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Summary
Summary

This report aims to explore literature and research concerned with attitudes to death and dying, end of life issues and planning for end of life care. It will also synthesise knowledge of existing interventions currently in place to encourage people to plan for their end of life care. It will inform the next stage of the research to enable Ipsos MORI to gain further insight as to how a successful social marketing intervention can be designed and delivered. In addition to this, it will ensure existing knowledge can be easily utilised and built upon in the planning of any intervention.

This section provides a summary overview of the literature reviewed to explore the issues surrounding end of life and, more specifically, care at the end of life. It will also summarise any interventions put in place to address the lack of awareness and other issues in planning for end of life care.

Key research

While the literature and research reviewed was extensive, there was a focus on work from the last twenty years. Journals were used to identify the most relevant work based on detailed searches. Key pieces of research emerged as crucial in helping gain an understanding of public attitudes towards death, dying and planning for end of life care. These included:

- “Research for Dying Matters Coalition” - Quantitative survey conducted by National Centre for Social Research with 1,375 residents in England, Scotland and Wales in 2009 for Dying Matters Coalition.

- “King’s Fund End of Life Care Poll” - Quantitative survey conducted by ComRes with 501 GPs in the UK in 2009 for King’s Fund.

- “Death Poll” - Quantitative survey conducted by ComRes with 1000 UK residents in 2009 for Theos.

- “How to have a Good Death” - Quantitative survey conducted by ICM with 1000 UK residents in 2006 for Endemol UK.

- “Audience Insight and Communications Testing” - Qualitative groups and depth interviews with UK residents in 2010 for Dying Matters Coalition.
A. Why don’t people talk about death and plan for end of life care?

The literature has shown there is a reluctance to put plans in place for the end of life, in particular end of life care, and this is often put down to the fact that death is regarded as a taboo subject in society today. The literature identified several key influencing factors behind this attitude:

- **Death is ‘hidden’** as it occurs predominantly away from the home and removed from the community and therefore, it does not feel like part of everyday life for many people.

- Medical advances mean life expectancy is longer and people often do not have a close experience with death until they are middle-aged and so are unfamiliar with the process of dying. The feeling that death is a ‘long way off’ is a common reason given for not planning for the end of life and, in particular, end of life care.

- Many people may be **unaware of the plans that can be made** in order to ensure preferences are upheld in end of life care. This could stem from a lack of understanding surrounding what palliative care entails. However, research suggests people would like more information, or at least knowledge, of where to go to obtain advice and guidance on the issues.

- **GPs are often the first port of call for guidance** on end of life care issues but research has shown some GPs often find it difficult to discuss these issues themselves. Indeed, many GPs have not discussed their own preferences and this could impact on their ability to do so with patients.

- Healthcare professionals often report they are **unsure of when to prompt discussions surrounding end of life care**. They would welcome assistance in identifying cues from patients as well as training on handling this subject sensitively.

- Research shows that most people favour open disclosure of a terminal prognosis and this could act as a prompt for discussion of end of life care. However, some ethnic minorities view the discussion of death as hastening its arrival and are, therefore, against open disclosure. Some ethnic minorities and cultures are highly uncomfortable discussing death, for example the Japanese dislike for discussing details of a terminal illness, which makes discussions surrounding preferences for end of life care extremely difficult. The influence of culture and religion will be explored further in the qualitative stage of Ipsos MORI’s research.

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B. What would encourage people to make plans for end of life care?

While most people have not put into place plans for their end of life care, the literature suggests that people would like to be empowered to do so. Older people, in particular, are often keen to ensure that their affairs are in order and that they will be comfortable.

- Many would like to discuss these preferences with healthcare professionals. They think it is the responsibility of the healthcare professionals to raise the issue of end of life care planning. Better training for healthcare professionals in the identification of patient needs in relation to end of life care could help these professionals identify when to prompt discussions.

- There are certain milestones in life that could act as ‘triggers’ for people to plan for their death, such as making a will, when children are born or retirement. These ‘trigger’ points could also provide opportunities for end of life care preferences to be put into place. Ipsos MORI will explore further these ‘triggers’ and others such as the death of a parent or grand-parent in the next stage of our research.

