



Advance Care Planning in Care Homes for Older People: A Survey of Current Practice

Funded by The Nuffield Foundation

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EXECUTIVE SUMMARY

Background

Advance care planning (ACP) as a process of discussing and recording wishes for future care and treatment is increasingly being promoted and discussed in the UK, reflecting changes in recent legislation. The Nuffield Foundation has funded Counsel and Care, Lancaster University and the University of the West of England to undertake the first survey of ACP practice in English care homes.

Purpose of Study

The purpose of this study was to describe current ACP practice in care homes for older people; to what extent this is currently undertaken, how this is done and to highlight good practice already in use within the sector in order to develop a good practice guide.

Research Methods

A questionnaire survey and interviews with care home managers were undertaken. In the first phase, 500 managers of care homes for older people were surveyed. A response rate of 42% (n=213) was achieved. In the second phase, qualitative telephone interviews were undertaken with 15 care home managers. These managers were selected to reflect the range of (good) practice occurring in care homes across the UK. This approach offers a richness of data when relatively little is known about current ACP and consultation practices in care homes for older people. It is important to note that further output can be expected from this study, as it is beyond the scope of this report to analyse and present all data gathered.

Key Findings

Consultation

Consultation about general care is taking place in the majority of homes surveyed in a variety of ways. Managers report consulting with residents and relatives using both formal and informal processes.

Advance Care Planning

Managers taking part in this study overwhelmingly viewed ACP as a positive and beneficial process which they recommend residents complete. However, the number of residents that have completed any ACP processes (advance decisions, statements of

wishes and preferences, lasting power of attorney) generally remain low, with some exceptions. End of life tools promoted by the government are not currently widely used in the homes surveyed, however managers report having created their own tools tailored to their home's needs.

Staff Training

Care homes surveyed report varying levels of staff training. Most had staff trained in communication and listening skills, palliative care and bereavement care. Fewer have staff trained in advance care planning, religious practices or spiritual care.

Managers' Views

The majority of managers indicated that consultation with residents about specific and general end of life issues (including resuscitation wishes and hospital admissions) was "very important". Managers report varying levels of confidence in addressing end of life issues with residents, relatives and staff, but indicate feeling most confident when consulting with relatives. Managers report lower levels of confidence regarding their knowledge of end of life issues and supporting staff to undertake discussions.

Factors Influencing Advance Care Planning in Care Homes

Challenges faced by managers appear to be dependent on the element of ACP being addressed: be it ascertaining or implementing wishes. Managers reported staff confidence as one of the biggest barriers to consultation with residents about end of life care. Managers surveyed also reported varying challenges in finding out and carrying out a resident's wishes. Although similar issues appeared in responses for both ascertaining and implementing wishes, challenges relating to the resident, staff and communication process were more strongly related to ascertaining a resident's wishes, whereas issues pertaining to the structures in the care home or external factors such as external health care providers were more frequently cited as barriers to implementing wishes. Family-related challenges occurred in both ascertaining and implementing wishes.

Elements of Good ACP Practice

Good ACP practice in care homes comprised of attention to ensuring that ACP was focused on the individual and tailored to their needs and abilities through inclusion,

where appropriate, of family, friends, care home staff and external health and social care providers in the process. This was enhanced where the processes used had been integrated into the usual home approaches to general care planning and review.

Recommendations

For Policy

- ACP needs to fit into a wider Transforming Social Care personalisation agenda. LAC(DH)(2008)1 does not mention end of life care, but does implicitly refer to care homes when it states 'in any setting'. We recommend that the government look at joint health and social care initiatives for ensuring 'choice and control' extends to older people who will end their lives in a care home.

For Commissioners

- We recommend that as well as 'long term conditions', the social care transformation agenda includes 'life-limiting conditions' so that the Public Service Agreements to ensure 'better care for all' includes ACP and other end of life tools.
- Community public education initiatives need to be developed to ensure the general public are given opportunities to consider ACP ahead of the time when care issues are immediately being addressed for themselves or family members.

For Educational Commissioners and Providers

- The findings of this research highlight that care staff need to have tools to develop the skills they need to undertake ACP with residents. The proposed Social Care Skills Academy and the preceding Adult Workforce Strategy needs to examine how it can equip social care workers in care homes with the right skill set.
- Accredited training courses that address all elements of ACP need to be developed and delivered to multi-disciplinary teams (internal and external to care homes) that are involved in the ascertaining and implementing of people's wishes.

For Care Home Sector

- ACP needs to be addressed in each care home for all residents, either in situations where an individual is unable to communicate their wishes and/or for the end of life.
- Education and training needs to be sought for all levels of staff regarding the *Ascertaining Wishes: A Good Practice Guide* (Butterworth et al 2008), the Mental Capacity Act, communication skills and engaging with families, if staff are to be enabled to ascertain wishes from residents.
- Care home managers need to engage in discussion with the wider primary care team and palliative care specialists in order to ensure they are all prepared to implement residents' wishes, particularly towards the end of life.

For Researchers

- Further research is required with regard to ascertaining the views and understanding of family members' and care staff in relation to ACP in care homes.
- Similarly, research with primary care staff will enable a better understanding of the complexities of working across the health and social care boundaries with respect to ACP.
- The development of integrated models of ACP need to be tested and trialled.

DEFINITIONS AND GLOSSARY

Advance Care Planning

Advance Care Planning (ACP) is a process of discussion between an individual and their care providers. This is different from general care planning in that ACP usually takes place in the context of an anticipated deterioration of an individual's condition in the future, with the expected result that the individual will lose their capacity to make decisions and/or ability to communicate their wishes to others. An ACP discussion might include:

- the individual's concerns;
- their important values or personal goals for care;
- their understanding about their illness and prognosis;
- their preferences for types of care or treatment that may be beneficial in the future and the availability of these.

The term **statement of wishes and preferences** is a summary term that embraces a range of written and/or recorded oral expressions of future preferences for care and treatment. A statement of wishes and preferences may take the form of an advance refusal of a specific treatment (see advance decision), but it may also be a more general reflection of a person's hopes, beliefs, values and wishes for care.

The term **advance decision** relates to a specific medical treatment and specific circumstances. It will only come into effect when the individual has lost capacity to give or refuse consent.

Adapted from Henry and Seymour (2007)

ACP	Advance Care Planning
ADRT	Advance Decision to Refuse Treatment
<i>'best interests'</i>	Determining a person's best interests will include a wide range of factors, for example, considering all the relevant circumstances, their wishes and values, and the views of others close to the person. See the Code of Practice (Department for Constitutional Affairs 2005)
<i>'care'</i>	Help with actions, which are needed to keep a person comfortable, sometimes called 'basic' or 'essential' care, for example hygiene and offers of oral food and fluid. An advance decision cannot refuse these actions. See the Code of Practice (Department for Constitutional Affairs 2005)
Care home	The term care home in this report is used as a generic term to describe institutions that provide long-term nursing and/or personal care for older people
<i>'consultee'</i>	A person who is asked for their views and opinions, particularly about what the resident would want. An explanation can be found in the Code of Practice (Department for Constitutional Affairs 2005)
CPR	Cardio-pulmonary resuscitation
family carers	Residents' family, relatives, or close friends who provide care and support to the person
LPA	Lasting Power of Attorney (LPA) is the authority given to another person to make decisions on behalf of someone else, within the rules of the Mental Capacity Act 2005. See the Code of Practice (Department for Constitutional Affairs 2005)
<i>representative</i>	the term used in the Care Standards Act 2000 for someone who can be consulted
<i>'resident'</i>	A person who lives in a care home. The term 'resident' has been used for ease
SWP	Statement of Wishes and Preferences
<i>'treatment'</i>	interventions, which may be medical or nursing

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1. INTRODUCTION

Care homes were the place of residence for 410, 000 older people in the UK in 2004 (OFT 2005). They remain an important place of care until death for a significant number of very frail older people. One in five of the UK population aged 65 years and older die in such institutions (ONS 2000). Although approximately 9% of people who die in care homes do so with a recognisable terminal illness, such as cancer, a further 42% die following a long period of general deterioration (Sidell et al. 1997). Advance care planning (ACP) is a process of discussion that usually takes place in anticipation of a future deterioration of a person's condition between that person and a care worker (Henry and Seymour 2007). Consequently, engaging with a process of Advance Care Planning could be seen as an important priority in the care home setting. Little is known about current practice in this area in care homes in the UK. To address this gap in knowledge, this descriptive study has been undertaken, funded by the Nuffield Foundation and carried out by Counsel and Care, a national charity whose aim is to get the best care and support for older people, their families and carers, and researchers from Lancaster University and the University of the West of England.

2. BACKGROUND AND POLICY CONTEXT

The background to understanding the context for this ACP care homes study is in the following four areas: trends in health and social care, care homes as settings of care, end of life care and advance care planning processes.

2.1 Health and Social Care

A key element in recent and proposed changes in health and social care concerns the personalisation agenda, which has implications for a process such as ACP, focused as it is on the articulation of personal choices and preferences. This has been present in a number of recent White and Green papers (Department of Health 2005, 2006), and more explicitly in recent concordats (Putting People First (Department of Health 2007)) and the Local Authority circular LAC 1 (DH) (2008)¹: 'Transforming social care' circular (Department of Health 2008). Whilst these initiatives aim to transform health and social care through the development of a personalised approach to the delivery of adult care, with respect to end of life care in care homes there is no explicit mention, although their values of promoting independence, well-being and dignity have resonances with end of life care.

2.2 The Care Home Context

A small, but significant, proportion of older people reside in care homes (Laing and Buisson 2007). These figures increase with age, so that just under 17% of people aged 85 years and older live in such settings. This context is a complex one as care home organisations support and care for diverse populations through the provision of a range of types of care and support and are themselves located in a mixed economy for care (Froggatt et al. In press). High quality care that incorporates user choice and involvement is a priority for care delivery in care homes (Department of Health, 2001, 2003). The practices of how care is planned, for all aspects of care between staff, residents and relatives in care homes, create the foundations upon which planning for care at times of serious illness, or at the end of life, is based. Difficulties in engaging with these issues are further increased when older people experience communication and cognitive problems, as is the experience of many frail older people living in care homes. For example, it is estimated that approximately 62% of residents living in UK care homes have some degree of dementia (Matthews and Denning 2002).

2.3 End of Life Care

Given the importance of care homes as a place where dying and the end of life are encountered (Froggatt 2001) it is unsurprising that the Department of Health's End of Life Care Programme and the anticipated End of Life Care Strategy address programmes of development that aim to improve end of life care in care homes. Three tools are being promoted to ensure good end of life care for people dying of any condition and are now being specifically promoted to care homes for older people: the Gold Standards Framework (GSF), Preferred Priorities for Care Plan (PPC) and Liverpool Care Pathway (LCP) (Henry et al. 2007). The concept of ACP is explicitly present in both the GSF and the PPC and implicitly in the LCP, and much development is being undertaken to support the introduction of ACP in care homes through supporting information, training and education in this area (Henry and Seymour 2007).

ACP is not solely concerned with end of life issues, rather with any situation where people are no longer able to communicate their wishes and preferences. However, its increased prominence in the UK has been greatly supported by national End of Life Care initiatives and new legislation in the different nations. An informed understanding of, and support for, ACP between care home staff, residents and relatives is identified as being important to help ensure quality care at the end of life.

2.4 Advance Care Planning Processes

Advance Care Planning (ACP), while widely used in other countries, is a relatively new intervention in the UK, and little explored within the context of care homes. A number of ACP programmes have been established worldwide, notably in parts of the United States, Australia and Canada. The goals of ACP in such programmes are to establish a process of communication that facilitates a person's involvement in decisions about their current and future care, and to put in place plans to ensure that these wishes can be met (Teno 2000).

Work in this area is less advanced in the UK, probably reflecting the historically unclear legal status of advance statements in the UK compared to the US, Canada, or Australia

(Seymour et al. 2004). In England and Wales¹ there was recognition that under common law, a specific anticipatory statement (usually referring to the refusal of a medical treatment) has legal status. The Mental Capacity Act 2005, which came into force in October 2007, addresses this area of legislation and seeks to ensure that people even without mental capacity are enabled to make known their wishes and preferences for care and support, in anticipation that these will then be carried out. Advance decisions now have legal recognition, and further safeguards on the advance refusals of treatment are provided. Under this law, advance decisions about treatments that could be received, as opposed to refused must be given consideration by the person making the decision, and if nominated by the person receiving the care, carers and family members gain a right to be consulted about care decisions.

Adults' views about ACP have not been well documented in the UK. The British Social Attitudes survey in 2005 considered issues of advance documentation such as living wills, alongside resuscitation, euthanasia and assisted suicide (Clery, McLean and Phillips 2007) and found that the majority of respondents felt that the content of a living will was more important in determining end of life care than the views of doctors or relatives. Related work concerning older people's views regarding resuscitation orders is ongoing (Vandrevala et al. 2002, 2006). More recently Seymour et al. (2004) indicated that older people can see the value of advance statements as an aid to personal integrity and their potential as aids to communication and to reduce the burden on families with respect to decision-making. However, the ACP process takes time and requires older people to trust professionals in order to talk about such sensitive issues. Health and social care professionals have an important role in ensuring decision making and ACP is undertaken and implemented appropriately.

