and 80% of the CNSs surveyed had worked with residential care homes, the responses showed that this work was primarily reactive and undertaken infrequently. The majority of the work undertaken by CNSs involved caring for patients with cancer with a focus on management of physical symptoms.	Critical appraisal score = 33 Only quantitative data presented in this paper. Good response rate reported, although a recognised limitation was the inability to be able to direct mail all CNSs. Only a database of those with Macmillan roles was available. Response rates for other CNSs therefore could only be described by site not numbers of post-holders. Second paper from one study; the other paper is Froggatt and Hoult (2002).

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Froggatt, K; Vaughan, S; Bernard, C and Wild, D (2008) *Advance Care Planning in Care Homes for Older People: A Survey of Current Practice. Final Report*. International Observatory on End of Life Care, Lancaster University.	To describe current ACP practice in care homes for older people: to what extent this is undertaken, how it is done and to highlight good practice already in use within the sector, in order to develop a good practice guide.	UK	Postal survey and qualitative telephone interviews. Descriptive statistical analysis of quantitative survey data and content analysis of open survey questions. Interview data analysed using thematic analysis.	500 care home managers surveyed and 15 care home managers interviewed.	ACP viewed as a positive, beneficial process but the number of residents who had completed ACP processes was generally low. Challenges faced by managers appeared to be dependent on whether it was ascertaining or implementing wishes being addressed. Issues related to external factors, including external health care providers, were more frequently cited as barriers to implementing wishes.	Critical appraisal score = 32 Sample size was not explained. Interviewer reflexivity was not explored. Paper presents findings from both quantitative and qualitative data. Qualitative questions were included in the survey. A copy of the survey included in the report, but interview schedule not provided. This combines data from residential and nursing homes, and it was not possible to differentiate between data from the two settings. This impacts the transferability of the data to only nursing homes, as health care professional involvement will differ between these settings.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Furman, C D; Kelly, S E; Knapp, K; Mowery, R and Miles, T (2006) Eliciting Goals of Care in a Nursing Home. *Journal of the American Medical Directors Association* 7(8): 473-479	To identify enablers and barriers facing experienced providers and staff in initiating goals of care discussions with patients in the nursing home.	US One nursing home	Qualitative interview study	2 physicians, 3 nurse practitioners, 1 director of nursing, 2 administrators, 2 social workers, 1 chaplain, 7 nurses, 2 certified nursing assistants, 1 nutritionist, 1 speech pathologist and 1 activity director.	Five barriers to discussing goals of care: 1) Fear of legal ramifications; 2) Not enough education on how to have a goals of care discussion; 3) Family not involved on a regular basis; 4) Time pressure; 5) Interdisciplinary team not involved. Five enablers to goals of care discussions: 1) Education/experience with the goals of care discussion; 2) Interdisciplinary team involved in the discussion ; 3) Established trusting relationship with the patient/family/other staff; 4) Terminal diagnosis/hospice involvement; 5) Discussion occurs in-person.	Critical appraisal score = 30 Small study but offered insights into staff perceptions of discussing goals of care. Minimal details of data analysis provided or the influence of the interviewer. Focus limited to medical components of ACP but identified who it was thought had a role in this.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Gilissen, J; Pivodic, L; Gastmans, C; Vander Stichele, R; Deliens, L; Breuer, E and Van den Block, L (2018) How to achieve the desired outcomes of advance care planning in nursing homes: a theory of change. *BMC Geriatrics* 18: 47	To develop a theory that outlines the hypothetical causal pathway of ACP in nursing homes, i.e. what changes are expected, by means of which processes and under what circumstance.	Belgium	Participatory design and evaluation. Two theory of change workshops held.	21 stakeholders, including 2 GPs, 1 coordinating and advisory physician, 3 nurses, 2 palliative care reference nurses, 2 psychologists, 1 social worker, 1 physiotherapist, 3 nursing home managers, 2 ethicists, 1 representative of council for the elderly and 1 dementia reference person.	A theory of change map was plotted. This included: the desired ultimate impact that should be achieved in nursing homes; the ceiling of accountability; two long-term outcomes that are desired to be achieved by ACP; 13 important preconditions that need to be fulfilled for the desired long-term outcomes to be achieved; and nine intervention components required to fulfil each precondition.	Critical appraisal score = 33 There was a clear aim and background. A prescribed Theory of Change approach was followed. The sample size for the stakeholder workshops was not justified although acknowledged as small. It was recognised that because there was not enough information about the effectiveness of separate components of ACP in the scientific literature, that the stakeholders and core research were the main contributors to the development of the overall map. It was not possible to provide quality scientific evidence for each link in the causal pathway. The theory of change map provided a basis for further research and implementation in practice.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Gjerberg, E; Førde, R and Bjørndal, A (2011) Staff and family relationships in end-of-life nursing home care. *Nursing Ethics* 18(1): 42-53	To explore staff – family relationships in nursing homes.	Norway 364 nursing homes	Postal survey. Descriptive statistical analysis and answers to open-ended questions analysed for prominent meaning units which were then used as analytical categories.	664 nurses working at a range of levels across the nursing homes	A need for better procedures in the involvement of relatives in nursing home end-of-life care. A need to strengthen the involvement of nursing home physicians and staff communication skills.	Critical appraisal score = 33 Formed part of a larger project on end-of-life care in nursing homes. There were acknowledged difficulties in identifying response rates as the nursing home was not identified on all questionnaires. However, the response rate provided was good at 78% and considered an underestimate. Highlights physician role from the viewpoint of nurses.
Gorlén T F; Gorlén T and Neergard M A (2013) Death in nursing homes: a Danish qualitative study. *International Journal of Palliative Nursing* 19(5): 236-242	To describe the perceptions of nursing staff of end-of-life care in Danish Nursing Homes, with particular focus on medication administration and collaboration with GPs.	Denmark Three nursing homes	Focus group study. Qualitative description analysis.	2 nurses and 14 nursing assistants	Four main categories of problematic issues described: medication, interpersonal relations, decision-making and professional development.	Critical appraisal score = 29 Findings limited by small sample size. The large number of nursing assistants compared to nurses may have skewed the findings. The number of focus groups was also small, although the authors reported data saturation.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Hall, S; Goddard, C; Stewart, F and Higginson, I J (2011) Implementing a quality improvement programme in palliative care in care homes: a qualitative study. *BMC Geriatrics* 11: 31	To explore the perceived benefits of and barriers to implementation of the GSF for Care Homes programme.	UK Nine nursing homes	Qualitative interview study. Analysed using the Framework Approach.	9 managers, 8 nurses, 9 care assistants, 11 residents and 7 family members	Participants described effective communication within the homes and with external providers, although many had experienced problems with GPs. The benefits of supportive care registers, coding predicted stage of illness and ACP were reported but some felt the need for more experience of using these. There were concerns about discussing death.	Critical appraisal score = 32 The sampling strategy was not fully described although including staff, residents and relatives enabled a broad set of experiences to be explored. The impact of the researchers on the interviews was not explored.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Hanson, L and Henderson, M (2000) Care of the Dying in long-term care settings. *Clinics in Geriatric Medicine* 16(2): 225-238	Paper aims to provide an overview of the roles and responsibilities of certified nursing assistants, nurses and physicians who provide care to residents dying in long-term care facilities and describe the challenges and unique strategies used to provide compassionate care of people dying in this setting, drawing on data from the focus group study reported in Hanson et al (2002).	US Two long-term care facilities	Feature article drawing on data from a focus group study.	Draws on data from 77 participants in 11 focus groups – 4 groups of nurses, 4 groups of nursing assistants and 3 groups of physicians.	The roles of the following caregivers were outlined: certified nursing assistants, nurses, physicians. Nursing home caregivers' perspectives were reported under the following sub-headings: The effect of long-term care facility as site of care; Predicting death in a long-term care population; Characteristics of bad deaths in nursing homes; Characteristics of a good death in a long-term care facility; and Caregiver roles during the dying process.	Critical appraisal score = 24 The paper provided limited details of the study. It is a feature article rather than a study report, drawing on the same study reported in Hanson et al (2002). It provided additional information regarding the roles of nurses, nursing assistants and physicians not included in the other paper.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Hanson, L; Henderson, M and Menon, M (2002) As Individual as Death Itself: A Focus Group Study of Terminal Care in Nursing Homes *Journal of Palliative Medicine* 5(1): 117-125	To 1) define a good death in a nursing home and 2) describe factors which promote or prevent good care of the dying in this setting.	US Two long-term care facilities	Focus group study	77 participants in 11 focus groups – 4 groups of nurses, 4 groups of nursing assistants and 3 groups of physicians	Three major themes emerged to define a good death in a nursing home: highly individualised care based on continuity relationships with caregivers; effective teamwork by staff, physicians and family; and comprehensive ACP. A lack of training, regulatory emphasis on rehabilitation and a resource-poor setting were identified as barriers to high quality care of the dying. The value of staff experience and personal relationships with residents were the basis for good care.	Critical appraisal score = 32 The number of participants and percentage of total staff from each professional group not indicated. Findings might have been enhanced with inclusion of other members of the multi-professional team, beyond carers, nurses and doctors. Other members were excluded because of a lack of primary clinical role in end-of-life care and an expectation that their views might be different. Data from the same study referred to in Hanson and Henderson (2000).