- The lack of public awareness of end of life care issues needs to be addressed. Within this, there is a need to increase familiarity with the process of death and what happens at the end of life. This could help counter some of the fear resulting from a lack of awareness of what the process of dying will be like.

- Raising the awareness of end of life care and the plans that can be put into place is key to ensuring people are well empowered to make choices about their preferences for end of life care.

C. What do people want from end of life care?

Preferences for end of life care are highly contextual and are often dependent on past experience and cultural background. However, there is strong agreement on certain elements that constitute a ‘good death’. These include:

- Being free from pain.

- Being surrounded by family and friends.

- Not being a burden to others.

- Dying in a preferred place.
Various studies have shown people’s views regarding a hypothetical situation often differ to when talking about their own death. For example, people’s support for voluntary euthanasia is higher in fictional scenarios relating to an ‘other’ than it is when considered in relation to themselves. This highlights a key issue in research into end of life care issues, as views expressed can be hard to transfer into actual decision making.

There are **key preferences regarding place of death** with the majority of people reporting they would like to die at home. However, evidence suggests that this does not always happen, with approximately 60% dying in hospitals¹. This highlights a key problem arising from lack of planning as this is vital to ensure people can die in their preferred place.

**D. Interventions**

Ipsos MORI conducted extensive secondary research into the existing interventions. For the purposes of this report, we have only reviewed a selection, aiming to showcase the range of approaches healthcare providers and other organisations have taken to address the issues. We have reviewed one or two examples of different types of interventions to avoid repetition and have explored the key learnings and how these could be applied to any future interventions. Ipsos MORI identified three types of interventions amongst those reviewed:

- **Interventions aimed at raising awareness through targeted communications campaigns**, such as leaflets or more general events, to tackle issues related to a lack of discussion of death and dying.

- **Interventions aimed at helping the general public make plans for end of life care by increasing awareness and knowledge of what plans can be made and how to make them.**

- **Interventions aimed at enabling healthcare professionals to help people make plans by encouraging them to start discussions of end of life care and helping them identify ‘triggers’ to prompt such discussions with patients.**

Interventions often address the over-arching issue of raising awareness of death as part of life or focus on putting into place plans for end of life care and ensuring people are well informed to do so.

Key learnings of interventions

- Generally the **response of healthcare providers has been to disseminate information** by way of events, for example holding ‘drop-in’ sessions for members of the public to obtain more information regarding end of life care, distributing booklets or providing information on websites.

- There have also been **community-based interventions**, often funded by SHAs or local service providers such as hospices. These often **focus on opening a ‘dialogue’** about death and dying, amongst the general public. These initiatives aim to be **highly accessible** to all and include peer education programmes, delivering presentations to local community groups as well as using art and performance to encourage people to talk about the issues more generally. While there is **little formal evaluation** of such projects, the informal feedback obtained, normally by talking to or observing participants during an event, is predominantly extremely positive. These interventions are often viewed as helpful as they were highly accessible.

- A vital element in end of life care could be the enablement of people to put their plans into place. One key finding across the literature was the **need to ensure people know what choices they can make and how to ensure their wishes are fulfilled**. Further to this, it is important to **enable healthcare professionals to support and guide patients** in making these decisions. Several initiatives were identified that aim to meet these objectives including:
  
  - Ensuring accessible help for patients through help-lines and directories
  
  - Outlining clearly what people can expect in end of life care through charters and strategies.
  
  - Training and support groups specifically targeted at communication with terminally ill patients. Staff feedback on such training was very positive; they were praised for encouraging and enabling staff to better help their patients as well as identifying key triggers for instigating discussions.

- The literature has shown that **interventions to encourage people to make plans for end of life care are often best when they take a multi-faceted approach including**:
  
  - Raising awareness of end of life care and the need to plan;
  
  - Enabling people to make decisions by ensuring they are well informed; and
Addressing the needs of healthcare professionals so they feel empowered to encourage patients to make such decisions and able to put measures in place to ensure their wishes are fulfilled.