2.5 Advance Care Planning in Care Homes

A review of the literature specifically concerning ACP in care homes for older people has been undertaken (Appendix 1). This literature review considered:

- understandings of, and ways of undertaking, ACP in this context;

¹ Scotland and Northern Ireland have devolved Governments and thus have different policy contexts, legal frameworks and funding mechanisms in care homes. The policy context presented here reflects the focus in this study on care homes in England.

- the different perspectives on, and characteristics of residents, relatives and staff undertaking ACP;
- assumptions present in discussions about ACP.

Most literature currently available in English is from North America, with few papers from the UK, Australia or elsewhere. Given the different health systems operating in these different countries, care needs to be taken in terms of transferability between the countries. What is clear from the papers is the lack of consensus regarding the definitions, foci and outcomes of ACP, from residents, staff, family and academics, which is relevant in any consideration of these issues.

Advance Care Planning is understood in a variety of different ways. The term is often used without definition or explanation and different emphases are placed upon different elements of the ACP process, and the product of an ACP discussion (for example, completed documentation) may be valued more than the process. This raises the question, is it the process of having the discussion or the completed document that arises from this discussion that is most important (Pauls et al. 2001, Seymour 2004)? Much research focuses on ACP documents and older people's possession of them, rather than the process used to create the document or its subsequent use.

With regard to ACP documents specifically concerned with making an individual's wishes known about advanced decisions, two types have been identified: 1. *basic* (i.e. those assisting in immediate decisions such as treatment-specific advance decisions) and 2. *progressive* (i.e. those acting as a "springboard" for future decisions, such as a goal-based statement of wishes and preferences). Whilst there is evidence to support the view that some documents do accurately convey the end of life wishes of residents (Bercovitch and Gillick 2002; Meyers et al 2004), questions have been raised as to the value of stressing 'concrete complexities', as often occurs when discussing ACP (especially basic advance directives that document decisions for specific healthcare choices in specific scenarios). ACP can never be free from uncertainties such as how and when a person will die, and the preferences of that person under those circumstances (Vandrevala et al. 2006). Consequently, very specific directions in any form of ACP documentation may not be helpful in the later situations faced.

A range of approaches are adopted as to when ACP is undertaken in care homes. The majority of care homes in North America and Australia which undertake some form of ACP, document such discussions using a form (Cohen-Mansfield et al. 2003; Brown et al. 2004). ACP mainly takes place upon admission, with reviews at times of crisis or transition (Happ et al. 2002), which imitates the usual care planning processes required by regulatory bodies.

It is suggested, however, that current approaches that focus on solely on complying with regulations and remaining fault-free do not go far enough to ensure quality care; instead energy could be focussed on the needs of the resident and minimum standards exceeded. There is limited evidence that the implementation of initiatives to increase the completion rates of ACP documents is beneficial for those involved, although there is some evidence that service utilisation in the wider health care system decreases (Molloy et al. 2000). ACP also appears to play an important role in ensuring residents are not hospitalised to die (Pekmezaris et al. 2004; Degenholz et al. 2004; Mitchell et al. 2007). It is proposed that resident outcomes can be improved by adopting a client-centred philosophy that embraces care for dying people and integrated care planning (Forbes-Thompson and Gessert 2005). A comprehensive approach that addresses prognosis, emotional preparation and appropriate use of medical treatment is a major factor in defining a good death (Hanson et al. 2002), with timing and review of discussions important factors to consider alongside the content of the ACP process.

ACP is contingent upon the organisational context in which it takes place. Inconsistencies both within and between care homes exist with respect to documentation used and where wishes are recorded (Brown et al. 2004). This reflects the heterogeneity of care homes with respect to the population residing in them, their structures, location, and staffing patterns, all of which can influence how (and if) ACP takes place (Hilmer et al. 2005; Forbes-Thompson and Gessert 2005; Hodgson 2006; Mitchell 2007). Care homes are an important place for ACP to take place and there is a higher completion rate of ACPs for people living in care homes than for people living in settings other than hospices (Casarett et al. 2001; Parker Oliver et al. 2003).

2.5.1 Characteristics of Care Home Residents

The characteristics of older people entering care homes are changing. Residents are now frailer on admission (Wowchuck et al. 2000); have a good chance of dying within two years of admission (Bridges Initiative 2004); and are more likely to have healthcare decisions made by a family member after 12 months of living in residential care (McAuley et al. 2006). Care home residents are a heterogeneous group, and factors such as age, ethnicity and social engagement are associated with different ACP completion rates (Dobalian et al. 2006). In the US, very old residents and those with dementia or a cancer are more likely to possess an advance care plan, whereas non-white residents or those with lower incomes are much less likely to do so (McAuley and Travis 2003; Dobalian 2006). Different cultural backgrounds also affect the way residents view and plan for their deaths (Chan et al. 2007). Residents of care homes are more likely to make decisions based on the source of the information they receive, privileging people close to them, and emotional factors such as past experiences of death (Lambert et al. 2005).

2.5.2 Staff Perspectives

Staff often play a crucial role not only in caring for a resident at the end of life, but also in decision making; and whether or not to hospitalise a resident is the most common decision made by physicians and nurse practitioners (Cohen-Mansfield and Lipson 2003). Higher levels of engagement with ACP were identified in the US in nursing homes employing advanced nurse practitioners or physician's assistants (Mitchell et al. 2007). Many care homes do not have a clear medical decision-making process, and the transition of residents from active to palliative care modes are often delayed by indecision or inaction by key decision makers (Travis et al. 2001). Some health care decisions are made by the process of reaching "staff consensus" (Nair et al. 2000). However, a consensus is not always reached between staff and it has been shown that key decision-makers appear to be taking positions not consistent with palliative care experts' guidelines; for example tube feeding, the use of antibiotics and hospitalisation for residents with end-stage dementia may be recommended inappropriately (Lacey 2005).

2.5.3 Family Perspectives

Family (and friends) have important, direct and indirect, roles in ACP processes. When making decisions on behalf of residents, physicians and nurse practitioners report involving family members more than nurses, and the wishes of the family are considered to be one of the most important factors in making such decisions (Cohen-Mansfield and Lipson 2006). Concern for family members may be a key motivation for older people in care homes to undertake ACP, as it is seen as a way to reduce the “burden” that families of older people may face in having to make decisions on behalf of their loved ones at the end of life (Seymour et al. 2004; Vandrevalla 2006). Family attitudes towards ACP may well be another key factor in a resident undertaking the process, as the possession of ACP is related to their relatives’ possession and absence of religious views (Allen et al. 2003). Family attitudes are becoming increasingly more important as the number of care home residents with dementia is increasing. Family members of residents with dementia place more importance on advance care plans than physicians (Rurup et al 2006).

This role is acknowledged in much of the literature, and it is suggested that education and involvement of families in the ACP process is key to improving uptake and success for residents of care homes (Gillick 2004). A more recent approach that has been debated is the idea of ACP by proxy, an alternative suggested to improve care for residents that lack decision-making capacity (Volicer et al. 2002) as older people believe families are capable of making such decisions, and are more likely to ensure wishes are respected (Vandrevalla 2006). Research has shown that a high majority of residents retain capacity to execute a healthcare proxy even when cognitive functioning is poor (Mezey et al. 2000). This has obvious implications for a more cognitively impaired care home population. However, relatives may be unprepared to make end of life treatment decisions due to lack of information and support, but also due to unresolved emotional needs stemming from their loved one’s illness and placement in a care home (Furman et al. 2006).

2.5.4 Assumptions and Challenges

A number of assumptions underpin current practice in ACP which shape how this issue is approached and is being developed. Firstly, it is usually assumed within discussions of ACP that autonomy and individual choice are desirable, and it is often within this

particular framework that the completion of documentation has gained prominence. However, a debate over current understandings of the terms 'choice' and 'autonomy' exists (Drought and Koenig 2002; Hughes 2004; Vandrevalla 2006) indicates that such assumptions can be challenged. Secondly, care home staff are being encouraged to ensure that ACP is being offered to residents on admission (Henry and Seymour 2007). This assumption that care providers should take responsibility for initiating and facilitating ACP remains unquestioned in the literature. For example, both Teno (2003) and Lacey (2005) discuss and promote the need for ACP within care homes without a critical consideration of these underlying assumptions. Thirdly, throughout the literature ACP is often assumed to refer only to an outcome, i.e. a completed document, rather than an integrated concept that includes the actions undertaken prior to and after the completion of this document. For example, Cantor and Pearlman (2003) propose that ACP comprises the following elements:

1. consideration of options and expression of values;
2. communication of decisions;
3. documentation of these choices.

These stages are focused on the ascertaining of people's views only. Little work appears to have addressed the implementation of such expressed preferences, an issue considered further in this study.

3. RESEARCH METHODOLOGY

3.1 Aims

This study aimed to describe current advance care planning practice in English care homes for older people, and to highlight good ACP practice already in use within the area.

3.2 Objectives

The study specifically sought to:

- identify how and which residents and relatives are consulted and involved in decision making about general care;
- describe the extent to which ACP is undertaken in care homes for older people;
- examine which ACP 'tools' or other decision-making processes are currently in use;
- consider how staff are prepared and trained to undertake consultation and ACP;
- explore managers' attitudes towards residents' and relatives' end of life issues;
- identify models of good practice in ACP currently in use in care homes.

3.3 Research Design

A mixed methods design was adopted in this descriptive study, incorporating quantitative and qualitative methods of data collection. The study comprised two phases:

- Phase 1: A postal questionnaire survey
- Phase 2: In-depth telephone interviews.

3.4 Phase One: Postal Survey

A postal questionnaire survey was undertaken of managers of care homes for older people in two English regions.

3.4.1 Sampling

Care homes were purposively selected using information freely available from the Commission for Social Care Inspection (CSCI). Care homes were initially selected by locality from three local authority areas in the North West and South West of England (n=1131). These two regions were selected as they represented the locations of the researchers and it was anticipated that local research connections might improve the response rate. As the study focus was on ACP in care homes for older people, all care homes registered for drug or alcohol dependents were excluded as were care homes for

people with learning disabilities or mental disorders where less than half of the registered places were for people over the age of 65 (Table 1). This left 690 care homes to be sampled.

Table 1: Care homes excluded from the sample

Care Homes	Excluded	n = 1131
CHs registered for drug dependents	n = 13	→ n = 1118
CHs registered for alcohol dependents	n = 4	→ n = 1114
CHs registered for Learning Disability	n = 314	→ n = 800
CHs with <50% places registered for older people	n = 110	→ n = 690

A sampling frame was the constructed to identify 500 care homes from this population to ensure representativeness across the following factors:

- location – area (i.e. North West or South West) of England in which the care home is located
- type of care provided – according to the type of care a home is registered to provide, i.e. personal care only or nursing care;
- size of chain – the number of homes within one ownership group determined the size of chain. The categories comprised: single owner, small (2-9 care homes), medium (10-29), large (30-99) and very large (100+). This categorisation was undertaken using information available from Laing and Buisson (December 2006/January 2007), along with internet searches of care services databases.

3.4.2 Questionnaire Design

The questionnaire utilised in this study (Appendix 2) was developed from a previous study into end of life care in nursing homes in the UK (Froggatt and Payne, 2006). In order to reduce the length of the questionnaire, information about the organisational characteristics of the care homes surveyed was identified from the CSCI database. This database provided information regarding:

- place of registration;
- location of care home;
- type of owner (private, voluntary, local authority or other);
- category of service offered (nursing care and/or personal care);

- Category(ies) of service user cared for (older people);
- Number of beds registered in care home.

The questionnaire addressed five thematic areas: consultation with residents, consultation with relatives and representatives, discussions of future decision-making, staff training and managers' perspectives on ACP. The qualitative element of the questionnaire included three open questions addressing the following issues: situations where a resident's wishes were not implemented, challenges ascertaining a resident's wishes and challenges implementing a resident's wishes. The questionnaire was developed through consultation with care home owners and managers.

3.4.3 Pilot Survey

A pilot questionnaire was sent to care home managers that agreed to take part after being contacted through existing networks (n=20). All categories identified in the sampling frame were represented in the pilot group and all consent and confidentiality procedures were followed. The final response rate was 75% (n=15). A feedback form was included in the questionnaire pack and this highlighted areas of repetition that were amended accordingly. Respondents indicated that the content of the questionnaire and completion time to be acceptable and several welcomed the opportunity to discuss the issues raised.

3.4.4 Main Survey

Following the pilot survey and the amendments, questionnaires were posted with a covering letter, information sheet, and reply sheet (allowing managers to opt out and/or request a copy of the final report and the Good Practice [Guide](#)) to the 500 selected care home managers. Respondents were tracked and those who had not responded by the completion date printed on the questionnaire were followed up with a reminder letter and second questionnaire pack. Managers who did not respond by the second completion date were telephoned and were offered the option to complete the questionnaire via telephone, opt out of the survey or receive a further questionnaire by post or email.