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Hov, R; Athlin, E and Hedelin, B (2009) Being a nurse in nursing home for patients on the edge of life. *Scandinavian Journal of Caring Sciences* 23(4): 651-659	To acquire a deeper understanding of what it is to be a nurse in a nursing home for patients on the edge of life.	Norway Two nursing homes – one in a town and one rural home	Phenomeno-logical interview study	6 nurses from the town nursing home and 8 nurses from the rural nursing home.	Two main themes: 'Striving to do right and good for everyone' and 'Being a vulnerable helper – the prize and the price'.	Critical appraisal score = 31 Sampling strategy not fully explained. Limited details provided about participants, in particular the different nursing roles, which makes it difficult to assess relevance to the UK setting. No differentiation was made between the experiences of the two grades of nursing staff in the findings. Ethics discussed but informed consent not mentioned. Analysis process described in depth.
Jeong, S Y-S; Higgins, I and McMillan, M (2010) The essentials of Advance Care Planning for end-of-life care for older people. *Journal of Clinical Nursing* 19(3-4): 389-397	To investigate the phenomenon of ACP for end-of-life care for older people.	Australia Three high-care Residential Aged Facilities in one area health service.	Case study Critical Incident Technique and thematic content analysis were used.	Clinical Nurse Consultants involved in implementation of ACP plus residents, families and RNs from the facilities.	The components and factors involved in the ACP process and attaining desired outcomes were mapped.	Critical appraisal score = 28 Neither the recruitment processes nor the number of residents, family members and RNs involved in participant observation or interviews were stated. Limited data was presented to support findings. Findings provided some detail as to how professionals can work together to support ACP.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Kaasalainen, S; Ploeg, J; McAiney, C; Martin L S; Donald, F; Martin-Misener, R; Brazil, K; Taniguchi, A; Wickson-Griffiths, A; Carter, N and Sangster-Gormley, E (2013) Role of the nurse practitioner in providing palliative care in long-term care. *International Journal of Palliative Nursing* 19(10): 477-485	To explore the Nurse Practitioner role in providing palliative care in long-term care.	Canada Five long-term care homes across the country.	Qualitative descriptive design using individual interviews and focus groups.	9 physicians, 20 licensed nurses, 15 personal support workers, 19 managers, 10 RN team managers or leaders, 31 allied health care providers, 4 nurse practitioners, 14 residents and 21 family members.	Three main themes: 1) Caring for residents with complex issues and their family members; 2) Working with other health-care providers; 3) Working with the organisation/system.	Critical appraisal score = 31 Part of a larger mixed-methods study that examined the integration of nurse practitioners in Canadian long-term care homes. The authors acknowledged that limited demographic information was collected on the residents and family members, but few details are provided about the professionals in the paper either. Method and analysis described clearly.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Kastbom, L; Milberg, A and Karlsson, M (2019) ‘We have no crystal ball’ – advance care planning at nursing homes from the perspective of nurses and physicians. *Scandinavian Journal of Primary Health Care* 37(2): 191-199	To investigate clinicians’ perspectives on the factors that shape the process of advance care planning in a nursing home context.	Sweden Nine nursing homes, 2 rural and 7 urban, in one district.	Qualitative interviews Latent qualitative content analysis	11 nursing home nurses and 14 physicians working with these nursing homes.	Four manifest categories and one latent theme constituting the ACP process were reported. Manifest categories were: Exploration of preferences and views; Integration of preferences and views; Decision and documentation of the ACP; Implementation and re-evaluation of the ACP. The latent theme was Establishing beneficence – defending oneself against tacit accusations of maleficence.	Critical appraisal score = 30 The methods and findings were described clearly. Information was provided about the participants, although the sample size was not justified nor details provided about how many nurses and physicians worked at each of the nursing homes. The description of the settings was limited to whether a nursing home was in a rural or urban area, with no other contextual detail provided. There was an aknowledged potential for bias due to all the researchers being physicians.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Lee, R; Bamford, C; Poole, M; McLellan, E; Exley, C and Robinson, L (2017) End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PLOS One* 12(6): e0179355	To explore the views of service managers and frontline care staff on key aspects of good end-of-life care for people with dementia.	UK Focus groups were held in two care homes (nursing and residential), two specialist elderly mentally infirm services; two hospices and two services providing supported living and home care.	Interviews with service managers and focus groups with frontline staff. Thematic analysis.	Interviews with 33 service managers: 4 doctors, 7 nursing, 12 nursing and residential home managers, 5 service development leads and 5 senior managers/ directors. Focus groups involved 54 frontline staff: 18 care assistants, 7 senior care assistants/team leads, 17 nurses, 1 doctor, 4 service development leads and 7 managers.	Seven key themes: Recognising end-of-life and tools to support end-of-life care; Communicating with families about end-of-life; Collaborative working; Continuity of care; Ensuring comfort at end-of-life; Supporting families; and Developing and supporting staff.	Critical appraisal score = 29 Services were selected to participate if they were identified as providing good or standard practice, but this was not defined. The study included a range of services providing care to people with dementia, including nursing homes, but there was no information about the specific settings. Although, there was a breakdown of number of service managers and frontline staff from each type of service, nursing and residential care home staff were categorised together. There was no breakdown of the disciplines of the managers or frontline staff or the composition of each focus group. There was minimal description of data analysis and the researcher-participant relationship.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Ling (2005) Palliative care in Irish nursing homes: the work of community clinical nurse specialists *International Journal of Palliative Nursing* 11(7): 314-321	To assess the level of input from community CNSs in palliative care into nursing homes in Ireland.	Ireland	Postal survey	63 CNSs	The main focus of CNS work in nursing homes was pain and symptom management and this was often provided by telephone. Only 40% of respondents cared for patients with non-malignant disease.	Critical appraisal score = 27 Small number of participants: all CNSs in Ireland invited to participate with a response rate of 55%. There was no discussion of analysis which would have involved quantitative and qualitative methods as the survey included both open and closed questions. Findings similar to Froggatt et al (2002) but with some data presented relevant only to the Irish context.
Lopez, R P (2009) Decision-making for acutely ill nursing home residents: nurses in the middle. *Journal of Advanced Nursing* 65(5): 1001 – 1009	To explore and describe the decision-making process used by nursing home nurses to respond to acute illness in residents.	US Four nursing homes	Grounded theory, with data collection methods of non-participant observation, informal interviews and formal interviews	4 Licensed Practice Nurses, 3 RNs and 3 Nurse Practitioners	Nurses were found to strive to create a plan of care acceptable to family members and doctors consistent with wishes of residents and most comfortable for residents. A theory: “Satisfying All Sides” was proposed.	Critical appraisal score = 33 Methods, sampling and analysis clearly outlined. Minimal information about the nursing homes provided. Findings differentiated between the grades of staff allowing any differences to be identified. It was acknowledged that decision-making processes were not consistent with informed consent.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Luckett, T; Chenoweth, L; Phillips, J; Brooks, D; et al. (2017) A facilitated approach to family case conferencing for people with advanced dementia living in nursing homes: perceptions of palliative care planning coordinators and other health professionals in the IDEAL study. *International Psychogeriatrics* 29(10): 1713-1722	To explore palliative care coordinator and health professional perceptions of the benefits of facilitated case conferencing and identify factors influencing implementation.	Australia Ten nursing homes	Qualitative interviews. Thematic approach to analysis.	11 palliative care planning coordinators, 8 nurses (including 2 managers), 10 assistants in nursing, 3 physiotherapists (or aides), 4 diversional therapists, 1 dietician and 3 physicians	Perceived benefits of facilitated case conferencing: 1) Better communication between staff and families; 2) Greater multidisciplinary involvement in case conferences and care planning; 3) Improved staff attitudes and capabilities for dementia palliative care. Key factors influencing implementation: 1) Staffing levels and time; 2) Support from management, staff and physicians; 3) Positive family feedback.	Critical appraisal score = 29 The small sample was an acknowledged limitation, with direct care staff from only seven of the ten homes represented. It was unclear how many staff were eligible to participate. The data used to support the findings is primarily quotes from palliative care planning coordinators. A likely explanation was because the interviews of these professionals were audio-recorded whereas those of the other professionals were not, written notes being used to record the content of these interviews. There was no explanation for a different approach being used.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
McDermott, C; Coppin, R; Little, P and Leydon, G (2012) Hospital admissions from nursing homes: a qualitative study of GP decision making. *British Journal of General Practice* 62(601): 538-545	To explore GPs' views on factors influencing decisions on admitting frail nursing home residents to hospital.	UK	Qualitative interviews. Thematic analysis.	21 GPs	While clinical assessment, perceived benefits and risks of admissions, and patients' and relatives' preferences are key factors in determining admissions, other important factors influencing decision-making include medico-legal concerns, communications, capability of nursing homes and GP workload.	Critical appraisal score = 28 Unclear sampling strategy presented. Thematic analysis mixed with constant comparative method. Themes and subthemes were not clearly articulated. Useful study as provided GP perspective on decision-making, although limited reference to ACP.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
O'Brien, M; Kirton, J; Knighting, K; Roe, B and Jack, B (2016) Improving end of life care in care homes; an evaluation of the six steps to success programme. *BMC Palliative Care* 15:53	To evaluate the implementation of the Six Steps to Success programme with the first cohort to complete the programme in the North West of England.	UK Six Nursing Homes for Case Study	Online qualitative questionnaire, telephone interviews and Case Studies, incorporating interviews and documentary analysis. Thematic analysis used.	Sixteen Six Steps Facilitators completed the questionnaire and nine completed a telephone interview. Six nursing homes were included as Case Studies.	The findings suggested an overall positive impact from the programme, identifying both benefits and challenges.	Critical appraisal score = 28 Provided evidence as to the influence of palliative care education on multi-professional working. Minimal information was provided about the case study interviews - there was no information relating to recruitment of clinical staff for interviews and the number of interviews that took place. The thematic approach to analysis was also minimally described.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Park, M S; Lee, S J and Chang, S O (2019) Exploring a nursing home-specific interdisciplinary approach: toward palliative care for the demented and complex-disabled elderly. *Journal of Hospice & Palliative Nursing* 21(6):E9-E15	To explore an interdisciplinary collaborative care approach between nurses and related practitioners for the demented and complex-disabled elderly in nursing homes that focuses on palliative care based on an ethical point of view.	Korea Five nursing homes	Qualitative interviews Thematic analysis	11 nurses, 6 physical therapists, 2 OTs and 10 social workers participated in 1 to 2 interviews.	Three themes were identified regarding a nursing home-specific interdisciplinary palliative care approach: 1) Identifying: constantly tracking down clues to gradual functional deteriorations. 2) Connecting: consistently responding to the subtle expressions of the elderly. 3) Maximising: expanding the optimized opportunity for an improved quality of life.	Critical appraisal score = 23 The study investigated an interdisciplinary approach but the findings provide limited detail about how being interdisciplinary contributed to the approach to palliative care outlined. Information about interdisciplnary relations raised in the discussion are not supported by data presented in the findings. There is no information about the interviewer or their influence on the study findings, the rationale for selecting interviews as the sole data collection method or who was interviewed more than once and the reason for this. Information about the five nursing homes is limited to their size. Trustworthiness of the findings was enhanced by cross validation of theme development between researchers.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Phillips, J; Davidson, P M; Jackson, D and Kristjanson, L J (2008) Multi-faceted palliative care intervention: aged care nurses' and care assistants' perceptions and experiences. *Journal of Advanced Nursing* 62(2): 216-227	To describe residential aged care nurses' and care assistants' perceptions of a multi-faceted palliative care intervention and to identify areas to be addressed during subsequent phases of the larger Residential-Palliative Approach Competency Project of which this study was phase 3.	Australia Nine residential aged care facilities.	The overall project was undertaken using action research. This phase used focus groups. Thematic content analysis was used.	4 directors of nursing, 7 link nurses, 8 RNs and 9 care assistants participated in 4 focus groups.	Four themes: 1) Targeted education makes a difference 2) A team approach is valued 3) Assessment tools are helpful 4) Using the right language is essential.	Critical appraisal score = 32 It is unclear how many of the residential aged care facilities involved were high care and therefore equivalent to a UK nursing home. Information about participants was limited to their role and it is unclear what the response rate was at both individual and facility level. Focus groups were held at four of the nine participating facilities so there may have been more staff members from those facilities represented. The impact of the researchers on the focus groups was not explored.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Phillips, J; Davidson, P M and Willcock, S (2009) An insight into the delivery of a palliative approach in residential aged care. *Journal of Applied Gerontology* 28(3): 395-405	To explore GPs' perceptions and beliefs about providing palliative care to older people in residential aged care and explore their capacity to deliver a palliative approach. This formed part of the larger Residential-Palliative Approach Competency Project.	Australia Seven GP practices	The overall project was undertaken with an action research process. This phase used focus groups. Thematic content analysis was used.	13 GPs attended one of three focus groups.	Four themes: 1) Uncertainty about a palliative approach; 2) A need to re-orientate providers; 3) The challenges of managing third parties; 4) Making it work and moving forward.	Critical appraisal score = 30 The study referred to GP practice in residential aged care facilities in general which includes the equivalent to both nursing and residential homes in the UK. The sample size was small but GPs from multiple practices participated. The authors acknowledged that no demographic or details relating to the GPs' experience of palliative care or current caseloads was sought, but do not state the reason for this.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Phillips, J L; West, P A; Davidson, P M and Agar, M (2013) Does case conferencing for people with advanced dementia living in nursing homes improve care outcomes: Evidence from an integrative review? *International Journal of Nursing Studies* 50(80): 1122-1135	To appraise the evidence for case conferencing as an intervention to improve palliative care outcomes for older people living with advanced dementia in nursing homes.	N/A	Integrative Review	9 studies were included in the review.	The highest level of evidence was generated by two randomised controlled trials which demonstrated enhanced medication management. Several pre-post-test studies suggest that case conferencing enhances palliative care symptom management and care outcomes. Qualitative evidence suggests that case conferencing is feasible and worthwhile if the identified barriers are addressed and the facilitators optimised.	Critical appraisal score = 32 The paper mentioned assessment of quality and critique of papers, but no details were provided in the table of papers. A small number of papers were included and reported a broad spectrum of issues relating to the review question, so it was not possible to generate a high level of evidence in conclusions. Papers reviewed were mainly from Australia where there are differences in the health care system.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Seymour, J E; Kumar, A and Froggatt, K (2011) Do nursing homes for older people have the support they need to provide end of life care? A mixed methods enquiry in England. *Palliative Medicine* 25(2): 125-138	To identify key factors in the wider health and social care system influencing the quality of end-of-life care provided in nursing homes.	UK One rural and one city nursing home.	Postal survey and 2 qualitative case studies. Survey analysed using descriptive statistics with open questions subject to content analysis. Thematic analysis used for the interviews.	Surveys were sent to the managers of 180 nursing homes. 4 staff members and 4 external stakeholders from the city nursing home and 3 staff members and 6 external stakeholders from the rural nursing home participated in case study interviews.	Problems accessing support for end-of-life care reported in the survey included: variable support by GPs; reluctance among GPs to prescribe appropriate medication; lack of support from other agencies; lack of OOHs support; cost of syringe drivers; and lack of access to training. The case studies suggested that critical factors in improving end-of-life care include: developing clinical leadership; developing relationships with GPs; the support of key external advocates; and leverage of additional resource by adoption of care pathway tools.	Critical appraisal score = 28 Limited information was provided about choice of homes for the postal survey and sampling within case studies. There was limited explanation of theme development. No details of ethical issues were provided. Good amounts of data were presented to support the findings. The paper does not discuss ACP explicitly but provided evidence on support for end-of-life care generally.