There have been many initiatives developed in response to the need to raise awareness and enable people to make plans for their end of life care. However, it is important to note that evaluation of their effectiveness is somewhat limited and in most cases, non-existent. This means it is difficult to establish the impact of such initiatives and whether or not they have been successful in raising awareness or encouraging people to plan for their end of life care.
Introduction
Introduction

Background and objectives

Ipsos MORI have been commissioned by East of England SHA to undertake research to inform social marketing interventions aimed at raising awareness of End of Life care and encouraging people to plan for their end of life care. The research will explore attitudes towards discussing and planning for death and provide insight as to what would encourage people to plan for the end of their life and the care they want to receive. It will also aim to contribute to guidelines on how to implement social marketing interventions and enable some evaluation of any interventions put in place.

The first stage of the project is to conduct secondary research of existing literature on the subject and existing interventions. This will inform the next stage of the research; primary qualitative work with the general public and specific ethnic minorities, GPs and practice / district nurses across the East of England. Alongside this, a quantitative survey with residents in the East of England will provide insight into and a baseline of attitudes to end of life issues. The secondary literature review, reported here, will ensure existing knowledge is fully utilised and built upon, to help direct and focus the research as well as inform social marketing interventions. It will also examine interventions already in place to learn from what has already taken place to address the issues surrounding planning for end of life and their desired care.

Search criteria and method

The scope of the desk research is:

- Identification of key issues behind any reluctance to talk about death or discuss and plan end of life care;
- Identification of preferences in end of life care;
- Identification of barriers and potential triggers for people to plan for end of life; and
- Identification of previous interventions aimed at improving the planning for end of life care and raising awareness of the issues related to end of life care.

The literature review involved identifying sources, developing detailed search terms, defining inclusion and exclusion criteria (such as location-based findings and work produced since the
1990s) and deciding on quality assessment criteria. A simple data extraction tool was then developed to record each study that met the criteria and to give a measure of relevance, reliability and validity. Once literature was collected, results were synthesised, key ideas and project outcomes summarised and key areas of difference and similarity explored.

Report structure

This report is presented in three sections:

- The Executive Summary which summarises the findings of the review
- Public Attitudes and Experience which explores the issues surrounding discussing and planning for end of life care
- Interventions which reviews previous and current interventions.

All sources used to inform this report are referenced and a reading list is provided in the appendices.
Public attitudes and experience
Public attitudes and experience

This section will explore general attitudes towards death and dying, and more specifically attitudes towards end of life care. It will then look at the barriers that prevent people from putting plans into place for the end of their life and the care they will receive.

Public Attitudes

Attitudes towards death and dying

<table>
<thead>
<tr>
<th>Key Learnings</th>
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<tbody>
<tr>
<td>▪ There is a reluctance to discuss death and dying in society despite many people stating that they are comfortable talking about death.</td>
</tr>
<tr>
<td>▪ People tend to be unfamiliar with what the process of dying will be like because few people have any experience of the death of a close one until later in life.</td>
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<tr>
<td>▪ Two mind-sets have been identified: the fearful and the non-fearful which has a direct impact upon how comfortable people feel discussing death and dying.</td>
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<tr>
<td>▪ Further research is needed to unpick the key factors influencing a fearful mindset and a reluctance to discuss death in order to identify what would encourage people to plan for end of life care.</td>
</tr>
<tr>
<td>▪ It is important to address the distinction of discussing death generally compared to discussing one’s own death.</td>
</tr>
<tr>
<td>▪ People’s attitudes towards death may differ to their feelings about the process of dying. Further research can explore these differences</td>
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Death has come to be regarded as a taboo in Western society with people reluctant to discuss dying or death. There are several factors identified as contributing to this reluctance. Death has become ‘hidden’ in today’s society with most deaths occurring in a hospital setting, far removed from the community. To an extent, death and dying have been isolated and left to specific members of society, such as funeral directors or religious leaders, to deal with.

Furthermore, medical advances in extending life mean the majority of people in Western society will die ‘expected deaths’, i.e. those occurring at the end of chronic illness, usually in old age and when doctors can often predict how long a patient has left to live. This means people often do not have a close experience of death until later in life and are less familiar with the process and any plans that might need to be made. The experience of someone’s

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death could be a ‘trigger’ for people to discuss their plans for end of life and their care as they witness what they would and would not like for themselves³.