3.4.5 Response Rate

Responses were obtained from 63% (n=313) of the managers surveyed (Table 2), although the response for useable questionnaires was only 42% (n=213). Although a low

usable response rate for surveys, this is comparable to previous work in the area (Szczepura et al. 2003, Froggatt and Payne 2006; Katz and Peace 2003), which used external rather than in-house researchers. (See Bowman et al. (2004) for a higher response rate (97%) obtained within a large care home chain of 244 care homes.)

Table 2: Response rate

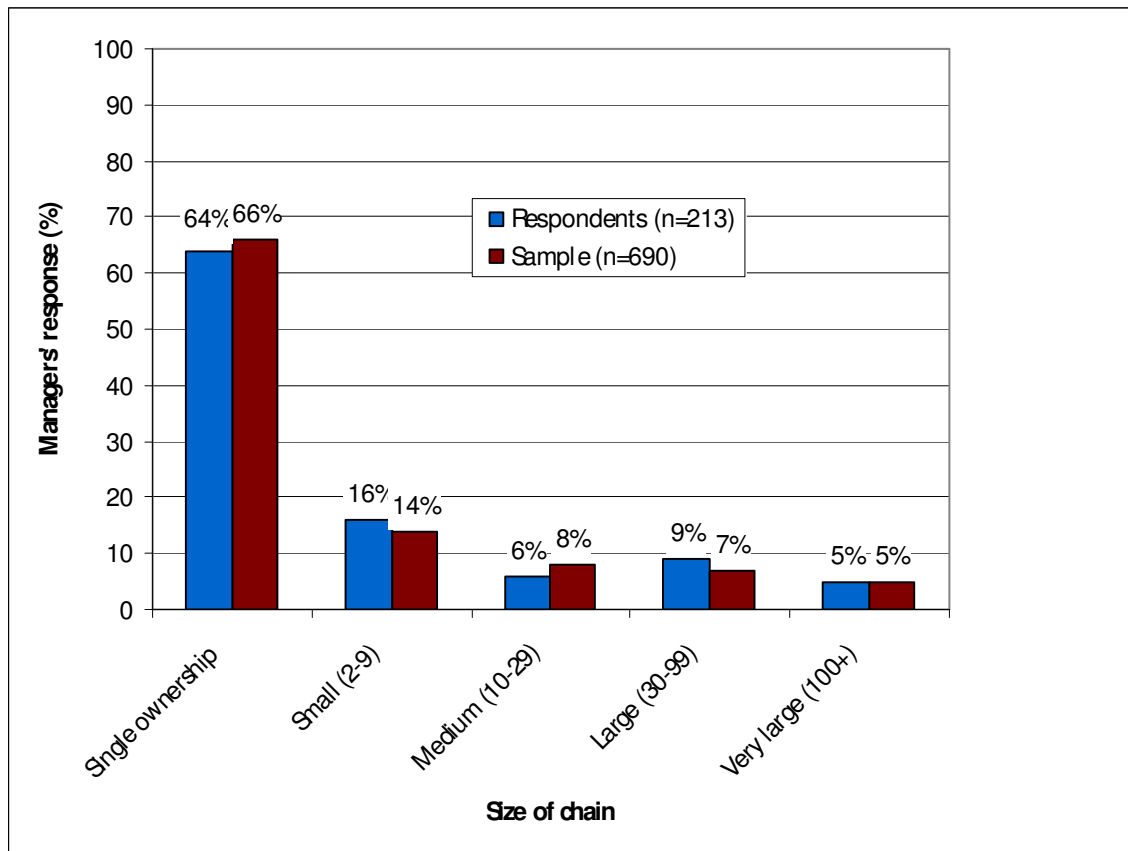
		Response	%
Care homes surveyed	n= 500		
Response		n= 313	63%
Declined to participate		n= 98	
Unusable	n=2		
Completed and useable		n= 213	42%

With respect to care home ownership and chain size, the majority of respondents were managers of privately owned care homes, not in any chain (Table 3). This reflects the dominance of this type of home in the areas surveyed, with responses being representative across other categories of ownership type and chain size (Figure 1).

Table 3: Ownership of respondents' and sample care homes

Ownership type	Respondents (n=213)	Sample (n=690)
Private	84% (n=179)	84% (n=580)
Local authority	10% (n=22)	10% (n=69)
Voluntary	5% (n=10)	5% (n=36)
Other	1% (n=2)	1% (n=5)

Figure 1: Chain size of respondent care home



There was a representative response by location. Of the 213 respondents, 111 (52%) managed homes in the North West of England and 102 (48%) in the South West. With respect to the type of care respondents' homes were registered to provide, as with the sample, the majority provided personal care only (69%, n=147), and 66 (31%) respondent managers worked in care homes with nursing. All respondents worked in care homes registered for the care of older people, aged 65 and above, with over half of managers working in homes registered for the care of residents with dementia (52%, n=110). A smaller proportion of responses were received from managers in homes registered for older people with a physical disability (18%, n=39) or mental disorder (18%, n=39).

3.4.6 Data Analysis

The data from the questionnaires was entered into the statistical package SPSS V14 (SPSS Inc., Chicago IL). The data was cleaned using descriptive analysis tools provided by the software to ensure the data entered appeared to be a valid response for

the question. A random sample of one in every 15 cases was thoroughly examined for errors. A descriptive statistical analysis was undertaken. Relationships between variables were identified using backwards stepwise binary logistic regression, and significance tested using crosstabs analysis. A content analysis of the data provided in the open questions was undertaken using a template approach (Miller & Crabtree 1999) to categorise common issues and themes.

3.5 Phase Two: Interviews with managers

The aim of this phase was to identify good practice occurring in the area of ACP in care homes for older people and to provide a greater depth of data to build upon that identified in phase one. Qualitative interview data provided information on the experiences and practices of care home managers who volunteered to participate in a further interview. One purpose of this second element in this mixed methods design was to obtain information to create a Good Practice Guide.

3.5.1 Sampling strategy

Managers were identified from those that indicated a willingness to take part on the questionnaire, from existing networks, and by recommendation. There was a very positive response from managers surveyed, with 14% (n=72) of the 500 managers initially surveyed indicating that they would be happy to be considered for participation in the interview process. Fifteen managers were purposively selected using information about the number of residents reported to have completed an ACP process, ACP approaches and tools in use, as well as attempting to ensure representation across the following categories: size of home, size of chain and ownership type. Although not a specific inclusion criteria, all 15 managers were using at least one of the end of life tools promoted by the End of Life Care Programme in the home.

3.5.2 Interview schedule

An interview schedule was developed in consultation with the research team, advisory group and an external care home managers' online forum. The interview schedule included questions to elicit data about general care consultation with residents and relatives, views and practices of ACP, effects and benefits of undertaking ACP, challenges faced and advice for others. Interviews were semi-structured and whilst the interviewer used an interview schedule, the interviewer was flexible in terms of the order

of questioning and the appropriateness of the foci in different contexts. Interviews lasted between 28 and 51 minutes. All interview data was digitally recorded with consent from participants and subsequently transcribed verbatim.

3.5.3 Qualitative data analysis

A thematic analysis of the data was undertaken to determine how interview themes related to the aims of the study, and to identify examples of good practice in each of the four previously identified elements of ACP. Atlas/ti software specifically designed to assist in coding and managing data for qualitative analysis of audio-tape materials, was used to facilitate coding. The data was examined iteratively using standard thematic analysis techniques (Miles and Huberman 1994, Ryan and Bernard 2000).

3.6 Ethical Approval

Ethical approval was sought and gained from Lancaster University Research Ethics Committee. Research Governance approval was given by the three local authority social services departments responsible for the sample areas. Informed consent was assumed at questionnaire stage upon the return of the survey, and obtained directly at the interview stage. All participants were assured of their right to withdraw at any time, and all managers contacted by post were provided with a means to opt out of further contact. Participants were assured of their anonymity in the questionnaire survey; however consent was obtained to disclose identities for the purposes of the Good Practice Guide for those participating in the in-depth interviews. After obtaining consent, all participants were identified by a code randomly assigned to their care home. These codes were known only by the research team members involved in data processing and analysis, ensuring confidentiality was maintained at all times.

3.7 Rigour of the study

The rigour of this study was ensured in a number of ways: through the methods adopted, but also in the broader oversight provided. Attention was paid to the development of the questionnaire, to ensure it would ascertain the information required. The choice of a mixed methods approach to the study allowed for the triangulation of data from the different types of data collection (postal survey and interview).

An advisory group was established to oversee the work and included experts from the care home sector, palliative care and gerontology. Consultation with the group took place four times over the course through face-to-face meetings and teleconferences. A roundtable consultation event, with a larger number of individuals working within geriatric medicine, the care home sector and other statutory and campaigning organisations with an interest in this topic was held in December 2007. Hosted by the Nuffield Foundation, and supported by Friends of the Elderly, this event provided an opportunity for preliminary findings to be presented and the focus and content of the Good Practice Guide to be discussed.

Independent review of the projects' methods, conduct, reporting of results and analysis has also taken place, separate to the project management oversight. Professor Jane Seymour, Sue Ryder Care Centre, School of Nursing, University of Nottingham has taken on the role of evaluator. She has reviewed pilot material (questionnaires, interview schedules) and provided expert advice as required by the research team.

3.8 Limitations

As with studies of this type, a number of limitations exist that shape the findings and interpretations that can be drawn from them (Froggatt and Payne 2006). First, given the low response rate the extent to which the responding care home managers can be seen to represent the total population of care homes within their regions or even nationally can be questioned. As indicated above (Section 3.4.5) the care homes run by the responding managers were representative of the two regions they were drawn from with respect to ownership type, chain size and type of care provided. Second, it is acknowledged that the survey technique can limit a manager's ability to present the complexity of their engagement with ACP. The follow up interviews allowed a sub-sample of managers to provide further in-depth information in this regard. Third, the focus of the questionnaire may also have shaped the responses with respect to understandings of ACP. A working definition of ACP as understood by the research team was provided, but in some of the questions terms were used that were not defined (eg. advanced directive) that may have led to confusion and a range of responses on the basis of different understandings.

4. FINDINGS

The findings presented here consider the following areas of interest, utilising data gained from both stages of the study:

- how are residents consulted and involved in decision-making about general care (4.1);
- the extent to which ACP is undertaken in care homes for older people (4.2);
- which ACP 'tools' or other decision-making processes are currently in use (4.2);
- how staff are prepared and trained to undertake consultation and ACP (4.3);
- managers' attitudes towards residents' and relatives' end of life issues (4.4);
- factors influencing the ACP process in care homes (4.5)
- models of good practice in ACP currently in use in care homes (4.6).

Although the two phases of the study provide information specific to the different aims, data gathered in the qualitative interviews is used to support findings from the survey phase.

4.1 Consultation about General Care Issues

We first present an account of the extent to which care homes were reported as undertaking general consultation activities with residents and representatives, in order to contextualise the specific consultations about end of life issues that occur.

4.1.1 Consultation with Residents

Of the 200 managers who completed these questions, 81% (n=162) indicated that the care home they worked in held meetings with residents. It should be noted that several respondents who indicated their home did not hold such meetings (19%, n=38) justified this by explaining that their home is registered for and inhabited by residents with dementia, and, therefore, the residents were incapable of participating in such meetings. The majority of managers surveyed (93%, n=194) indicated that residents were given satisfaction questionnaires, with the majority of those managers reporting that this took place annually (33%, n=70), or every six months (26%, n=55).

4.1.2 Consultation with Relatives

Care home managers were also asked to provide details about the types and frequencies of consultations with relatives and representatives². Fifty-eight percent of all respondents (n=124) indicated that their home held joint meetings with residents and relatives, 47% (n=99) holding relatives' meetings, and 95% (n=202) managers reporting providing relatives with a satisfaction questionnaire. Other methods of consultation reported included contacting relatives by telephone, mail and e-mail, the use of newsletters and events, information notice boards, holding a home manager's surgery, social gatherings and the availability of a suggestion box. Managers referred to the most common form of consultation as being one-to-one, personal, informal discussions:

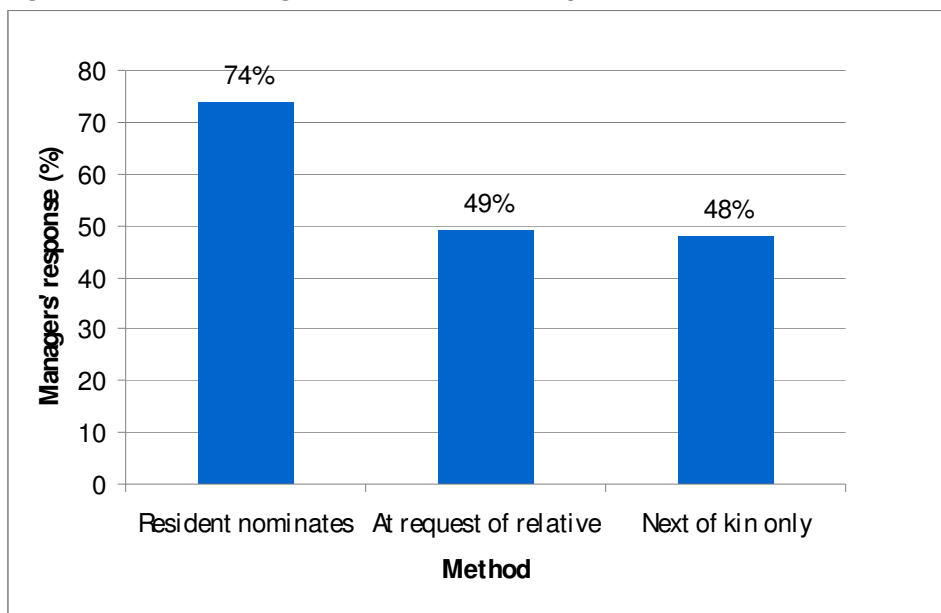
I've got what I call an open door approach. The residents' families all know where my office is, and they know that they can come to me at any time you know – and they do. And that's nice because I think communication is ... they need to know exactly what's going on. They have a right to know, you know, what's going on. And likewise if they've got any information they can give me. And I get frequent visitors to the office. (Manager 186)

Of the 123 (58%) managers who indicated their home had an "other" mechanism for consulting with relatives, the majority (74%, n=91) reported these consultations occurred as needed, rather than on a formalised basis.