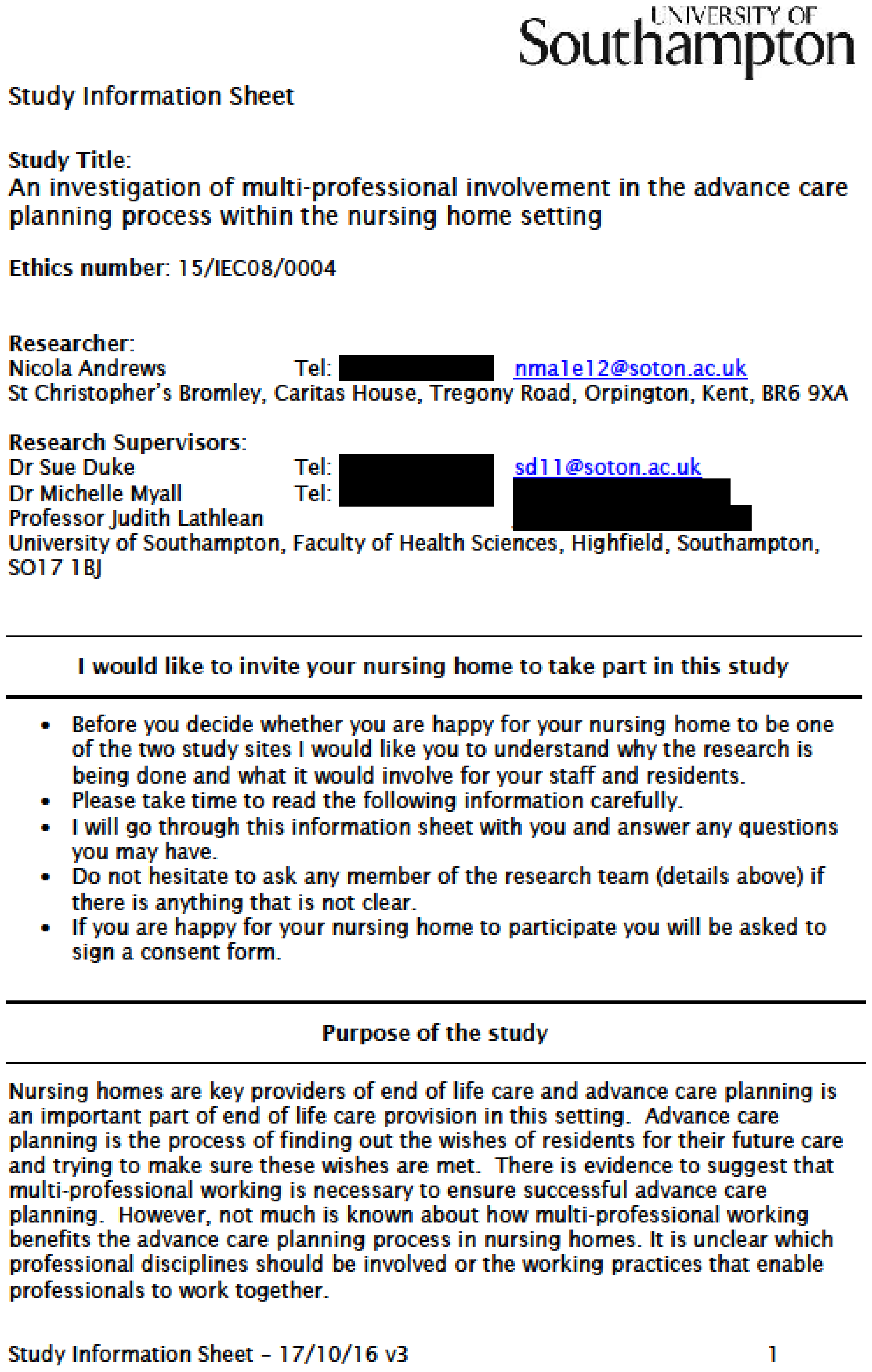
Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Shield, R R; Wetle, T; Teno, J; Miller S C and Welch, L (2005) Physicians “Missing in Acton”: Family Perspectives on Physician and Staffing Problems in End-of-Life Care in the Nursing Home. *Journal of the American Geriatric Society* 53(10): 1651-1657	To understand the roles of physicians and staff in nursing homes in relation to end-of-life care through narrative interviews with family members close to a decedent.	US	Qualitative telephone follow-up interviews with a subset of respondents who had participated in an earlier national survey. A thematic approach to analysis used.	54 “informants” (close family member or person closest to the decedent) from the death certificates of decedents who had spent at least 48 hours in a nursing home during the last month of life.	Two themes: 1) Physicians were viewed as “missing in action” in nursing homes 2) Family members reported a need for more and better trained staff.	Critical appraisal score = 26 There was an acknowledged time delay of one to two years between the death of the resident and the interview which may have impacted the findings. Sampling was not clearly described – oversampling for decedents who received hospice care was reported but not justified. There was no mention of ethical issues. The influence of the interviewer was not explored. The main qualitative findings were corroborated by the quantitative findings.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Travis, S; Moore, S; Larsen, P D and Turner, M (2005) Clinical Indicators of Treatment Futility and Imminent Terminal Decline as Discussed by Multidisciplinary Teams in Long-term Care. *American Journal of Hospice and Palliative Medicine* 22(3): 204-210	To describe how members of multidisciplinary teams in long-term care facilities recognise when residents are approaching end-stage disease, document evidence that associated treatment futility has occurred, and convey this information to others.	US Two nursing facilities	Focus group study	Two focus groups each with 7 multidisciplinary participants – representing nursing, social work and physical therapy.	In addition to typical clinical indicators of treatment futility participants described additional physical and affective changes that were apparent to them as their residents approached the end of life.	Critical appraisal score = 30 This was a small study but was enhanced by use of two sites, each very different in organisational structure. It was not clear why the multi-professional participants did not include medical personnel. No specific named approach to analysis but process of analysis outlined in detail. Although the focus was on treatment futility, the findings also revealed characteristics of multi-professional working.