A survey by ComRes⁴ showed that around 50% of respondents fear the process of dying and 30% of these respondents said they fear the way they will die but not death itself. While it is true that there is a general sense of unease in discussing death in society, there have been certain differences in attitudes identified across age and gender. Within the ComRes⁵ survey, it was younger people (those aged 18-24) who were most fearful of dying. However, data from an earlier ethnographic study used to explore attitudes to death showed those in middle-age (aged 45-54) expressed the strongest fears⁶. These fears were, to some extent, resolved amongst older participants (those aged 65-74)⁷ but research in America suggests older people are more likely to have specific fears related to dying alone or being forgotten after death⁸. In addition to this, studies in America have shown that women express greater concern regarding death and dying⁹. However, it is important to note the different dates and locations of these research studies as views may change over time and vary from place to place.

Recent discussion groups found that people are often superstitious regarding talking about death and that there is a strong desire not to destroy people’s hope¹⁰. These themes were also highlighted in discussions conducted by Social Action for Health¹¹ amongst Muslims in London, where participants felt many Muslims would be reluctant to talk about death as they believed those very discussions might make it happen.

Qualitative research conducted by Nfp¹² identified a clear distinction in mindsets between the fearful and the non-fearful and found clear differences in how comfortable they would feel making plans for their own death. Those with a non-fearful mindset were more comfortable discussing death and dying. It will be interesting to explore in further research the key influences of a fearful and non-fearful mind-set to investigate how best to address the needs of both.

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³ Nfp Synergy, 2010 Audience Insight and Communications Testing - Groups and Depth interviews with UK residents for The Dying Matters Coalition. www.nfpsynergy.com
⁴ ComRes, 2008, Death Poll with 1,000 UK residents, for Theos, http://www.comres.co.uk/page165151329.aspx
⁵ As above
⁷ As above
⁹ As above
¹⁰ Nfp Synergy, 2010 Audience Insight and Communications Testing. Research for Dying Matters Coalition
¹¹ Social Action for Health, 2009, Engaging in dialogue for St Joseph’s Hospice
¹² As above
While the ComRes survey\textsuperscript{13} highlighted that people fear the dying process, another recent survey\textsuperscript{14} for the Dying Matters Coalition showed sixty-eight percent of people were fairly or very comfortable talking about death. Only seventeen percent said they felt fairly or very uncomfortable talking about death. This could suggest people are more comfortable talking about death as opposed to the process of dying. It is also important to make the distinction between discussing death generally and discussing one’s own death. In addition, much of the research into attitudes to death and dying refer to a fictional, hypothetical scenario. This means people may not be considering their attitudes towards their own death when answering, which Ipsos MORI will consider in its primary research. This should also be taken into account in the consideration of any intervention aimed at encouraging people to plan for the end of their life and the care they would like to receive.

Much of the research into attitudes to death and dying has been quantitative which does not allow for deeper exploration of the issues or for further reflection. It will be interesting to explore in further research the difference between people’s attitudes to talking about death as opposed to talking about the process of dying and whether a distinction is made between the two.

Finally it is important to note that there is currently very little research exploring how a lack of knowledge and understanding impacts on attitudes towards death and dying. This means it is hard to know to what extent, if at all, increasing peoples’ understanding of the process of dying, and plans that can be made, would impact on people’s attitudes towards death.

### Attitudes towards End of Life Care

**Key Learnings**

- People’s attitudes towards end of life care often differ for a hypothetical or fictional situation compared to thinking about their own death.

- It is important to make the distinction between a hypothetical situation and planning for one’s own end of life care in research, to fully explore why people do not put plans into place.

- There is evidence that people want more information about palliative care services, or at least to know where to find more information before it is needed.

It is important to make a distinction between attitudes to end of life care generally and attitudes towards one’s own end of life care as there may be variation between the two. This

\textsuperscript{13} ComRes , 2009, \textit{Death Poll with 1000 UK residents}, for Theos
Raising awareness in End of Life care is evident in attitudes towards assisted dying where support is higher when asked in relation to a fictional scenario as opposed to one’s own situation\textsuperscript{15}. This shows people’s preferences for their own death may differ, reiterating a need for end of life care plans to ensure an individual’s preferences are upheld. This will be explored further in the second stage of Ipsos MORI’s research and should be considered in the design of a social marketing intervention.