How managers decide which relatives to consult with appears to happen in a variety of ways that are not mutually exclusive (Figure 2). The majority of managers (74%, n=158) indicated their decision is based on the wishes of the resident. Twenty-two percent (n=46) of all respondents reported deciding which representative(s) to consult with on an "other" basis, and whilst responses varied, a theme often cited was the need to decide on a case-by-case basis.

² We used the term relatives/representatives in the questionnaire. The term 'representative' has now been replaced with the term 'consultee'. We will henceforth use the term 'relative' as an inclusive term to encompass friends and other people significant to the older person.

Figure 2: How managers decide which representatives to consult with



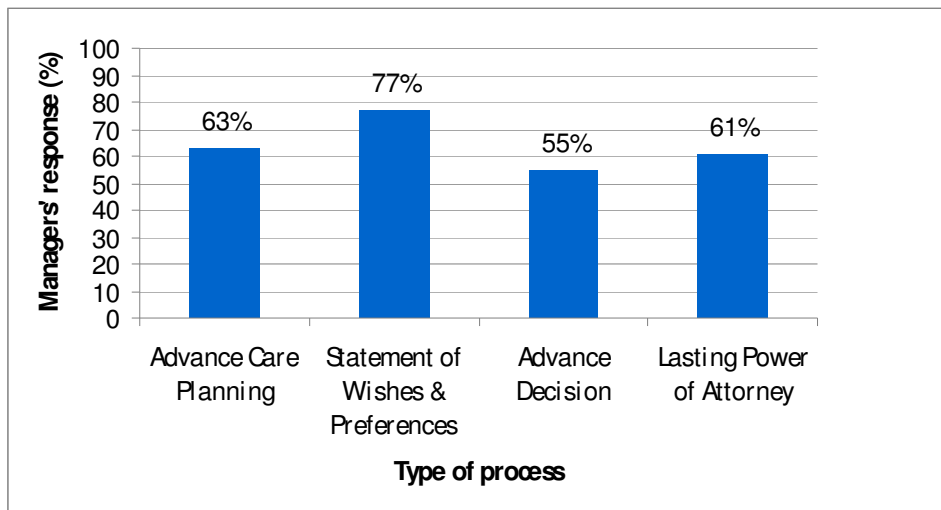
Almost all managers (96%, n=205) stated their home recommended the use of an advocate in the absence of a suitable relative.

4.2 Consultation about End of Life Issues

4.2.1 End of Life Consultations

Managers were asked to indicate if their care home recommended or required the completion of any ACP processes. Whilst 89% (n=189) managers recommended ACP, the figures vary by the type of process recommended (Figure 3).

Figure 3: ACP approach recommended by managers



For each approach, the majority of managers reported that their home did recommend the completion of such process, with the majority (77%, n=163) indicating their home recommends or requires that residents document a Statement of Wishes and Preferences (SWP). There was a significant difference between the regions with respect to the recommended completion of any ACP process. Care home managers in the South West were more likely to recommend any process compared to managers in the North West (p=0.005) (Table 4).

Table 4: Managers recommending any ACP process by region

Any process recommended	North West % within region (n)	South West % within region (n)	Total
Yes	85% (93)	96% (96)	90% (189)
No	16% (17)	4% (4)	10% (21)
TOTAL	100% (110)	100% (100)	100% (210)

Managers were asked to provide information on the number of residents in their home that had documented their wishes using an ACP process. Approximately one-third of respondents did not provide data for any of these processes. Despite the high percentage of managers that recommended completion of an ACP document, the reported proportion of residents that had undertaken ACP in these care homes was low. In over a third of the care homes surveyed, managers reported that 25% or less of their residents had completed an ACP, an Advance Directive, a Statement of Wishes and Preferences or a Lasting Power of Attorney (Figures 4 and 5). In just over a fifth of homes, more than 75% of residents had completed some form of ACP. Demographic characteristics do not appear to play a role in the number of residents that have completed an ACP process.

Figure 4: Percentage of residents in care homes having undertaken ACP

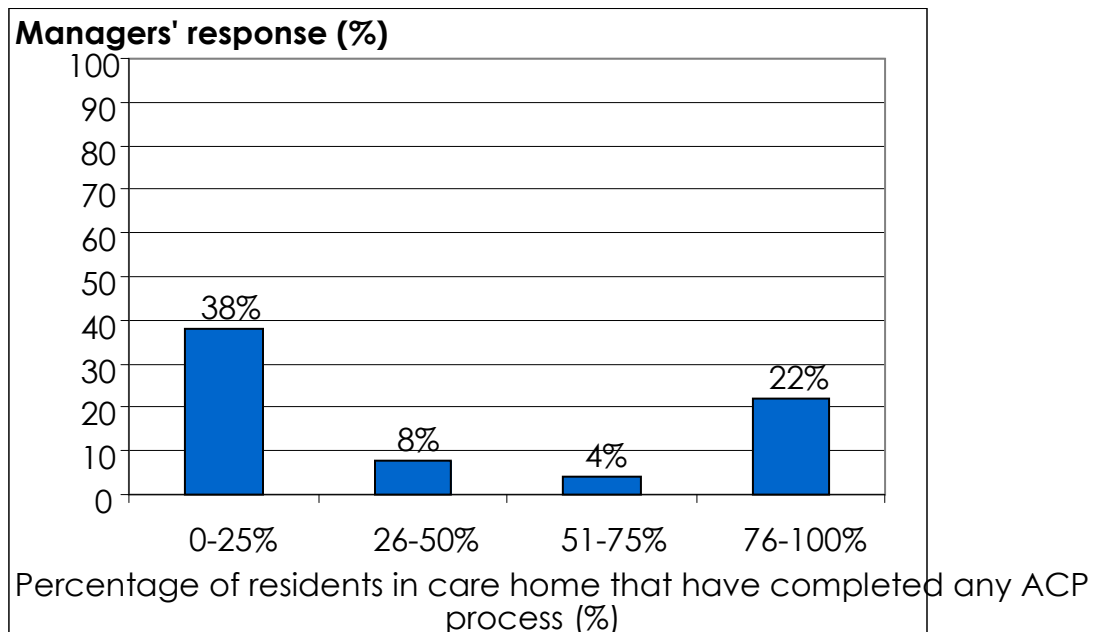
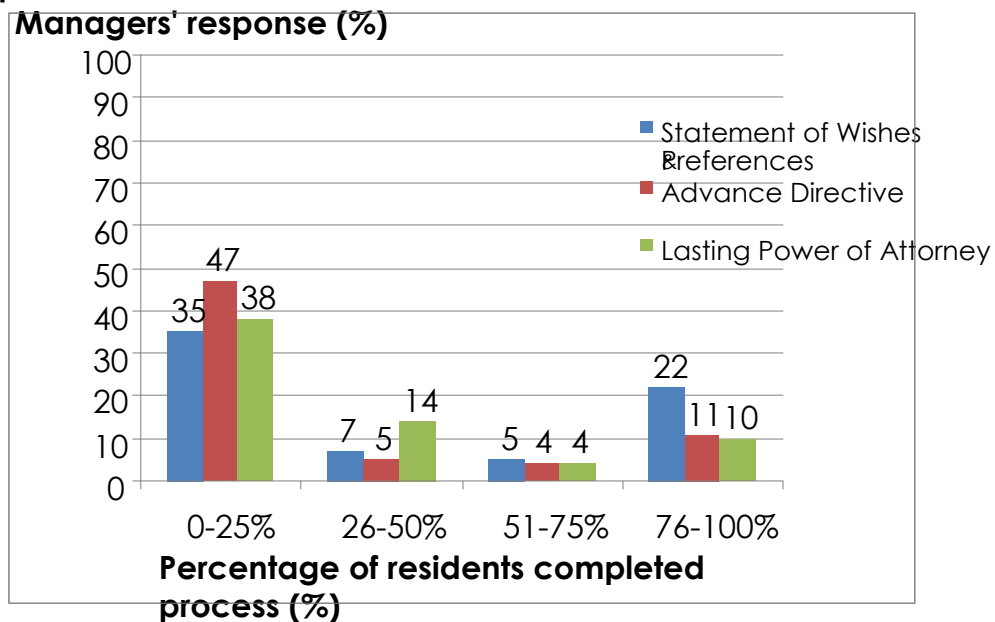


Figure 5: Percentage of residents in care homes having completed an ACP process

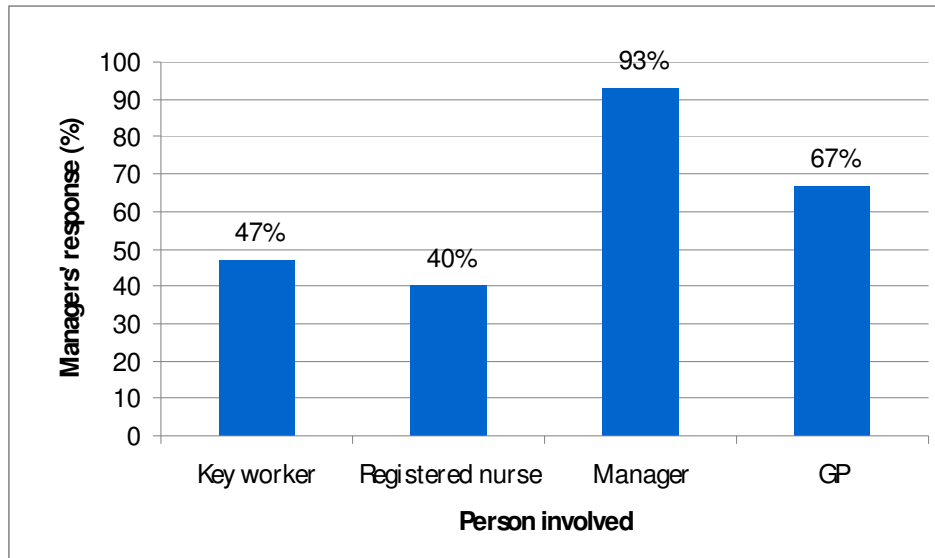


4.2.2 Who Discusses?

According to responses from care home managers returning the survey, a range of people discuss future decision making with residents in their care home, including key

workers (in 46% of care homes), registered nurses (40% care homes) and GPs (67% care homes). In the majority of care homes, 93% (n=199) managers reported that they themselves were involved in these discussions (Figure 6).

Figure 6: People involved in ACP discussions

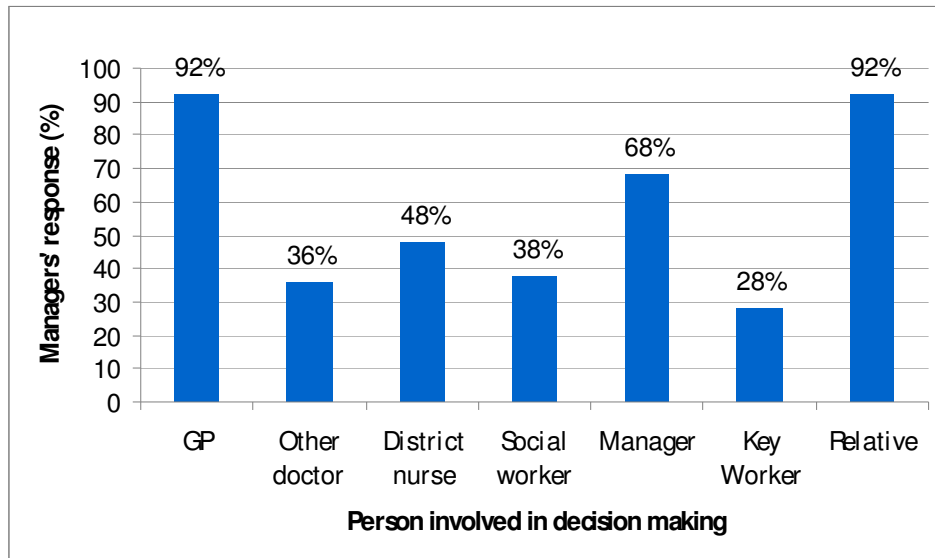


Other people listed as being involved in these discussions included care workers in the care home, primary care staff such as District Nurses and community health team personnel, social workers and other advocates.