Paper	**Aim(s)**	**Setting**	**Study Design**	**Participants**	**Reported Main Findings**	**Critique**
Watson, J; Hockley, J and Dewar, B (2006) Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing* 12(5): 234-240	To explore the barriers that needed to be overcome during the process of implementing an integrated care pathway for the last days of life as a way of developing quality end-of-life care in nursing homes.	UK Eight nursing homes	Action research Thematic analysis used.	Participants included managers, RNs, care assistants, GPs and relatives (numbers not specified).	Six main barriers: 1) A lack of knowledge of palliative care drugs and control of symptoms at the end-of-life 2) Lack of preparation for approaching death 3) Not knowing when someone is dying or understanding the dying process 4) Lack of multidisciplinary team working in nursing homes 5) Lack of confidence in communicating about dying 6) Some nursing homes are not ready or able to change.	Critical appraisal score = 28 The paper lacked details about the numbers of participants who took part in focus groups or interviews – either by role or by nursing home. There was also a lack of detail about the nursing home settings and local healthcare provision, in particular GP cover, to enable assessment of transferability of the findings to another area.

Paper	Aim(s)	Setting	Study Design	Participants	Reported Main Findings	Critique
Wilson, E and Seymour, J (2017) The importance of interdisciplinary communication in the process of anticipatory prescribing. *International Journal of Palliative Nursing* 23(3): 129-135	To explore the social interactions, behaviours and perceptions as they occurred within community-based teams of health professionals providing anticipatory prescribing to patients living at home or in a care home at the end of life.	UK Four community nursing teams and four nursing homes.	Ethnography using interviews and observations. A thematic approach to analysis used.	Nurses, GPs and pharmacists – up to 15 at each site participated in individual or small group interviews.	That good interdisciplinary communication is essential to the process of anticipatory prescribing and end-of-life care. Three key issues can influence the quality of communication between professionals: access, clarity about professional responsibilities and the degree of trust within the professional relationship.	Critical appraisal score = 30 Although 72 interviews were completed, including 3 group interviews, there was no detail as to how many participants there were from each professional group or from each setting. Limited information was provided about the settings and the findings are combined for the two types of setting (community and care home) which limited transferability of findings. Ethical issues reported but researcher reflexivity was not mentioned.

Appendix E. Study Information Sheet



UNIVERSITY OF Southampton

Study Information Sheet

Study Title:
An investigation of multi-professional involvement in the advance care planning process within the nursing home setting

Ethics number: 15/IEC08/0004

Researcher:
Nicola Andrews Tel: [redacted] nma1e12@soton.ac.uk
St Christopher's Bromley, Caritas House, Tregony Road, Orpington, Kent, BR6 9XA

Research Supervisors:
Dr Sue Duke Tel: [redacted] sd11@soton.ac.uk
Dr Michelle Myall Tel: [redacted]
Professor Judith Lathlean
University of Southampton, Faculty of Health Sciences, Highfield, Southampton, SO17 1BJ

I would like to invite your nursing home to take part in this study

- Before you decide whether you are happy for your nursing home to be one of the two study sites I would like you to understand why the research is being done and what it would involve for your staff and residents.
- Please take time to read the following information carefully.
- I will go through this information sheet with you and answer any questions you may have.
- Do not hesitate to ask any member of the research team (details above) if there is anything that is not clear.
- If you are happy for your nursing home to participate you will be asked to sign a consent form.

Purpose of the study

Nursing homes are key providers of end of life care and advance care planning is an important part of end of life care provision in this setting. Advance care planning is the process of finding out the wishes of residents for their future care and trying to make sure these wishes are met. There is evidence to suggest that multi-professional working is necessary to ensure successful advance care planning. However, not much is known about how multi-professional working benefits the advance care planning process in nursing homes. It is unclear which professional disciplines should be involved or the working practices that enable professionals to work together.

Study Information Sheet – 17/10/16 v3 1

UNIVERSITY OF Southampton

This study will examine how multi-professional working impacts the advance care planning process and the factors that influence multi-professional involvement in this process in two nursing homes. Hopefully the study findings will lead to a better understanding of multi-professional working in this area of care to inform developments in multi-professional and advance care planning practice in the nursing home setting.

What does the study involve?

I will observe what goes on in day to day practice in the home, focussing on multi-professional working, advance care planning discussions and end of life care decision making. I will observe both nursing home staff and visiting health or social care professionals engaged in advance care planning. This may be discussions between professionals or with residents or relatives. I will refer to relevant documents, such as policies and procedures, and the end of life care plans, advance care planning documentation and multi-professional communication sheets from the nursing home notes of residents (where written consent has been given by the resident). I will also talk to staff, residents and relatives. I will be present in the nursing home for around ten shifts per month for six to seven months. This will include night and weekend shifts.

Why has your nursing home been selected as a potential study site?

I have selected your nursing home as a potential study site as you expressed interest in being involved in the study. The multi-professional provision to your nursing home also fits with the requirements of the study. I am looking for two sites, each with different multi-professional provision, for example different numbers of GPs providing care within the home, different provision of specialist nursing services and different provision of specialist palliative care.

Does your nursing home have to take part?

It is up to you to decide whether you agree to the nursing home being a study site. You may wish to consult with staff, residents, relatives and visiting professionals before making your decision.

If you think that you would like to take part, I will arrange to meet with you. I will go through this information sheet with you and answer any questions you may have. If you then decide to take part, I will ask you to sign a consent form as representative of the home.

You are free to withdraw the nursing home at any time, without giving a reason.

What will happen to your staff, residents, relatives and professionals visiting the home if you become a study site?

If you become a study site, I will ask a range of staff members, residents, relatives and visiting professionals to take part. Written consent will be obtained from everyone taking part.

I will ask three to five residents to take part in the study. I will investigate the advance care planning 'journeys' of these residents in detail. These may be residents recently admitted but with a short prognosis so that the entire advance care planning process can be observed. Or they may be residents who are thought to have only a few weeks or months to live and who have engaged with the advance care planning process previously. Relatives, friends, staff and visiting professionals involved in the care of these residents will also be asked to take part in the study.

Participation in the study will involve participants being observed whilst providing or receiving care. Participants may also be asked to participate in an interview and documents will be reviewed. I will focus specifically on advance care planning and the practices and working relationships of members of the multi-professional team.

I will observe a range of situations involving a range of people. I will observe general routines for example multi-professional decision-making forums such as 'ward' rounds or end of life care coding meetings. I will observe interactions relating to advance care planning between professionals and the participating residents and their relatives. I may discuss things with the participants whilst observing. I will make notes of what is observed and what is discussed. I am likely to observe participants on more than one occasion as the study will take place over six to seven months.

With your written consent, I will review nursing home documents such as policies and procedures relating to advance care planning. If a participating resident gives consent, then I will review end of life care plans, advance care planning documentation and multi-professional communication sheets from their nursing home records. This is so that any aspects of the advance care planning process that occurred prior to the start of the research study or that occur when I am not present in the nursing home can inform the research. I will agree a protocol with you for accessing these aspects of a resident's notes, whereby a member of the nursing home team extracts this data from the nursing home records for me to review. Care records will not be removed from the home or photocopied but I may make anonymised notes. I will ask you to give specific written consent for this to happen.