Research in Australia\textsuperscript{16} exploring attitudes towards palliative care indicated some awareness of what palliative care is at a general level, with around eighty percent of respondents indicating they understood it to be care for the terminally ill. Awareness tended to be higher amongst females and older people. This knowledge is generally gained through personal experience as people tend not to actively seek information about end of life care unless it is relevant to them. Understanding of palliative care and the services it provides, was markedly higher amongst older respondents, which was usually attributed to having experienced the death of a friend or relative. Interestingly, although the majority did not have an in-depth knowledge of palliative care, most people thought they should have some basic knowledge of what palliative care is before it is needed. At the very least they felt people should know where they could obtain information about palliative care.

Social Action for Health’s recent work\textsuperscript{17} with Muslims in London indicated some lack of awareness of the palliative care services that were offered. Many felt this needed to be addressed within their community as often people were unaware that their specific religious or cultural beliefs would be considered. They felt GPs surgeries, libraries and other places in the community could be used to raise awareness of end of life care services\textsuperscript{18}.

Planning for death

Planning for death and dying

**Key Learnings**

- There is a distinction between planning for what will happen after one’s death and planning for preferences in dying and end of life care. Further research will explore this issue in more detail.
- Certain ‘triggers’ have been identified for prompting discussions about death and dying.

\textsuperscript{14} National Centre for Social Research, 2009, Research for Dying Matters Coalition
\textsuperscript{15} Seymour, 2009 \textit{Public Attitudes to death, dying and bereavement}
\textsuperscript{17} Social Action for Health, 2009, \textit{Engaging in dialogue} for St Joseph’s Hospice.
\textsuperscript{18} Social Action for Health, 2009, \textit{Engaging in dialogue} for St Joseph’s Hospice.
Raising awareness in End of Life care

- Further research could explore these triggers in more detail to fully understand how best to use them to prompt end of life care discussions and influence interventions.

A key consequence of the identified reluctance to discuss death is that people are less likely to make plans for their own death, including their preference for care at the end of their life.

The literature reviewed has highlighted that there appears to be two distinct ‘strands’ of planning:

- Planning for when you are dying, e.g. preferences for place of care; and
- Planning for what will happen after your death, e.g. finances, organ donation.

Research has shown people are more likely to prepare for the consequences of their own death, often by making a will or signing up to donate their organs, than to make plans for when they are dying. In both a survey for the Dying Matters Coalition\(^\text{19}\) and one for the BBC\(^\text{20}\), thirty-eight percent of respondents reported having made a will and around a quarter held organ donation cards\(^\text{21}\). The number of people who reported having made a will increased substantially with age. Putting into place plans for funeral wishes also increases with age and amongst those who were widowed, indicating experience of death has a strong influence on making plans for one’s own death\(^\text{22}\). In contrast to this, the NatCen survey showed only four percent had made plans for end of life care and the BBC survey showed eight percent had a living will\(^\text{23}\).

Comparisons have been made to birthing plans with suggestions that any plans for end of life should be as detailed as the plans some women make before they are due to give birth\(^\text{24}\). In an exercise with students, one professor asked them to make ‘death plans’ to encompass funeral wishes, care wishes etc\(^\text{25}\). The students found the exercise enlightening as it brought to their attention aspects of end of life that they may have overlooked. It made them realise the amount of work that is necessary in order to facilitate any plans for their own death, in particular with regards to the care they would like to receive at the end of their life.

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\(^{19}\) National Centre for Social Research, 2009. Research for Dying Matters Coalition.
\(^{20}\) ICM 2006, How to have a Good Death. Survey Endemol UK
\(^{21}\) National Centre for Social Research, 2009. Research for Dying Matters Coalition
\(^{23}\) National Centre for Social Research, 2009. Research for Dying Matters Coalition
\(^{24}\) Auger, 2007. Social Perspectives on Death and Dying.
\(^{25}\) As above
This lack of knowledge of the potential decisions regarding a person’s death could be a factor behind the relative lack of planning regarding end of life care compared with preparations for death, such as wills or organ donation. This highlights the importance of raising awareness generally of end of life care and the plans that can be put into place to help ensure people’s preferences are upheld.