4.2.3 Who Decides?

Where a resident's wishes were not known, managers were asked to indicate who would decide about the use of active and palliative treatments. Managers reported a range of people are involved in this decision-making process (Figure 7), including relatives (92%, n=196), GPs (92%, n=195) and care home managers themselves (68%, n=145).

Figure 7: People responsible for healthcare decision making on the behalf of residents



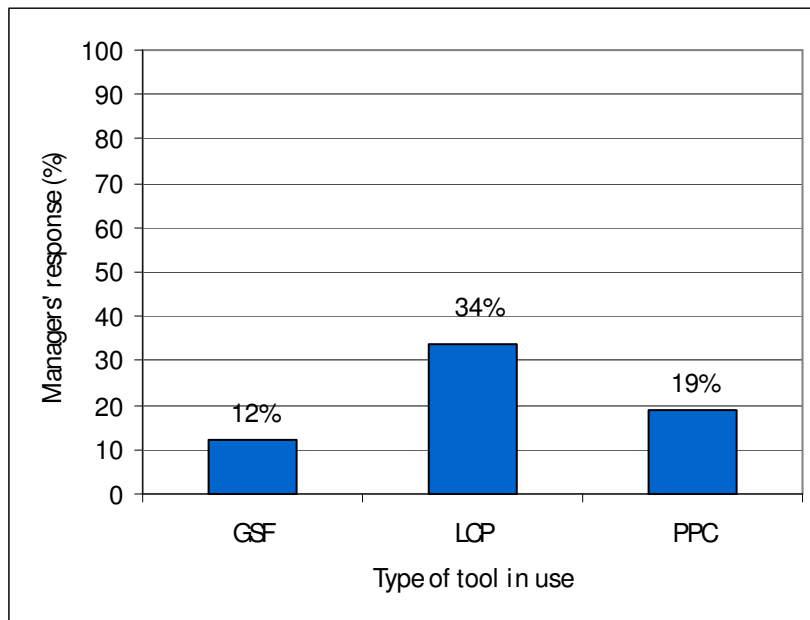
4.2.4 Use of End of Life Care Tools

The extent to which care homes were using end of life care tools promoted by the End of Life Care Programme (Department of Health 2007) was ascertained, as within these tools there is attention paid explicitly or implicitly to processes of ACP. Just under half the managers (47%; n=101) reported the use of at least one of the end of life tools in the care home they managed: the Gold Standards Framework (GSF), Liverpool Care Pathway (LCP) or Preferred Place of Care plan³ (PPC) (Figure 8). Of managers who reported using an end of life tool, the LCP was the most frequently cited (34%, n=73). The higher than expected reported use of the PPC document is probably due to the fact that the North West region was where the PPC was created and piloted.

The emphasis in the current initiatives around the implementation of these end of life tools in care homes (nursing) initially, rather than care homes (personal care) is reflected in these figures. For all three tools, a higher proportion of care homes (nursing) were using these tools, than care homes (personal care). For example, 42 (82%) care home managers of care homes (nursing) indicated that they used the LCP as compared to 31 (19%) managers of care homes (personal care). Similarly, single owner homes were less likely to use a tool than care homes part of a larger chain.

³ The Preferred Place of Care plan is now known as the Preferred Priorities of Care document.

Figure 8: Use of end of care life tools



4.2.5 Focus of End of Life Care Discussions

In order to ascertain the content of consultations with residents, managers were asked about specific areas of discussion with residents including: beliefs and values, active and palliative treatments and interventions, resuscitation wishes, hospital admissions and funeral wishes. The majority of managers (between 63% (n=134) and 83% (n=177)) indicated that in each case residents were asked about their specific wishes. Residents were most frequently consulted about their specific wishes with regard to hospital admissions (87%, n=185).

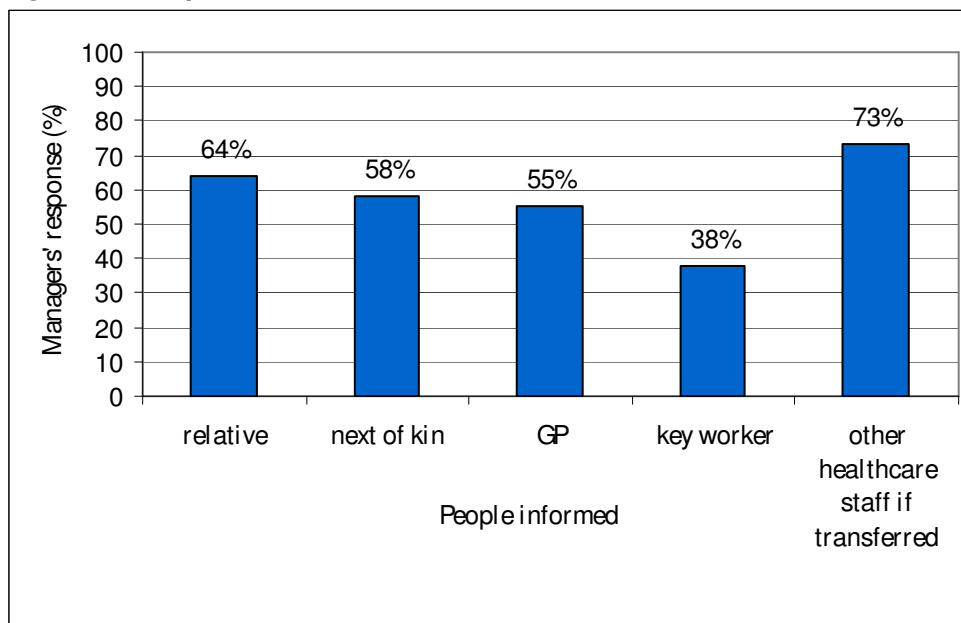
4.2.6 How Wishes are Recorded

ACP discussions were most frequently cited as being recorded in writing within the resident's care plan. Only eight managers (3.8%) reported using separate documentation to record a person's wishes. Documents of this type included specific initiative related documentation such as the PPC plan, or documents designed specifically for their individual home. Two managers made reference to the involvement of solicitors.

4.2.7 Who is Informed of Content?

Managers indicated that a number of people are informed of the content of the advance care plan, with most managers (73%, n=155) reporting informing other healthcare professionals specifically in the event that the resident should be transferred (Figure 9). Other parties informed include social services, community mental health teams and anyone the resident wishes or those on a need to know basis. Several managers added that people were only informed with the resident's permission (10%, n=22).

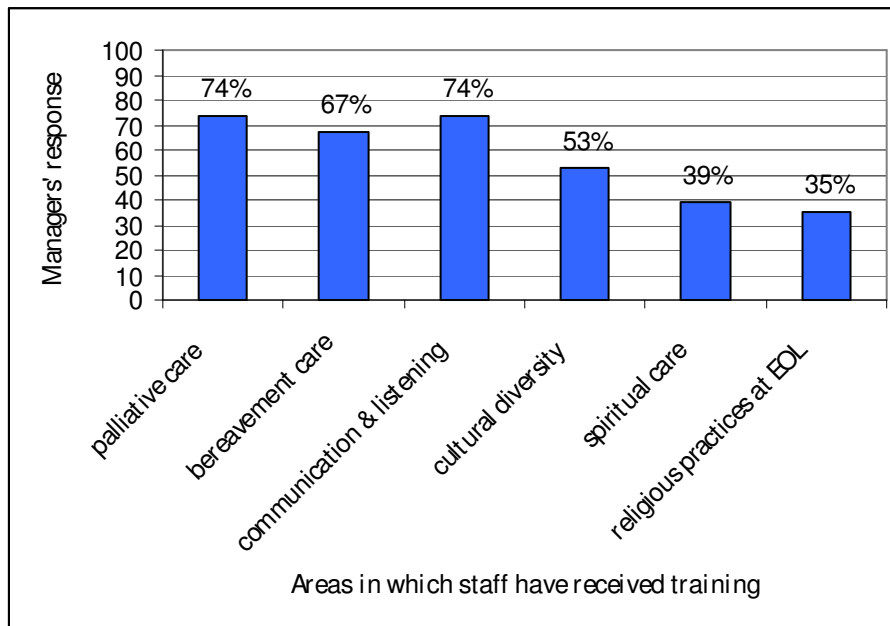
Figure 9: People informed of ACP document content



4.3 Staff Preparation and Training

Managers reported varying levels of staff training across different end of life care skill areas (Figure 10). Most care homes indicated that staff had received recent training (within the last three years) in palliative care (74%, n=157), communication and listening skills (74%, n=158) and bereavement care (67%, n=143). Fewer managers report staff are trained in advance care planning (44%, n=94), religious practices at the end of life (35%, n=74) or spiritual care (39%, n=84). Mental Capacity Act training is also less frequent in the respondents' care homes, with only just over half of homes (54%, n=115) reporting having trained staff in this area. However, this study was undertaken prior to the implementation of the Act in October 2007.

Figure 10: Areas in which staff have received training



A higher percentage of managers of care homes (personal care) reported training in most of the identified areas than care homes (nursing) (Table 5). The main exception was in the area of palliative care where 88% (n=58) of managers of care homes (nursing) indicated their staff had received training in palliative care.

4.4 Managers' Perspectives on Advance Care Planning

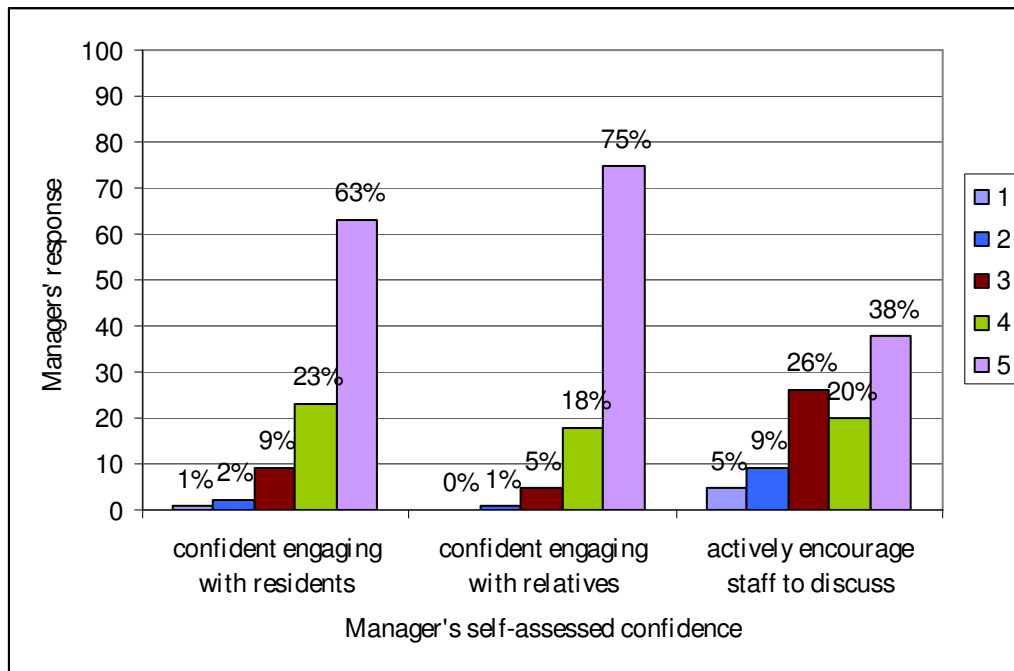
Managers were asked to indicate on a scale of 1 to 5, with 1 being 'not important' and 5 being 'very important', how important they felt it was that residents were consulted about their wishes regarding care if their condition deteriorates. At least 80% of managers gave a value of 5 for all issues, indicating they felt consultation around each issue was "very important".