Staff members, residents, relatives and visiting professionals may also be asked to take part in one or two interviews. I will interview participants face-to-face and one-to-one. I will arrange the interview at a convenient date and time for the participant and the nursing home. I expect interviews to take about 30 to 45 minutes. Interviews will focus on the participant's experiences of the advance care planning process and multi-professional working. They will also explore in more detail things observed and identified from documents. Interviews will be audio-recorded and I will transcribe the audio-recording word for word after the interview. I will ask the participant to give specific written consent prior to an interview taking place. I will not request an interview if the resident is considered by the nursing home staff to be too unwell or emotionally fragile to take part. I will not request an interview from a relative if the resident is poorly, dying or has recently died.

There is the possibility that residents may lose capacity to provide ongoing consent. Residents will therefore be asked to consider what they wish to happen in this situation at the outset of the study. I will ask them whether they give permission for ongoing observation of discussions that relatives or members of staff have about their care to be included in the study. And I will ask them whether they give permission for notes to be taken from documents recording these discussions and included in the study. I will also ask them to nominate someone to speak on their behalf in this situation. If they consent for data to continue to be collected when they can no longer provide consent then I will ask the person nominated to advise about ongoing participation.

If I observe poor care or practice that puts an individual at serious risk then I will report this. If information is divulged to me by a participant about substandard care that puts an individual at serious risk then I will report this. I will initially discuss the issue with the participant whose confidentiality will be breached through reporting the matter. The concern will then be raised with the most appropriate senior member of the nursing home team prior to reporting it via safeguarding channels.

What are the benefits of being a study site?

It is not clear at this stage what the findings may show. However, hopefully the understanding gained from this study will help to inform developments both in multi-professional working and advance care planning within the nursing home setting. Being a study site could therefore enable your staff, residents and relatives to contribute to improving the care of nursing home residents in the future.

What are the possible disadvantages of being a study site?

Discussing aspects of care whilst working may slow your staff down, which may cause inconvenience. I will try to minimise the impact of this by maintaining an awareness of the competing pressures on a participant's time and endeavouring not to hold them up.

Staff interviews will involve a time commitment which may cause inconvenience given nursing homes are busy environments. I will try to minimise the impact of these by ensuring strict adherence to interview duration and providing flexibility as to when the interviews take place.

As the focus of the research is advance care planning, some interview questions may involve sensitive issues relating to end of life care. This may be upsetting for residents, relatives or staff. If a resident, relative or member of staff becomes distressed in an interview, I will check with them whether or not they wish to continue. I will ensure that anyone who becomes distressed is followed up by either me or a member of the nursing home team, as appropriate.

As the advance care planning process ends when the resident dies, terminal care situations may be observed. This may cause additional distress to relatives and staff. I will always check with the relative and member of staff that they are happy for me to observe the care before entering the situation. After the period of observation I will check with the individuals involved that they are receiving the support they need.

Will the identity of the nursing home remain confidential?

Only I and my research supervisors will know the name and location of the nursing home. I may include things that participants have said or extracts from my notes about observations in study reports. However, I will not name the participant. I will use quotes or extracts from my notes referring to the participant only by a code or pseudonym. I will review all such anonymised quotes and research note extracts carefully to try to ensure that neither the nursing home nor the participants can be identified inadvertently.

All research data will be stored as anonymised data, with each participant allocated a unique code under which data is stored. I will label all notes, audio-recordings and transcripts using these unique codes only. Data that identifies the participant and links the participant to their unique code will be stored separately from the research data in an electronic password protected file only accessible by the researcher. This data will be kept to a minimum, consisting of:

- For residents – name, gender and age
- For relatives – name and relationship to the resident
- For nursing home staff and visiting professions – name and job role.

Consent forms will be stored in a locked filing cabinet that only I can access. I will not store any information specifically linking the nursing home to the study.

All research data will be held securely on a password protected and encrypted laptop during the study. The anonymised research data will be held securely at the University for 10 years after completion of the study. Data which identifies the participants will be securely disposed of within 3 months of the study completion. All data will be stored in accordance with the Data Protection Act (1998).

All information collected from participants is confidential to the research team. It will not be disclosed to anyone else unless they tell me something that suggests that someone is at risk of harm. I would discuss this with them first. I would then discuss this with the most appropriate senior member of staff before telling anyone else.

What do you do if you wish to withdraw the nursing home from the study?

You can withdraw the nursing home from the study at any time by informing me.

If you withdraw from the study, I will collect no further data from the nursing home staff or residents. If visiting professionals are happy to continue to take part I will continue with any planned interviews with them. I will keep existing data confidentially to inform the findings. This will be used in the data analysis but no quotes or extracts will be included in any publications or reports.

What will happen to the findings of the research study?

The findings of the study will form the basis of a thesis for the award of PhD in Health Sciences at the University of Southampton. An electronic copy of the thesis will be stored by the University of Southampton library. I will also seek publication in professional journals.

I will provide a summary report for the nursing home and for the visiting professional staff who have taken part. I will send a copy of this report to relatives who have participated in the study and requested a copy. I will send a copy of this report to the Research Governance Departments of the employing organisations of all professional staff who have taken part. This will include Hampshire County Council. The report will also be sent to the Social Care Research Ethics Committee.

Who is organising and funding the research?

I am completing this research for the award of PhD in Health Sciences at the University of Southampton.

I am studying part-time and work part-time as a Clinical Nurse Specialist in Palliative Care. I am employed by an independent hospice in South London.

The research is sponsored by the University of Southampton.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

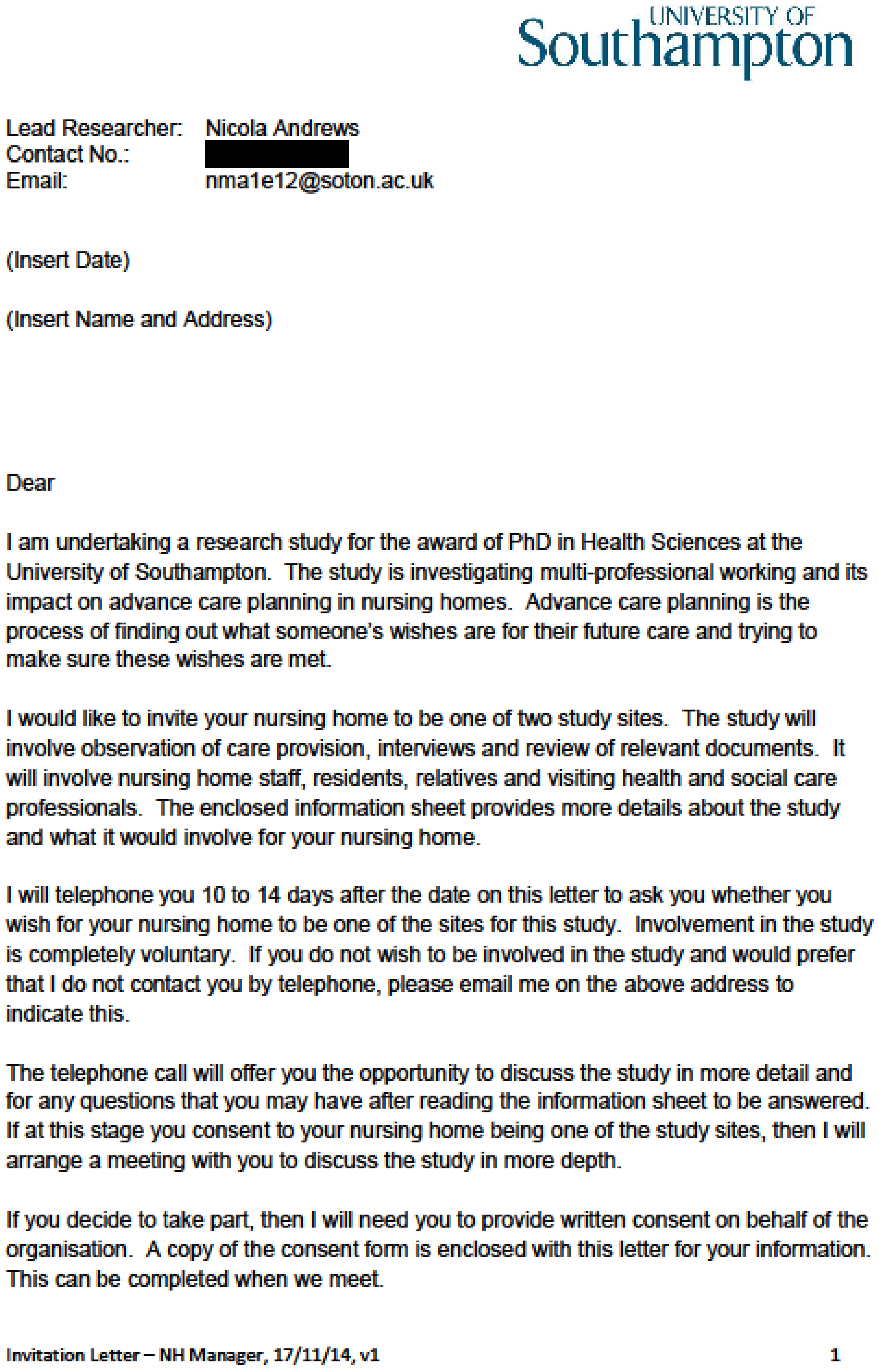
[redacted] County Council's Research Development and Governance Panel have also reviewed the study.

What if there is a problem?