A key influence in planning for death is triggers that prompt conversations or plans to be made. For example, having children could be a trigger for some to make a will as they want to ensure their children are looked after if they are no longer around. It could be argued that the much larger proportion of people holding a will amongst those aged 35-44 compared with those aged 18-34, is due to a higher proportion of those aged 35-44 being likely to have children. However, this is not exclusive to those aged 35-44 and the second stage of Ipsos MORI’s research will explore this further to establish whether having children does act as a ‘trigger’ itself or if there are other factors at play such as age of children. In addition to this, those aged 35-44 are more likely to have experienced the death of someone in the family, e.g. a parent, so this could also be a trigger for prompting discussions regarding planning for their own death.

Further ‘trigger points’ were also identified by Ipsos MORI in group discussions they conducted at the recent Dying Matters in East of England conference. These included when taking out life insurance policies, when soldiers are deployed they may think about their own death, when life limiting illnesses are first diagnosed or when people retire from employment. While there is much thought around those with life-limiting illnesses or the elderly planning for death, it would also be interesting to explore the potential of general ‘trigger’ points, such as becoming parents or retirement as prompts for the wider population to plan for death. These could then be used to encourage people to make more wide-reaching plans to encompass end of life care as well as financial and funeral arrangements.

**Planning for End of Life care**

**Key Learnings**

- Most people have not discussed plans for their end of life care. Death is not seen as part of everyday life despite the fact we all will die, so it is hard for people to see the need to plan for end of life care.

- GPs have been identified as a key source for information and help regarding end of life care planning but they are also unlikely to have made plans for themselves.

- Older people, in particular, would like more information regarding end of life care.
There needs to be agreement between healthcare providers and the general public on what is needed to enable planning for end of life care. This could be achieved through research and consultation work with the general public and healthcare professionals.

Looking more specifically at planning for end of life care, qualitative research has shown that there is great variation in views and these are highly contextual. They are often influenced by past experience and often change according to circumstance. Culture is often seen as the strongest factor influencing how people plan for end of life care, taking into account spiritual needs and religious beliefs.

Most people have not discussed their preferences for end of life care. Just over two-thirds (71%) said they had not done so in a recent NatCen survey and the most common reason given for lack of planning is that death ‘feels a long way off’. This was true, in particular, for younger age groups, i.e. those aged between 25 and 54, with fewer older people (those aged over 55) citing this as a reason. Many people simply do not think about end of life care because they have not had any experience of death and therefore have never considered the issues related to care for the dying.

For some ethnic minorities, planning for end of life care may not be considered as it is not seen as appropriate to discuss death. For example, in Chinese and Hispanic cultures it is seen as necessary to protect individuals from a prognosis of terminal illness therefore creating difficulties in planning for end of life care. Research could further investigate this effect of culture as well as further explore other influences, such as religious beliefs. It will be interesting to examine whether strong religious beliefs mean people are more or less likely to plan for death as these could already play a part in preferences for end of life care, for example, the desire of Muslims to be buried within 24 hours of death could impact upon any plans they have for end of life care and this was discussed in recent work by Social Action for Health. Furthermore, this work with Muslims in London highlighted the importance of religion for some members of this community. The need to be able to pray and have spiritual leaders available, were regarded as highly important for many, potentially even if the person had not followed Islam strictly throughout their life.

26 Auger, 2007, Social Perspectives on Death and Dying
27 National Centre for Social Research, 2009. Research for Dying Matters Coalition
28 As above
31 Social Action for Health, 2009, Engaging in dialogue, for St Joseph’s Hospice
32 Social Action for Health, 2009, Engaging in dialogue, for St Joseph’s Hospice
Attitudes to death have a strong influence on whether people make plans for their own death and the reluctance to discuss death in society has been linked to the lack of planning for end of life care. However, some research suggests that not all older people, i.e. those aged 65 and over, are reluctant to discuss death and plans for end of life care. Research in Canada showed that older people (those aged 65 and over), were favourable towards disclosure of a terminal prognosis in order to allow them to put plans into place regarding their own death33. A Peer Education Programme34 developed by The Health Foundation and Help the Aged showed a keenness amongst older people to discuss the issues related to death and dying.

Moreover, there is evidence of a desire for more information on where to obtain advice on end of life care indicating people may be more willing to discuss such plans35. Research in Australia showed palliative care providers tended to think that the general public were not interested in this information until it was required36. However, in the same research the general public expressed a desire to at least know where to obtain the information before it was required37. It is important to highlight this discrepancy between the providers’ perceptions and general public interest as the design of any intervention would need to consider this to ensure there is consensus over general public needs in relation to planning for end of life care.