Table 5: Training by type of care home

Focus of training	% (n) Care Home Managers indicating training provided in this area	
	Care Home (Personal Care)	Care Home (Nursing)
Mental Capacity Act	54% (n=79)	55% (n=36)
Advance care planning	38% (n=25)	47% (n=69)
Religious practices at the end of life	32% (n=21)	36% (n=53)
Spiritual care	41% (n=22)	38% (n=57)
Cultural diversity	44% (n=29)	56% (n=83)
Communication and listening skills	71% (n=47)	75% (n=111)
Bereavement care	56% (n=37)	72% (n=106)
Palliative Care	88% (n=58)	67% (n=99)

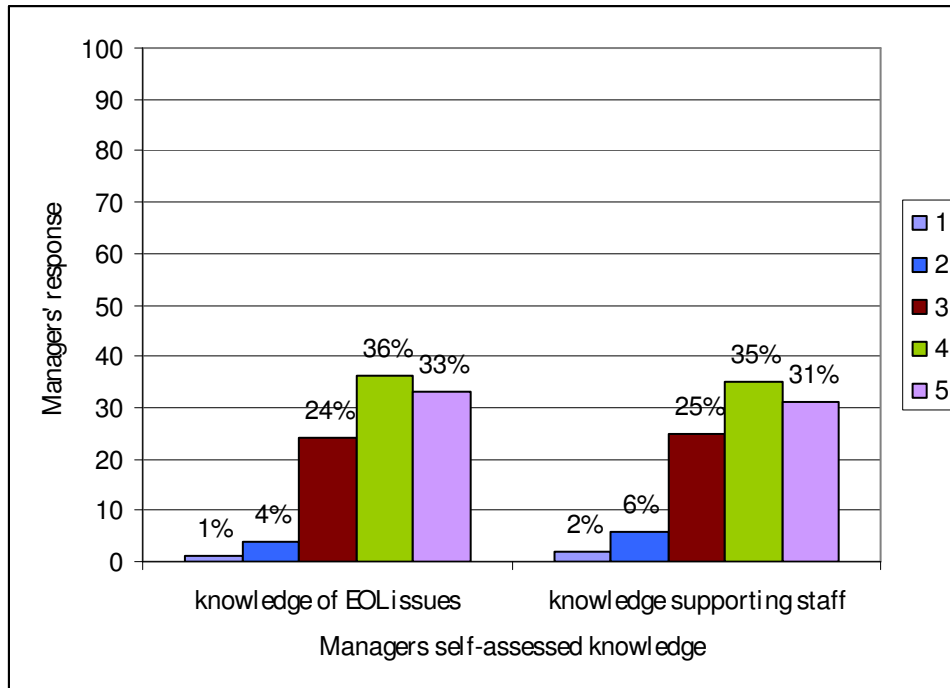
Managers were asked to indicate how far they agreed with statements about their confidence and in-depth knowledge of End of Life care issues (Figure 11). Results show managers to be more confident undertaking end of life care discussions with relatives, with 75% (n=159) managers indicating “5 – strongly agree”, compared with 63% (n=135) managers reporting a confidence level of 5 for discussions with residents. Managers who responded report being much less confident supporting staff to undertake End of Life care discussions, with over half of respondents indicating a confidence level of 4 or less.

Figure 11: Managers' confidence to undertake ACP and support staff



With regard to managers' self-reported areas of knowledge (Figure 12), managers were also asked to rate their level of knowledge on a scale of 1 (low) to 5 (high). The responses showed that fewer managers rated themselves as having an in-depth knowledge, either of end of life issues, or of how to support staff to undertake end of life discussions. Only 33% (n=70) of managers gave themselves the highest rating for in-depth knowledge of end of life issues and 31% (n=65) of managers with respect to knowledge about supporting staff in this area. There is a significant relationship between managers' confidence to undertake ACP discussions, and their self-reported knowledge; with managers who express a greater level of confidence to undertake discussions with both residents and relatives being more likely to rate their knowledge as higher (significant at the $p=0.01$ level). However, managers tended to rate their knowledge lower than their confidence level and often seemed to be uncomfortable assessing themselves as having a level of 5 relating to knowledge.

Figure 12: Managers' self-assessed knowledge around end of life issues and supporting staff

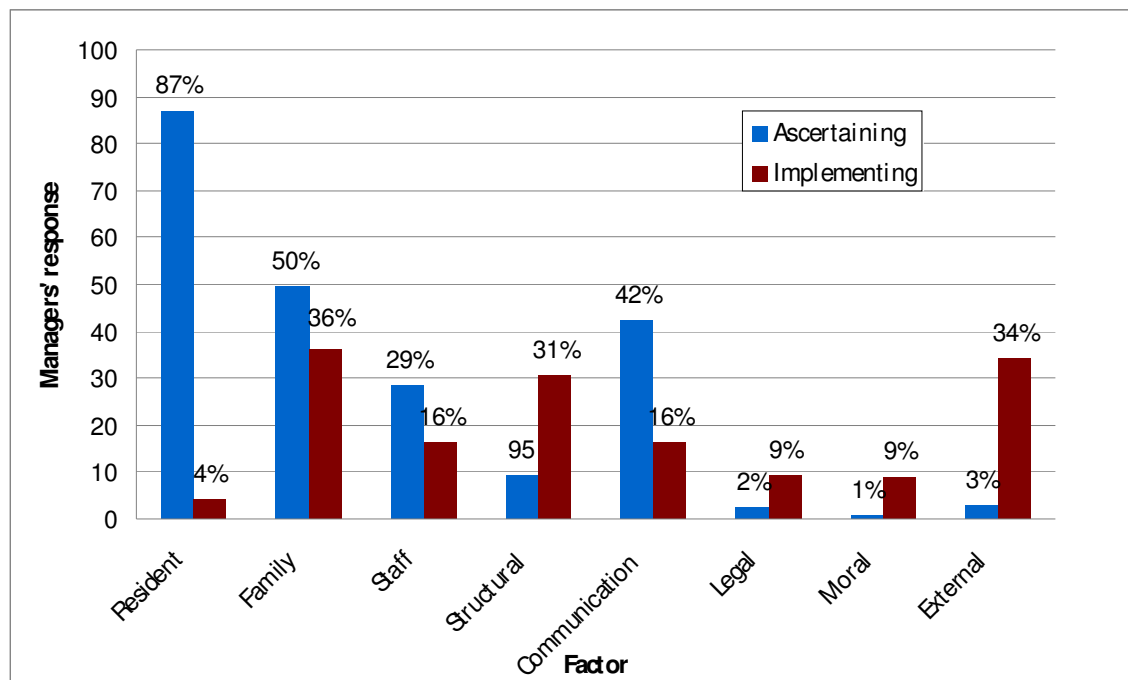


4.5 Factors that Influence the Advance Care Planning Process in Care Homes

This section draws upon data from the questionnaire and interviews to explore the factors that influenced ACP within the care homes surveyed.

Managers were asked to identify three key challenges they faced in ascertaining and implementing their residents' wishes. Responses were coded and the factors were categorised into the following main areas: resident, family, staff, structural, communication, legal, moral and external factors (Figure 13). Although similar issues appeared in responses for both ascertaining and implementing wishes, challenges relating to the resident, family, staff and the process of communication were more strongly related to ascertaining a resident's wishes, whereas issues pertaining to the structure of the home, legal, moral or external aspects were more frequently cited as barriers to implementing wishes. These two elements of the ACP process are described in further detail.

Figure 13: Factors influencing advance care planning in care homes



4.5.1 Challenges to Ascertaining Residents' Views

The factors that were described as influencing how resident's views were ascertained primarily concerned the processes of communication between staff, residents and families and attributes of the different parties that shaped this (Figure 14).

Resident attributes included their willingness and ability (physical, emotional and cognitive) to engage with this process. The majority of managers (81%, n=172) reported difficulties arising due to impaired communication in residents with dementia (Figure 15). Different experiences of ACP were recounted between homes registered for people with dementia and homes where people with dementia lived, but the home was not specifically registered for care for people with dementia. As one manager stated:

Short-term memory loss we call it. We're not actually dementia registered, although we have got some that ... are unable, a lot of them, to make that actual decision. (Manager 30)

Figure 14: Challenges to ascertaining resident’s wishes

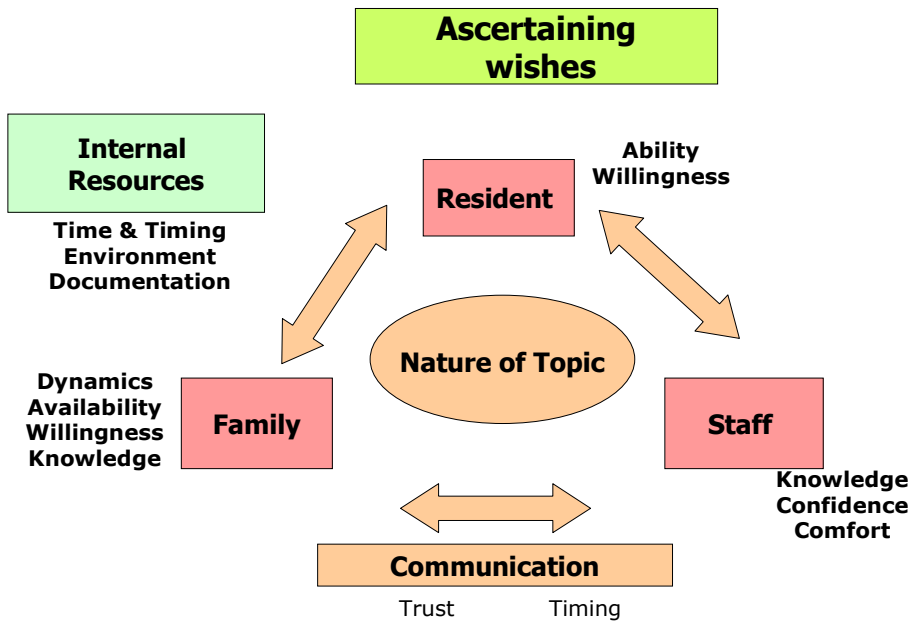
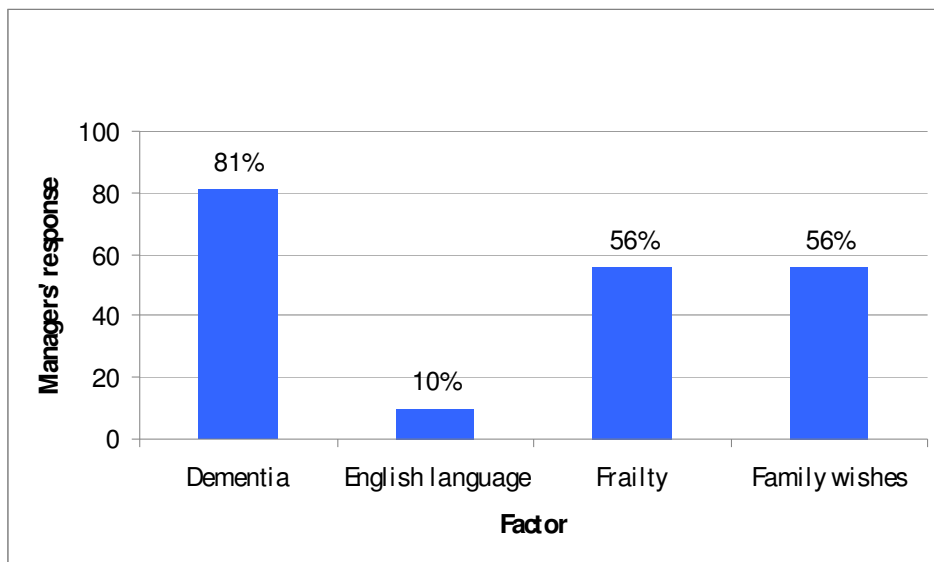


Figure 15: Factors affecting consultation with residents – family and resident



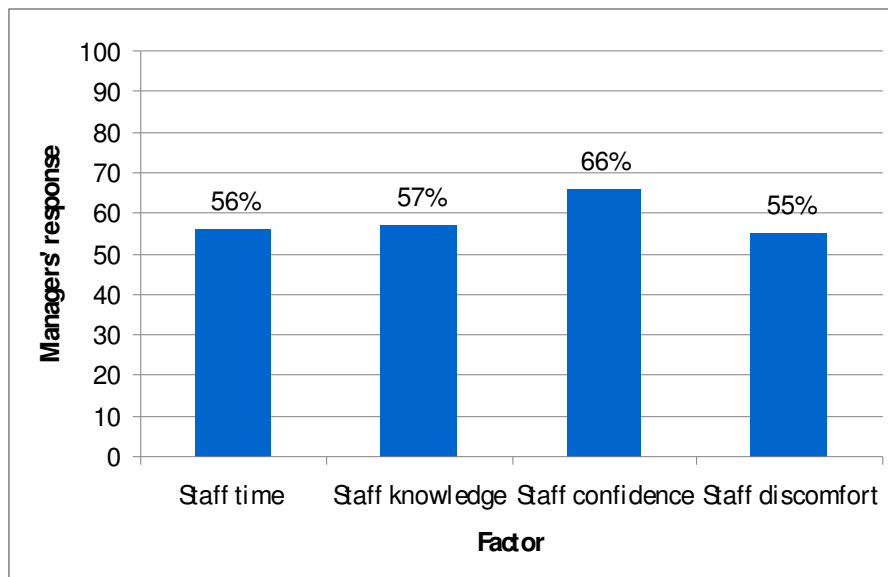
A small proportion (10%, n=21) of respondents indicated consultation with residents was restricted due to English not being the first language of the resident (Figure 15). This probably reflects the demographic profile of the areas sampled and is unlikely to be representative of all areas in the UK.

Family attributes identified that shaped the undertaking of ACP included: the willingness and availability of family members, alongside family dynamics which might mitigate against an agreement of views and decisions:

You have arguments between relatives sometimes. You know, one thinks one thing should happen, and another one thinks the other one should happen.
(Manager 145)

Staff issues identified by managers included: staff confidence, staff knowledge of ACP and resident's wishes, staff time and staff comfort with the ACP process (Figure 16).