If you have a concern or complaint about this study you should contact:
[redacted]
Head of IP, Contracts and Policy
Research Governance Office
University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ
Tel: [redacted]
Email: rgoinfo@soton.ac.uk

If you remain unhappy and wish to complain formally [redacted] can provide you with details of the University of Southampton Complaints Procedure.

Appendix F. Invitation Letter – Nursing Home Manager



Lead Researcher: Nicola Andrews
Contact No.: [redacted]
Email: nma1e12@soton.ac.uk

(Insert Date)

(Insert Name and Address)

Dear

I am undertaking a research study for the award of PhD in Health Sciences at the University of Southampton. The study is investigating multi-professional working and its impact on advance care planning in nursing homes. Advance care planning is the process of finding out what someone's wishes are for their future care and trying to make sure these wishes are met.

I would like to invite your nursing home to be one of two study sites. The study will involve observation of care provision, interviews and review of relevant documents. It will involve nursing home staff, residents, relatives and visiting health and social care professionals. The enclosed information sheet provides more details about the study and what it would involve for your nursing home.

I will telephone you 10 to 14 days after the date on this letter to ask you whether you wish for your nursing home to be one of the sites for this study. Involvement in the study is completely voluntary. If you do not wish to be involved in the study and would prefer that I do not contact you by telephone, please email me on the above address to indicate this.

The telephone call will offer you the opportunity to discuss the study in more detail and for any questions that you may have after reading the information sheet to be answered. If at this stage you consent to your nursing home being one of the study sites, then I will arrange a meeting with you to discuss the study in more depth.

If you decide to take part, then I will need you to provide written consent on behalf of the organisation. A copy of the consent form is enclosed with this letter for your information. This can be completed when we meet.

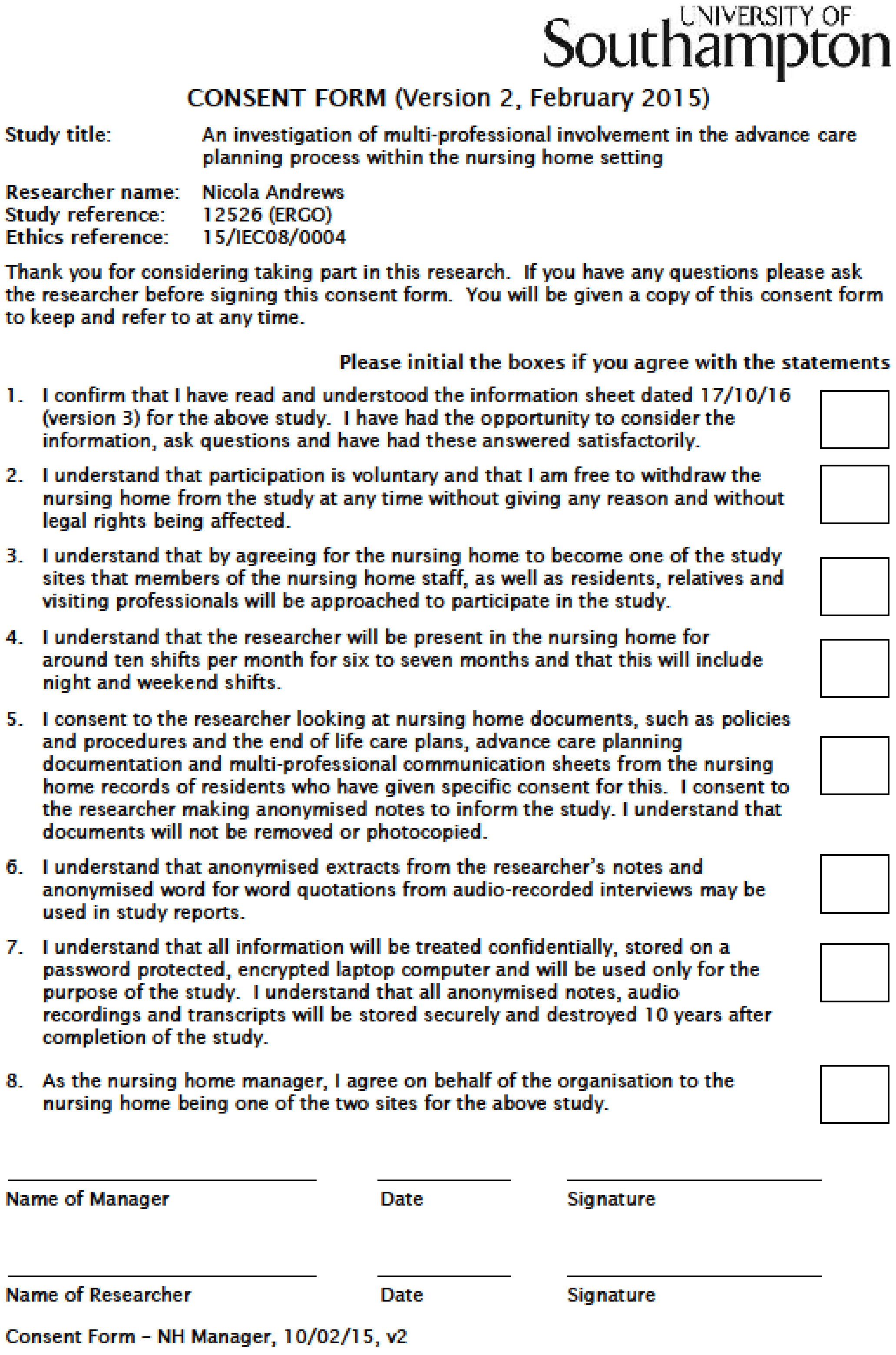
Invitation Letter – NH Manager, 17/11/14, v1 **1**

If you wish to contact me directly to discuss any aspect of the study, then please do not hesitate to do so using the contact details above.

Yours sincerely,

Nicola Andrews

Appendix G. Nursing Home Consent Form



UNIVERSITY OF
Southampton

CONSENT FORM (Version 2, February 2015)

Study title: An investigation of multi-professional involvement in the advance care planning process within the nursing home setting

Researcher name: Nicola Andrews
Study reference: 12526 (ERGO)
Ethics reference: 15/IEC08/0004

Thank you for considering taking part in this research. If you have any questions please ask the researcher before signing this consent form. You will be given a copy of this consent form to keep and refer to at any time.

Please initial the boxes if you agree with the statements

1. I confirm that I have read and understood the information sheet dated 17/10/16 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that participation is voluntary and that I am free to withdraw the nursing home from the study at any time without giving any reason and without legal rights being affected. ☐
3. I understand that by agreeing for the nursing home to become one of the study sites that members of the nursing home staff, as well as residents, relatives and visiting professionals will be approached to participate in the study. ☐
4. I understand that the researcher will be present in the nursing home for around ten shifts per month for six to seven months and that this will include night and weekend shifts. ☐
5. I consent to the researcher looking at nursing home documents, such as policies and procedures and the end of life care plans, advance care planning documentation and multi-professional communication sheets from the nursing home records of residents who have given specific consent for this. I consent to the researcher making anonymised notes to inform the study. I understand that documents will not be removed or photocopied. ☐
6. I understand that anonymised extracts from the researcher's notes and anonymised word for word quotations from audio-recorded interviews may be used in study reports. ☐
7. I understand that all information will be treated confidentially, stored on a password protected, encrypted laptop computer and will be used only for the purpose of the study. I understand that all anonymised notes, audio recordings and transcripts will be stored securely and destroyed 10 years after completion of the study. ☐
8. As the nursing home manager, I agree on behalf of the organisation to the nursing home being one of the two sites for the above study. ☐

Name of Manager	Date	Signature
Name of Researcher	Date	Signature

Consent Form – NH Manager, 10/02/15, v2

Appendix H. Invitation Letter – Residents

UNIVERSITY OF Southampton

Lead Researcher: Nicola Andrews
Contact No.: [redacted]
Email: nma1e12@soton.ac.uk

(Insert Date)

(Insert Name and Address)

Dear

I am carrying out a research study to investigate how professionals from different disciplines and specialities working together impact on advance care planning in nursing homes. Advance care planning is the process of finding out what someone's wishes are for their future care and trying to make sure these wishes are met.

I would like to invite you to take part in the study. Your nursing home, (enter name of nursing home), is one of two sites for this study.

The study will involve observation of care provision, interviews and review of relevant documents. It will involve nursing home staff, residents, relatives and visiting health and social care professionals. The enclosed information sheet provides more details about the study and what it would involve for you. Participation is completely voluntary.

If you are interested in taking part, then please ask a member of staff to contact me. I will then come and meet with you. We can discuss the study in more detail and I can answer any questions you may have. I can meet you with a relative or friend if you prefer.

If you do not wish to take part, then please ask a member of staff to let me know. If I haven't had a response from you within two weeks of the date of this letter then I will ask a member of staff to check whether you are interested in taking part or wish to discuss it further.

If you decide to take part then I will need your consent in writing. I have enclosed a copy of the consent form with this letter for your information. There is a separate consent form for interviews. I have also enclosed a copy of that for your information.

If you wish to contact me directly to discuss any aspect of the study, then please do not hesitate to do so using the contact details above.