Figure 16: Staff factors influencing consultation with residents



As this manager reported with respect to staff comfort around ACP:

I think there's a lot of staff that do feel uncomfortable around the issue of death. Some are frightened of the actual concept really and some are frightened of the families, of broaching the idea. (Manager 145)

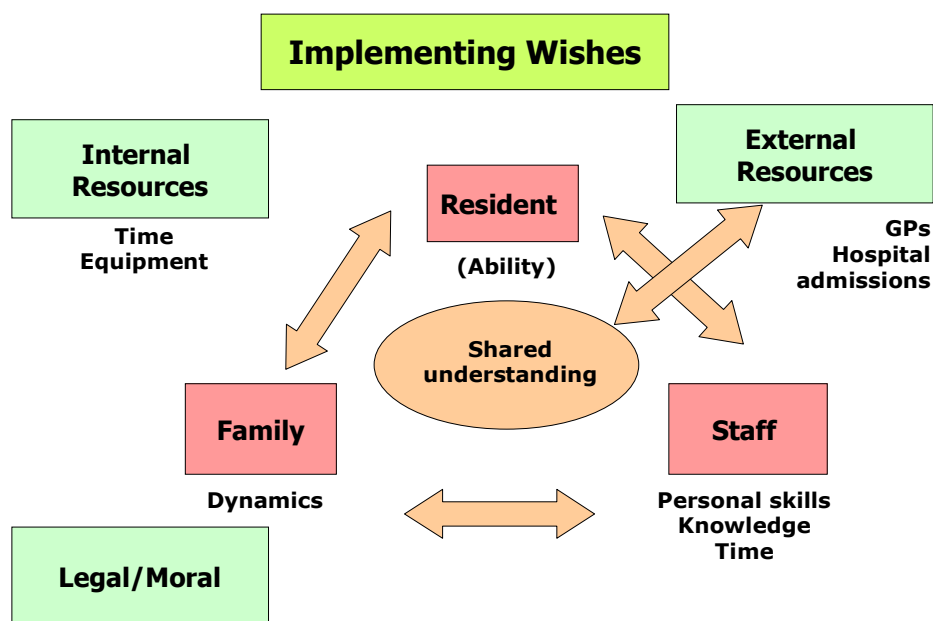
Staff confidence may be linked to their knowledge about the process of ACP from the focus of discussions, to how to have a conversation with a resident or family members about these issues. Managers did describe issues of training and a range of training approaches were indicated. Other issues raised, but less frequently, included structural

concerns such as time, the appropriateness of the environment to hold these discussions and the availability of appropriate documentation.

4.5.2 Challenges to Implementing Residents' Wishes

A consideration of the factors that shaped the implementation of resident's wishes indicates a shift in the identified locus of constraints (Figure 17). External factors are cited more frequently as influencing the process of implementation. Whilst family dynamics and staff skills, knowledge and time remain as factors, more emphasis is placed upon structural issues both internally with respect to resources available to meet a person's wishes and externally in terms of relationships with other health care professionals (GPs, District Nurses) and care settings (hospitals).

Figure 17: Challenges implementing resident's wishes



In the following example, an extreme response to engagement with primary care is described:

I think the challenges that we've had, is not so much with relatives and residents; it's been more with the primary health care. And because what we found was it was very dependent on which surgery some of you belong to as the amount of support you get. You almost dread it when it is one surgery. (Manager 68)

A shared understanding was identified as being helpful in ensuring all parties (staff, family and external health care providers) were working to the same goals when a resident was no longer able to communicate their wishes for themselves. This was perceived to provide clarity at a time when potentially people, usually family members, are less able to make decisions:

Well I think it gives them a clearer picture, the peace of mind, doing the right thing for them. They know everything's in order and things are going to be done the way that the residents wants them done. (Manager 25)

4.6 Features of “Good Practice” in Advanced Care Planning

The interviews conducted with care home managers sought to identify a range of good practice ongoing in care homes for older people. The discussion here presents elements of good practice identified from the examples provided by care home managers. Cantor and Pearlman's (2003) three stages of ACP are used to structure the following discussion, with the addition of a fourth stage, that of implementation.

4.6.1 Consideration of Options and Expression of Values

As with managers who participated in the questionnaire survey, managers reported that the consideration of options and opportunity to express values in an ACP discussion was very important. All managers reported that in their workplace this was encouraged and enabled. Although managers identified difficulties in helping people to consider their options occurred when people had communication difficulties either due to cognitive or physical impairments, they did describe the adoption of flexible approaches to overcome these. These ensured that residents were provided with as much opportunity as possible to discuss ACP and end of life issues. In this example of communicating with a gentleman with dementia, the manager described the need to:

.... just look out and when you get him on a really good day and when you think he's chatting and you think he's a bit more lucid than he sometimes is. (Manager 145)

Issues of timing were therefore important and it was recognised that people could not or would not consider or discuss these issues to organisational time frames.

Managers identified that it was important to address a range of general and specific wishes and values, with respect to future care needs in the different physical, social and spiritual domains of a person's life. They also stressed the importance of ensuring that the values and wishes expressed were those of the resident, rather than those of care home staff or relatives.

4.6.2 Communication of Decisions

The issue of communicating decisions are similar to those concerning the consideration of options, with flexibility in ways to communicate being required in order to to meet the specific needs of individuals:

[T]he only way to get over it is to have people that know the patient well, Just watching their facial expressions, if they can say yes or no, it's the only way that you can ask questions. "Do you want to talk about it now, yes or no?" (Manager 25)

Again the notion of time and timing was important. Managers stressed that the ACP process was open and always under review. They indicated that residents often changed their mind about medical treatments or hospitalisation, which meant a process of ongoing review was important:

Well if you ask a healthy person now and you say to them, "right, if you become ill while you're here, if you have a heart attack, do you want to be resussed? Or if you have a stroke, what do you want to happen?" And then when it actually happens, they change their minds because it's suddenly on them and so it's not "it might happen" it's "it has happened" and they still don't want to go then. They don't want to die, they're not ready. (Manager 30)

Time and timing are important elements of good practice and many examples were provided of managers ensuring flexibility, protected time to talk with residents and families, and using sensitivity to decide when the time is right to raise ACP.

4.6.3 Documentation of Choices

All managers interviewed used at least one of the end of life tools promoted by the End of Life Care Programme. The documentation that accompanied the tools were often

used in conjunction with each other, or with documents that the staff in the care homes had specifically created themselves. These documents were also integrated into care planning processes. This provided managers and staff with a legitimate time and place in which to first raise the issues. The documents also allowed staff to shift agency on to the forms by stating that it was policy to discuss these matters. They used the documents to provide prompts for discussion.

[W]e've been involved with the Gold Standard Framework now for probably about 2 years 2½ years and I think at the beginning, obviously, it's a very difficult conversation to have with anyone and it was quite a new thing for a lot of our staff to be doing so, in the early days it was quite difficult and I think people skirted around the issues and words to use and things like that, but what, what we've found is that once we've actually asked the questions some residents or relatives have actually said 'Oh I'm so glad you've asked'. (Manager 471)

The type of information recorded on these documents was both practical and personal. The managers saw the documents as a way of easing the end of life period and so they recorded basic information such as who to contact and when, as well as more personal information concerning resuscitation wishes and views on hospitalisation. These interviews were conducted prior to the enactment of the Mental Capacity Act. Managers were aware that their documents would need to be to be compliant with the Act. They also saw this as a positive step that would ensure documented wishes would be respected.

4.6.4 Implementation of Advance Care Planning

All managers considered the implementation of a resident's wishes to be a priority in the whole process and the reason why the previous stages of the process were undertaken. Managers often discussed situations where a resident's wishes were not carried out as a learning process, and had often been the catalyst for implementing ACP procedures.

The managers often likened their role to that of a guardian, ensuring the resident's wishes were upheld often in the context of opposing views from family or external healthcare professionals who had less contact with the resident. However, managers

did discuss good relationships with other professionals and their role in ensuring a high standard of practice.

Being able to implement a resident's wishes, and knowing this had been done was an important factor in managers' decisions as to whether the resident had a "good death" and whether the care home had done a "good job". As one manager said:

.... you should be proud of giving good end of life care. I mean, for somebody to die peacefully, we're really kind of congratulating ourselves when somebody dies well and I think you know, that you've got very old people, very frail people and when they die, it's not, you know, it's not a failure, it's, you know, real success if they've died well. (Manager 510)

5. DISCUSSION

The findings from this study raise a number of interesting issues pertaining to the role that care homes play in ACP, the preparedness of staff to undertake this work and helpful principles of ACP for managers and staff. A methodological question is also raised with regard to the development of future research in this area.

5.1 Care Homes' Role in Advance Care Planning

There is a current onus on care homes to initiate and coordinate ACP within policy and practice initiatives. We have differentiated, previously, between ascertaining and implementing wishes and an emphasis is placed upon care home staff ascertaining the wishes of residents. Much less attention is paid to the extent to which wishes are implemented and, as indicated, the greater reliance upon external organisations and staff for this to happen. However, even in considering the ascertaining of wishes, the findings of this report indicate that due to the changing health of residents entering care homes and the high incidence of dementia amongst care home residents, there are major challenges that mean a broader perspective on ACP and care homes needs to be adopted. The responsibility for ascertaining people's wishes around end of life care or situations when people are no longer able to communicate needs to be held more widely than by the care home sector. If individuals are admitted to care homes, already with advanced diseases, such as dementia, that prevent them from expressing and articulating their wishes for care, then this creates difficulties for care home staff and family members at points of crisis. Work undertaken by Allan Kellehear (Kellehear 2005) in Australia, which adopts a public health perspective to palliative care and the ownership of palliative care by communities rather than professional groups, may provide a way to develop public education about ACP for everyone in a more coherent way.

5.2 Staff Education and Training

There is a need to ensure that all levels of staff are appropriately trained and supported to undertake this work. As indicated in these findings, some care home managers indicate their lack of confidence and knowledge with respect to end of life care, ACP and communication around these matters with residents and relatives. Until managers are competent and confident to have decision discussions with residents themselves, they

are unlikely to be able to support other care staff in this work. Educational interventions therefore need to be directed at all levels of staff.

The reported levels of training in specific areas relevant to decision making and consultation about personal care wishes do not indicate how many staff have received this training or the level and length of the training. Previous studies have asked similar questions (Froggatt and Payne 2006; O'Shea et al 2008) about education provision and encountered similar difficulties in obtaining meaningful results.

5.3 Principles of Advance Care Planning

We have identified three principles that appear to underpin the ACP process in care homes for older people that may be helpful for managers and staff considering how to support staff and the process of ACP in their care home. These address how ACP can be undertaken in an individually focused, yet inclusive and integrated way.

5.3.1 Individually Tailored

Managers described individual approaches to ACP that were tailored to a resident's needs. The process of ACP was described as being resident-led as far as possible, and this also included respecting a resident's wishes who did not want to discuss or document their wishes. For managers, the ACP process existed to benefit the resident and to ensure that through the process a person's wishes were ascertained and implemented. By focusing on individuals there was a need for flexibility in all aspects of ACP. When initially raising the subject, managers referred to using tacit knowledge gained from their past experience and listening for cues and prompts specific to the resident.

5.3.2 Inclusive Participation

As with managers participating in the questionnaire survey, interviewees described a variety of people involved in the ACP process, decided on a case-by-case basis with the resident's wishes kept central. Care home managers interviewed had built strong relationships with external healthcare professionals and very often with family members. End of life was frequently described from the perspective of relatives and managers stressed the importance of involving all people who played an important role in the resident's care.

5.3.3 Integrated Processes

The managers interviewed described an integrated ACP process within their existing care planning processes. This allowed an “official” time and reason to initially raise the subject of end of life and ACP, and ensured wishes were ascertained, documented and implemented as far as possible. By integrating their ACP procedures and documents into the mainstream documentation, managers could ensure no unnecessary duplication in paperwork.

5.4 Methodological Issues

This descriptive study has provided some useful baseline data with regards to the extent to which ACP is being undertaken in care homes and allowed care home managers to identify factors that shape the ACP that occurs in the care home. A number of descriptive surveys have been undertaken with respect to end of life care in care homes (for example, Froggatt and Payne (2006); O’Shea et al (2008)). The National Audit Office in England is also currently surveying care homes about this aspect of care. There is a need to move beyond description to develop interventions that can be tested in terms of their effectiveness in assisting staff to engage with ACP, residents to articulate their wishes, and the extent to which the implementation of wishes then occurs.

6. CONCLUSIONS AND RECOMMENDATIONS

This descriptive study of current ACP practices in care homes for older people in two English regions presents an account of an increasingly important issue for the care sector. This is clearly a developing area of practice in care homes. Whilst its importance as an issue is recognised by managers, the presence of documented wishes or decisions appears low. It is easy to understand why, as recent legislation has meant that new legal frameworks have to be understood and adhered to, undertaking such discussions requires personal comfort and confidence to engage with potentially sensitive and upsetting issues with residents and their family members. This is skilled and potentially emotionally taxing work, and not to be engaged with lightly.