Yours sincerely,

Nicola Andrews

Appendix I. Participant Information Sheet – Residents

UNIVERSITY OF Southampton

Participant Information Sheet

Study Title:
An investigation of multi-professional involvement in the advance care planning process within the nursing home setting

Ethics number: 15/IEC08/0004

Researcher:
Nicola Andrews Tel: [redacted] nma1e12@soton.ac.uk
St Christopher's Bromley, Caritas House, Tregony Road, Orpington, Kent, BR6 9XA

Research Supervisors:
Dr Sue Duke Tel: [redacted] sd11@soton.ac.uk
Dr Michelle Myall Tel: [redacted]
Professor Judith Lathlean
University of Southampton, Faculty of Health Sciences, Highfield, Southampton, SO17 1BJ

I would like to invite you to take part in this study

- Before you decide whether to take part you need to understand why the research is being done and what it would involve for you.
- Please read the following information carefully.
- I will go through this information sheet with you and answer any questions you may have.
- Please do not hesitate to ask me if there is anything that is not clear. My contact details are above.
- If you are happy to participate I will ask you to sign a consent form.

Purpose of the study

Advance care planning is an important part of end of life care in nursing homes. Advance care planning is finding out what your wishes are for your future care and trying to make sure these wishes are met. It is thought that a range of people need to work together to make sure advance care planning is successful. This could include doctors, nurses and social workers. However, it is not clear how joint working between different professionals helps the advance care planning process in nursing homes. It is not clear who should be involved or what helps people work together. This is what this study is about. Hopefully the study findings will help us understand better how professionals work together in this area of care.

What does the study involve?

I will observe advance care planning discussions and professionals working with you and others. I will also refer to relevant documents and talk to staff, residents and relatives. I will be present in the nursing home for around ten shifts per month for six to seven months.

Why have I selected you to take part?

I selected you to take part because you are a resident in one of the nursing homes taking part in the study. I have chosen you because you have already started the advance care planning process. I will ask between three and five residents from your nursing home to take part.

Do you have to take part?

It is up to you to decide whether to take part.

If you decide to take part, I will ask you to sign a consent form. I will ask you to verbally confirm your consent on each date that I have contact with you.

You are free to withdraw at any time, without giving a reason. You are also free to refuse to take part on any occasion, without giving a reason. This would not affect the care or support you receive.

What will happen to you if you take part?

If you take part, these are the things that may happen:

- I will observe discussions about your future care. These may be discussions between you and members of the nursing home team or other health or social care professionals. I will focus on how the nursing home team and other professionals work with you and work with each other. I may ask you to explain things whilst I observe you. I will make notes about things that I see and the things discussed. I may observe you having these discussions on more than one occasion over a few months.
- I may ask you to take part in one or two interviews. I will arrange this at a convenient date and time for you. I expect interviews to take around 30 to 45 minutes. I will ask you to give written consent prior to an interview taking place. The interview will focus on your experiences of advance care planning. Interviews will be audio-recorded. I will transcribe the audio-recording word for word after the interview.
- I will ask you if I can look at parts of your nursing home notes. This will allow advance care planning discussions that take place when I am not present to

inform the research. I will only ask to look at end of life care plans, advance care planning documents and multi-professional communication sheets. I will not remove or photocopy your nursing home notes. However, I may make notes but I will not include your name. You can still take part in the study if you do not give consent for me to look at your notes.

- I would also like to hear the views of relatives and friends. I will ask you to let me know the names of people important to you. I may then invite them to take part in the study. They do not have to take part. I will give them information about the study and they can decide whether they wish to take part.

What are the benefits of taking part in the study?

I hope that this study will help to inform developments in how people work together in advance care planning within the nursing home setting. This could lead to improvements in the care of nursing home residents in the future.

What are the possible disadvantages of taking part in the study?

Being observed whilst you speak to nurses and other professionals may make you feel uncomfortable. This may be more likely at the start of the study until you get used to me being present in the home.

Advance care planning discussions may involve issues relating to end of life care. You may feel uncomfortable discussing these sensitive issues in my presence.

I will always check with you whether you are happy for me to observe you.

Some of the interview questions may be about end of life care issues, which you may find upsetting. If you become distressed during an interview, I will ask you if you wish to continue. I will make sure that support is offered to you after the interview.

Will what I observe or information you share with me be kept confidential?

I will not tell anyone that you have taken part in the study. I may include things you have said or extracts from my notes relating to your care in study reports. However, I will not name you. I will anonymise these quotes or extracts using a code.

Any data kept for the purposes of the study will not be named. The anonymised research data will be held at the University for 10 years after completion of the study. All data will be stored in accordance with the Data Protection Act (1998).

I will keep a list of names of everyone who has taken part in the study and their code. Only I will be able to access this. This list will include your gender and age.

It will not include any other personal data relating to you. I will store this separately from the anonymised research data. I will use this information to make sure that all research data is coded correctly. This information which personally identifies you will be securely disposed of within 3 months of the study completion.

All information collected from you is confidential to the research team. I will not tell anyone else unless you tell me something that suggests that someone is at risk of harm. I would discuss this with you before telling anyone else.

If I observe poor care or practice that puts you or someone else at serious risk then I will report this. I will initially discuss the issue with you if reporting the matter will breach your confidentiality.

What do you do if you don't want to carry on with the study?

You can withdraw from the study at any time by letting me know. Or you can ask a member of the nursing home staff to let me know on your behalf. If you withdraw from the study, I will collect no further data from you or about you. I will keep existing data confidentially to inform the findings. This will be used in the data analysis but no quotes or extracts will be used in any publications or reports.

What will happen if you lose the capacity to provide ongoing consent?

I will ask you to consider this at the start of the study. I will ask you whether you would be happy for observation of discussions about your care and review of your nursing home notes to continue.

If you agree to continue to participate if you lose capacity to provide ongoing consent:

- I will ask you to name someone to speak on your behalf. You should nominate someone who knows you well. This person should be interested in your welfare, for example a relative or a friend. You should not nominate someone who is paid to care for you, such as a nurse or carer.
- I will ask the person you have named to provide advice about whether or not you should continue to take part in the study when you cannot provide consent yourself. I will ask them to sign a form. Signing this form will confirm that they have been asked about your ongoing involvement in the study.

If you do not agree to continue to participate if you lose capacity to provide ongoing consent:

- I will withdraw you from the study when you are cannot provide consent yourself. I will not collect any further information relating to your care.
- All data collected up to this point will still be included in the study.

What will happen to the findings of the research study?

I will write up the study for the award of PhD in Health Sciences. I will also seek publication of the findings in professional journals.

I will provide a summary report for the nursing home. I will offer a copy of this report to all professionals and relatives who take part in the study.

Who is organising and funding the research?

I am completing this research for the award of PhD in Health Sciences at the University of Southampton.

I am studying part-time and work part-time as a Clinical Nurse Specialist in Palliative Care. I am employed by an independent hospice in South London.

The research is sponsored by the University of Southampton.

Who has reviewed the study?

The Social Care Research Ethics Committee has reviewed and approved this study. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of those who take part and the researchers.

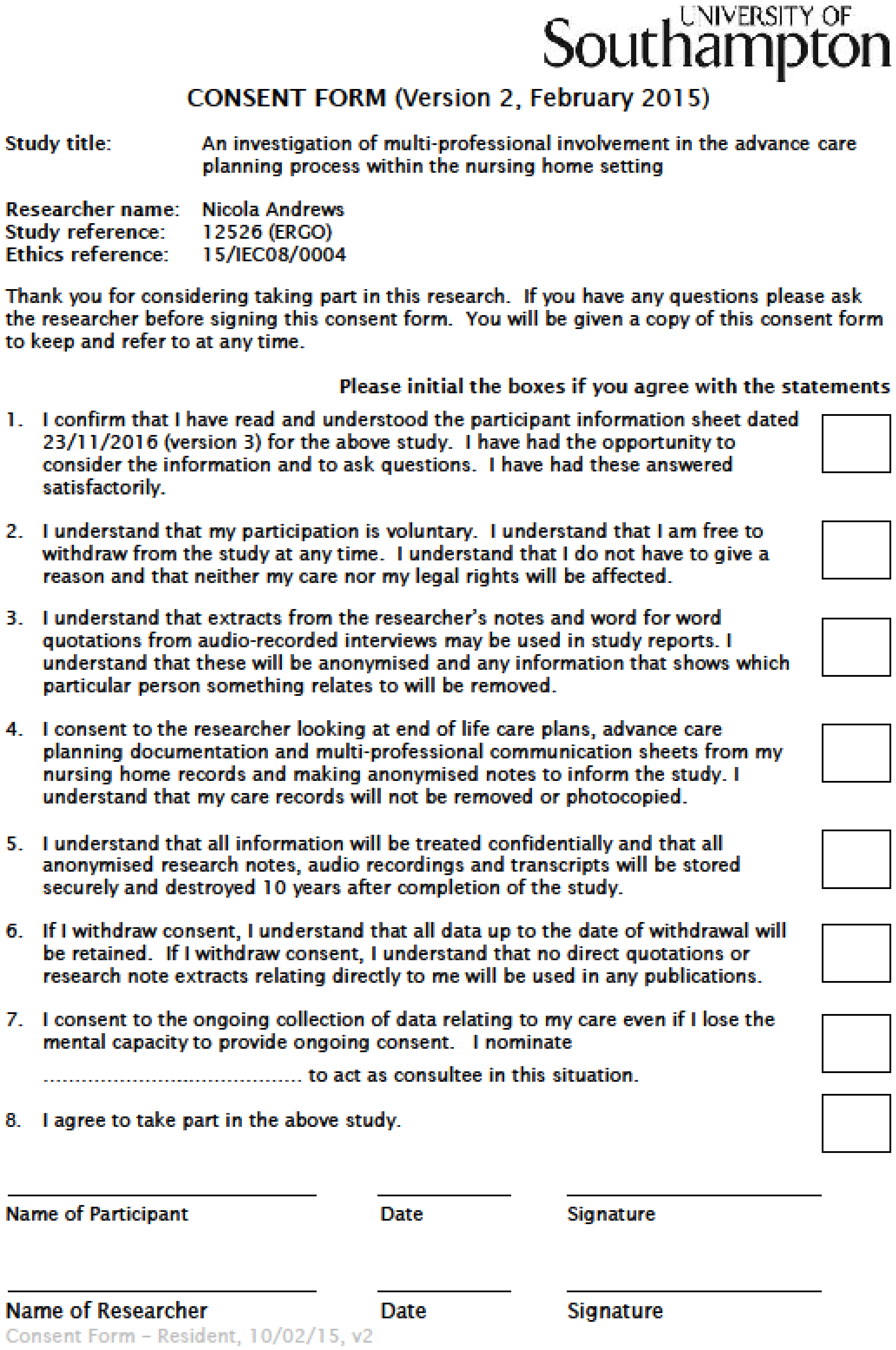
[redacted] County Council's Research Development and Governance Panel have also reviewed the study.

What if there is a problem?

If you have a concern or complaint about this study you should contact:
[redacted]
Head of IP, Contracts and Policy
Research Governance Office
University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ
Tel: [redacted]
Email: rgoinfo@soton.ac.uk

If you remain unhappy and wish to complain formally, [redacted] can provide you with details of the University of Southampton Complaints Procedure.

Appendix J. Consent Form – Resident



UNIVERSITY OF Southampton

CONSENT FORM (Version 2, February 2015)

Study title: An investigation of multi-professional involvement in the advance care planning process within the nursing home setting

Researcher name: Nicola Andrews
Study reference: 12526 (ERGO)
Ethics reference: 15/IEC08/0004

Thank you for considering taking part in this research. If you have any questions please ask the researcher before signing this consent form. You will be given a copy of this consent form to keep and refer to at any time.

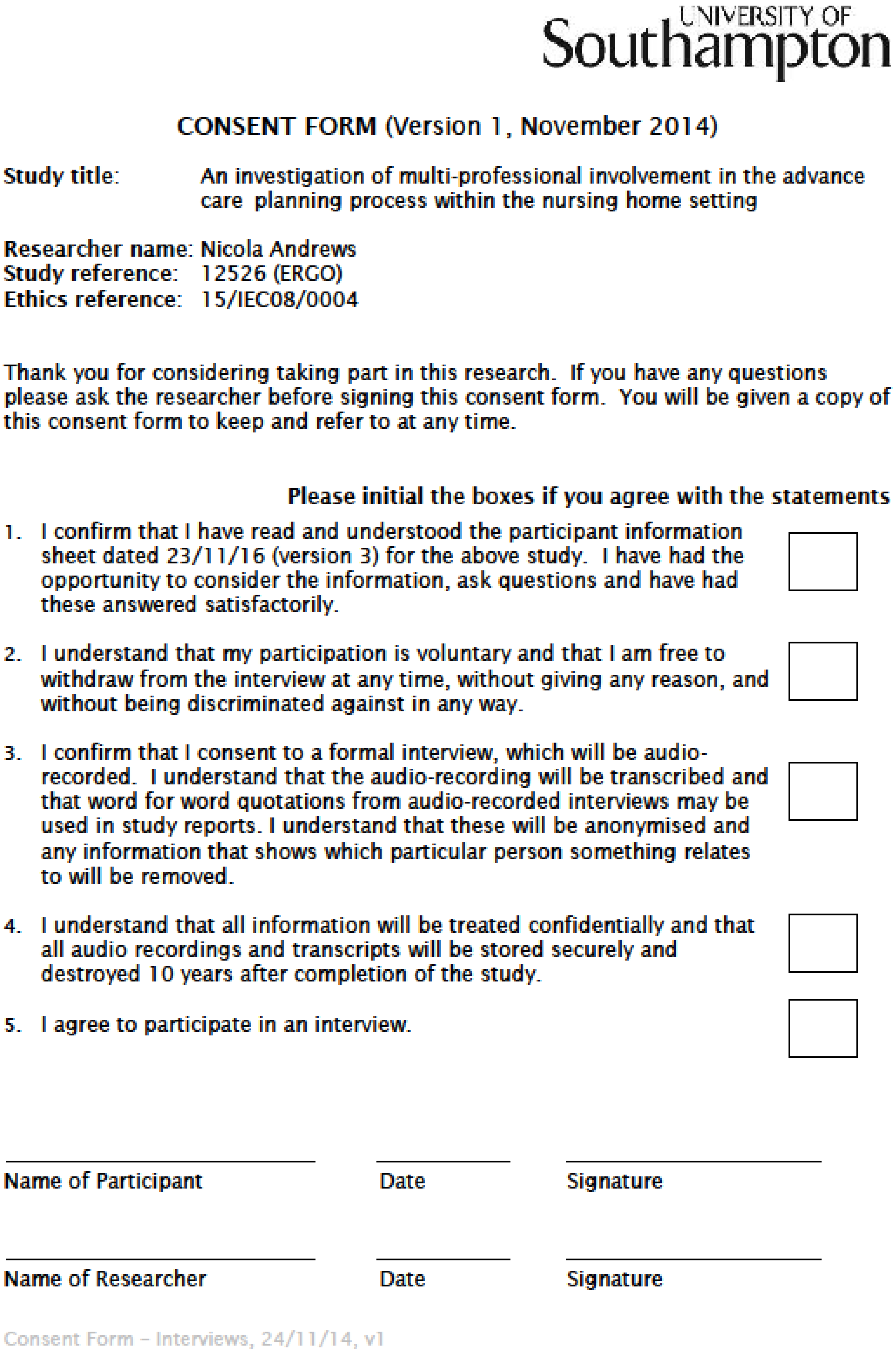
Please initial the boxes if you agree with the statements

1. I confirm that I have read and understood the participant information sheet dated 23/11/2016 (version 3) for the above study. I have had the opportunity to consider the information and to ask questions. I have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary. I understand that I am free to withdraw from the study at any time. I understand that I do not have to give a reason and that neither my care nor my legal rights will be affected. ☐
3. I understand that extracts from the researcher's notes and word for word quotations from audio-recorded interviews may be used in study reports. I understand that these will be anonymised and any information that shows which particular person something relates to will be removed. ☐
4. I consent to the researcher looking at end of life care plans, advance care planning documentation and multi-professional communication sheets from my nursing home records and making anonymised notes to inform the study. I understand that my care records will not be removed or photocopied. ☐
5. I understand that all information will be treated confidentially and that all anonymised research notes, audio recordings and transcripts will be stored securely and destroyed 10 years after completion of the study. ☐
6. If I withdraw consent, I understand that all data up to the date of withdrawal will be retained. If I withdraw consent, I understand that no direct quotations or research note extracts relating directly to me will be used in any publications. ☐
7. I consent to the ongoing collection of data relating to my care even if I lose the mental capacity to provide ongoing consent. I nominate .... to act as consultee in this situation. ☐
8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Consent Form – Resident, 10/02/15, v2

Appendix K. Consent Form – Interviews



UNIVERSITY OF Southampton

CONSENT FORM (Version 1, November 2014)

Study title: An investigation of multi-professional involvement in the advance care planning process within the nursing home setting

Researcher name: Nicola Andrews
Study reference: 12526 (ERGO)
Ethics reference: 15/IEC08/0004

Thank you for considering taking part in this research. If you have any questions please ask the researcher before signing this consent form. You will be given a copy of this consent form to keep and refer to at any time.

Please initial the boxes if you agree with the statements

1. I confirm that I have read and understood the participant information sheet dated 23/11/16 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the interview at any time, without giving any reason, and without being discriminated against in any way. ☐
3. I confirm that I consent to a formal interview, which will be audio-recorded. I understand that the audio-recording will be transcribed and that word for word quotations from audio-recorded interviews may be used in study reports. I understand that these will be anonymised and any information that shows which particular person something relates to will be removed. ☐
4. I understand that all information will be treated confidentially and that all audio recordings and transcripts will be stored securely and destroyed 10 years after completion of the study. ☐
5. I agree to participate in an interview. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Consent Form – Interviews, 24/11/14, v1

Appendix L. Interview Topic Guide

Interview Topic Guide

Broad interview topics may include:

- Experiences of involvement in discussions about future care and treatment.
- Professional roles in advance care planning discussions.
- Experiences of multi-professional involvement in advance care planning.
- Experiences of how information about wishes and preferences is shared.
- Experiences of how advance care planning impacts on care and treatment decisions.
- Factors that help or hinder multi-professional working in advance care planning.

Appendix M. Documentary Analysis Form

DOCUMENTARY ANALYSIS FORM			
Document name		**Document type**	
Document purpose			
Intended audience including accessibility & readability			
Overview of document layout and content			
Content reviewed (if not all)			
What meaning is overt and explicit in relation to multi-professional working?			
What meaning is overt and explicit in relation to ACP?			
What meaning reflects the rhetoric of the policy environment and the government's intentions in relation to multi-professional working, ACP or EoLC?			
What meaning reflects implicit ideology underpinning policies in the local area in relation to multi-professional working, ACP or EoLC?			
What meaning reflects implicit ideology underpinning policies at the level of the nursing home in relation to multi-professional working, ACP or EoLC?			

What meaning reflects implicit ideology underpinning policies at the nursing home organisation corporate level in relation to multi-professional working, ACP or EoLC?	
How is the content of this document enacted in the contents of resident notes? What does this say about the culture?	
How is the content of this document enacted in observation and interview data? What does this say about the culture?	
What is the explanation for any difference and how does this impact on multi-professional working?	

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