An increasing emphasis within wider health and social care policy and legislation upon choice and personal planning for anticipated future care needs has implications not only for care homes, their managers and staff, but also the wider primary care services that work alongside them. ACP is not just a personal planning issue, nor a care home issue, but a public health priority and as such the recommendations have relevance for primary care health and social care services and also wider society.

6.1 Recommendations

6.1.1 For Policy

- ACP needs to fit into a wider Transforming Social Care personalisation agenda. LAC(DH)(2008)1 does not mention end of life care, but does implicitly refer to care homes when it states 'in any setting'. We recommend that the government look at joint health and social care initiatives for ensuring 'choice and control' extends to older people who will end their lives in a care home.

6.1.2 For Commissioners

- We recommend that as well as 'long term conditions', the social care transformation agenda includes 'life-limiting conditions' so that the Public Service Agreements to ensure 'better care for all' includes ACP and other end of life tools.
- Community public education initiatives need to be developed to ensure the general public are given opportunities to consider ACP ahead of the time when care issues are immediately being addressed for themselves or family members.

6.1.3 For Educational Commissioners and Providers

- The findings of this research highlight that care staff need to have tools to develop the skills they need to undertake ACP with residents. The proposed Social Care Skills Academy and the preceding Adult Workforce Strategy needs to examine how it can equip social care workers in care homes with the right skill set.
- Accredited training courses that address all elements of ACP need to be developed and delivered to multi-disciplinary teams (internal and external to care homes) that are involved in the ascertaining and implementing of people's wishes.

6.1.4 For the Care Home Sector

- ACP needs to be addressed in each care home for all residents, either in situations where an individual is unable to communicate their wishes and/or for the end of life.
- Education and training needs to be sought for all levels of staff regarding the *Ascertaining Wishes: A Good Practice Guide* (Butterworth et al 2008), the Mental

Capacity Act, communication skills and engaging with families, if staff are to be enabled to ascertain wishes from residents.

- Care home managers need to engage in discussion with the wider primary care team and palliative care specialists in order to ensure they are all prepared to implement residents' wishes, particularly towards the end of life.

6.1.5 For Researchers

- Further research is required with regard to ascertaining the views and understanding of family members' and care staff in relation to ACP in care homes.
- Similarly, research with primary care staff will enable a better understanding of the complexities of working across the health and social care boundaries with respect to ACP.

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APPENDIX 1: Background to the literature review

In this literature review we sought to identify empirical research and other undertaken regarding any element of Advance Care Planning in care homes (or equivalent long-term care institutions) for older people. The methods used and background to the papers is provided in this Appendix.

A1 Literature Review Methods

An electronic search of the following databases was undertaken:

- Cumulative Index to Nursing and Allied Health (CINAHL)
- Medline
- Alternative Medicine (AMED)
- Academic Search Premier
- PsychARTICLES
- PsychINFO

The keyword search terms used were: “Advance Care Planning”; “Advance Directive”; “aged care facility”; “care home”; “decision making”; “DNR”; “DNAR”; “Living Will”; “long-term care facility”; “nursing home”; “residential care home”; “residential aged care facility”.

Only articles published in English were sought and initially a ten-year time period was used, i.e. only articles published since 1997.

Additional articles were obtained through a “snowball technique” by reviewing the reference lists of identified articles. A hand search of articles held by the research team was also undertaken.

Articles that appeared to be relevant from title and abstract were, where possible, downloaded or obtained in a hard copy format and read in full. All such articles were entered into Endnote and then an Excel database.

A2 Type of Papers

Whilst the majority of papers identified were reporting empirical research (n=47, 84%), these studies were mainly descriptive, rather than analytical (Table 1).

Table A1: Type of Paper

Type of paper	Number	%
Analytical	9	16
Descriptive	38	67
Opinion	3	5
Review	7	12
TOTAL	57	100

A3 Geographical Focus of Articles

Most research and publication of work has been undertaken in the United States to date (Table 2). The majority of articles were written from the US (% , n=41), with only a small number originating from other countries.

Table A2: Country of Origin

Country of origin	Number	%
Australia	3	5
Canada	4	7
China	1	2
Finland	1	2
Netherlands	2	4
UK	5	9
USA	41	72
TOTAL	57	100

A4 Methodological focus

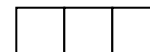
The majority of articles were based upon research conducted by the author(s) and had a quantitative focus. Articles that did not fall into this category were included as they

synthesised and added important information from empirical-based literature. The “tools” of investigation varied, with most articles detailing a mixed methods approach, with the retrospective use of medical records and the Minimum Data Set (MDS) also popular.

A5 Limitations

This literature review was by no means systematic. The search was limited to articles written in English and as such may have missed important literature from other countries. Restrictions of time, resources and the limitations of articles immediately available via Lancaster University Library also meant that some potentially useful literature may have been omitted.

Appendix 2: Postal Questionnaire



Advance Care Planning in Care Homes: A Questionnaire Survey

Thank you for agreeing to complete this questionnaire.

Please answer all the questions. If you require more space please use the back page. Please return in the enclosed pre-paid envelope.

If you have any questions please contact:

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SECTION 1: CONSULTATION WITH RESIDENTS

Questions in this section relate to how you consult with residents about general care issues.

1.1 Which of the following mechanisms do you have in place for consulting with residents?

If yes please indicate how frequently these are undertaken

Residents' meetings Yes No

Satisfaction questionnaires Yes No _____

Care plan review with resident Yes No _____

Other - Please specify: Yes No _____

1.2 Do you hold joint resident and representative's meetings?

If yes please indicate how frequently these meetings are undertaken

Yes No _____

SECTION 2: CONSULTATION WITH REPRESENTATIVES

We are also interested in finding out who else you consult with and how this is done.

2.1 Which of the following mechanisms do you have in place for consulting with relatives or representatives?

If yes please indicate how frequently these are undertaken

Relatives'/Representatives' meetings Yes No

Satisfaction questionnaires Yes No

Other - Please specify: Yes No

2.2 By which of the following means do you decide which relatives or representatives to consult with?

Nominated by resident Yes No

At request of relative or representative Yes No

Consult only with official next of kin Yes No

Other – Please specify Yes No

2.3 Do you recommend the use of an advocate where there is no appropriate representative?

Yes No

SECTION 3: ANTICIPATED CHANGES IN CAPACITY & DECISION MAKING

The following questions relate to anticipated changes in an individual's condition, affecting their capacity to make decisions and/or communicate their wishes.

Advance Care Planning

Advance Care Planning is a process of discussion between an individual and their care providers. This is different from general care planning in that ACP usually takes place in the context of an anticipated deterioration of an individual's condition in the future, with the expected result that the individual will lose their capacity to make decisions and/or ability to communicate their wishes to others. An ACP discussion might include:

- the individual's concerns,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences for types of care or treatment that may be beneficial in the future and the availability of these.

The term **statement of wishes and preferences** is a summary term that embraces a range of written and/or recorded oral expressions of future preferences for care and treatment. A statement of wishes and preferences may take the form of an advance refusal of a specific treatment (See advance decision), but it may also be a more general reflection of a person's hopes, beliefs, values and wishes for care.

The term **advance decision** relates to a specific medical treatment and specific circumstances. It will only come into effect when the individual has lost capacity to give or refuse consent.

Adapted from NHS End of Life Care Programme (2006)

3.1 Does your care home recommend completion of any of the following?

	Recommend	
Advance care planning	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Statement of wishes & preferences	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Advance decision	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Lasting Power of Attorney	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Other – please specify)	Yes <input type="checkbox"/>	No <input type="checkbox"/>

3.2 How many of your residents have undertaken and documented their wishes using the following processes:

	No. residents completed
Advance care planning	<input type="text"/>
Statement of wishes & preferences	<input type="text"/>
Advance decision	<input type="text"/>
Lasting Power of Attorney	<input type="text"/>
Other – please specify	<input type="text"/>

3.3 Who discusses issues of future decision making with residents and their representatives? (Please tick as many as are applicable)

Key Worker	<input type="checkbox"/>
Registered Nurse	<input type="checkbox"/>
Manager	<input type="checkbox"/>
General Practitioner	<input type="checkbox"/>
Other – Please Specify	<input type="checkbox"/>

3.5 In situations where a resident has not been asked about their future wishes and preferences, who decides about the use of active and palliative treatments?

(Please tick as many as apply)

- | | |
|-------------------------|--------------------------|
| GP | <input type="checkbox"/> |
| Other doctor | <input type="checkbox"/> |
| District Nurse | <input type="checkbox"/> |
| Social Worker | <input type="checkbox"/> |
| Care Home Manager | <input type="checkbox"/> |
| Key worker | <input type="checkbox"/> |
| Relative/Representative | <input type="checkbox"/> |
| Other – Please Specify | <input type="checkbox"/> |
-

3.6 Are there ever situations when the resident's wishes are not acted upon in respect of active and palliative treatments?

Yes No

If 'yes', please name such situations and indicate the circumstances that lead to their wishes not being followed

3.7 Which of the following factors influence the extent to which your staff are able to consult with residents about end of life issues? (Please tick all that apply)

- Staff time to spend with residents
 - Staff knowledge about end of life issues
 - Staff confidence to talk about end of life issues
 - Staff discomfort in talking about end of life issues

 - Resident unable to communicate clearly due to:
 - Dementia
 - Other physical conditions eg. Stroke
 - English not first language
 - Frailty

 - Family wishes regarding the discussion of end of life issues

 - Other – Please Specify
-

3.8 What are the 3 key challenges you face in finding out a resident's wishes with respect to end of life care?

3.9 What are the 3 key challenges you face in implementing a resident's wishes with respect to end of life care?

SECTION 4: CONSULTATION REGARDING END OF LIFE ISSUES

The following questions ask about any discussions you may have with residents about their views on specific end of life issues; how this is recorded and what is done with the resulting information.

4.1 Does your care home use any of the following End of Life Tools?

Gold Standards Framework	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Liverpool Care Pathway	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Preferred Place of Care Plan	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Other – Please specify	Yes <input type="checkbox"/>	No <input type="checkbox"/>

4.2 Are Residents asked about their specific wishes with respect to future and end of life care regarding:

Values and beliefs about care	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Palliative treatments and interventions	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Resuscitation	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Hospital admissions	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Other active treatments to prolong life	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Funerals	Yes <input type="checkbox"/>	No <input type="checkbox"/>

4.3 How are their wishes recorded?

4.4 If their wishes are recorded, where is the documentation that arises from these discussions kept? (eg. office)

4.5 Who is informed of what is written on this documentation?

Relative/Representative

Next of Kin

GP

Key worker

All care staff

Other healthcare professionals in event of resident transfer

Other – Please Specify

4.6 Who holds copies of the document?

4.7 How often are these documents reviewed?

SECTION 5: STAFF PREPARATION AND TRAINING
--

We are interested in finding out whether staff are trained or taught in the care of dying residents, their relatives and friends.

Have any of the current staff received training or teaching in the following areas in the last three years?

Palliative Care

Yes

No

Bereavement Care

Yes

No

Communication & Listening skills

Yes

No

Cultural Diversity

Yes

No

Spiritual care

Yes

No

Religious practices towards the end of life

Yes

No

Advance Care Planning

Yes

No

Mental Capacity Act (2005)

Yes

No

Life Transitions (NVQ module)

Yes

No

SECTION 6: MANAGER'S PERSPECTIVES ON END OF LIFE CONSULTATIONS

We are interested in understanding your views as the care home manager about end of life consultations and how staff are supported to undertake this work.

6.1 On a scale of 1 to 5 how important is it that residents are consulted about their wishes regarding care if their condition deteriorates with respect to the following issues:

	Not important			Very important	
	1	2	3	4	5
Values and beliefs about care	1	2	3	4	5
Palliative treatments	1	2	3	4	5
Resuscitation	1	2	3	4	5
Hospital admissions	1	2	3	4	5
Other active treatments to prolong life	1	2	3	4	5
Funerals	1	2	3	4	5

6.2 On a scale of 1 to 5 please indicate the extent to which you agree with these statements:

	Do not agree			Strongly agree	
	1	2	3	4	5
• I am confident to engage in discussions with residents about end of life issues	1	2	3	4	5
• I am confident to engage in discussions with relatives and representatives about end of life issues	1	2	3	4	5
• I have in-depth of knowledge of end of life issues	1	2	3	4	5
• I am confident in supporting staff to undertake end of life discussions with residents, relatives and representatives	1	2	3	4	5
• I have in-depth knowledge about supporting staff to engage in end of life discussions with residents, relatives and representatives	1	2	3	4	5
• I actively encourage staff to engage in end of life discussions with residents, relatives and representatives	1	2	3	4	5

SECTION 7: COMMENTS

Please add any further comments you may have about end of life issues, consultation and advance care planning for residents in care homes; please use the back of this sheet if you need more room.

Would you be interested in being interviewed about your practice in this area with a view to inclusion in a Good Practice Guide? If so please complete the enclosed form and return to us in the envelope provided.

Date Questionnaire Completed:

THANK YOU FOR TAKING PART IN THIS SURVEY

Please return questionnaire in freepost addressed envelope
by: **Friday 22nd June 2007**