The reluctance to discuss end of life care has been identified as an issue amongst healthcare professionals as well as the general public. Recent research38 showed sixty-eight percent of GPs had not discussed their own care preferences for the end of their life. As well as this, they also recognised that this could have an impact on how they deal with end of life care for their patients. This is particularly important in light of the fact GPs and other healthcare professionals are often cited as the first port of call for advice and information on end of life care39.

The preference for discussions, regarding end of life care, to be with healthcare professionals and, in particular GPs, also highlights the issue of identifying a need for such discussions to take place. If it is deemed difficult to make a confident prognosis on a patient’s condition, the relevant referrals to end of life care services may be delayed. Further

33 Auger, 2007. Social Perspectives on Death and Dying
34 Seymour et al, 2006. Planning for Choice in End of Life Care, The Peer Education Programme Help the Aged
36 As above
37 As above
38 ComRes, 2009. King’s Fund End of Life Care Poll for King’s Fund.
to this, some generalist staff such as GPs, feel it is difficult to identify when a patient is nearing the end of life\textsuperscript{40}.

Investigating further the potential sources of information, research in Australia showed some people, in particular those who were younger, mentioned the internet as a key source of information\textsuperscript{41}. However, they were unlikely to look specifically for palliative care but more likely to search for information on a specific condition that would then lead them to information on end of life care. There is often an assumption that information on end of life care would be available as soon as it is required, usually seen as the point of disclosure of a terminal illness. However, when some clients of palliative care were interviewed it was found that this wasn’t always the case and the information they desired was not always easily accessible\textsuperscript{42}.

There has been some suggestion of incorporating issues surrounding end of life care planning into ‘everyday’ life through popular culture. Healthcare professionals in Australia suggested using a similar approach to the promotion of HIV awareness, including the issues in storylines of programmes on television\textsuperscript{43}. Groups conducted by Ipsos MORI at the recent Dying Matters in the East of England conference highlighted this as a possible approach to raising awareness, as well as a means for disseminating information amongst the general population.

Knowledge and understanding of end of life care is vital for patients to make informed choices. Many people are often unaware of the specific services offered as part of palliative care and, therefore, they would not know they could access them. This is key in terms of ensuring end of life care plans encompass all they need to, to ensure a person’s final wishes are fulfilled. In order for patients to gain knowledge and understanding, strong communication is needed from healthcare professionals, in particular GPs as these have been highlighted as a key point of contact regarding end of life care especially for initial discussions.

\textsuperscript{40} Addicot and Ashton, 2010, \textit{Delivering Better Care at End of Life}
\textsuperscript{41} Campbell Research & Consulting, 2006. \textit{Community Attitudes Towards Palliative Care for The Australian Government Department of Health and Ageing.}
\textsuperscript{42} As above
\textsuperscript{43} Same as above
Advance Care Planning

Key Learnings

- People want healthcare professionals to prompt discussions on the specific ways in which they can plan for end of life care.
- People want their end of life care plans to encompass not only healthcare related issues but also emotional, spiritual and social needs.
- Further research could help identify ways in which people’s diverse needs could be addressed in any intervention.

There are two key pathways for advance care planning:

- **Preferred Priorities of Care (PPC)** gives patients the opportunity to discuss and write down preferences and priorities for end of life care. This is not rigid and allows for statements of wishes, preferences, beliefs and values encompassing written or verbally communicated desires of a patient. These are then recorded in medical notes and can relate to any element of their care at the end of their life.

- **Advance Decisions to Refuse Treatment** allows patients to refuse specific medical treatment in whatever circumstances they specify.

Despite the development of these tools, very few people have written any form of advance statement with only four percent in the recent survey by NatCen\(^{44}\) reporting having done so. This could be, in part, due to a lack of awareness and knowledge of this area of end of life care.

Many people would welcome discussions initiated by healthcare professionals and generally it is reported that GPs are regarded as the preferred point of contact for initial discussions. It is felt healthcare professionals should be the ones to initiate any discussion on advance care plans\(^{45}\). This highlights, again, the importance of healthcare professionals being able to recognise the needs of patients and to identify ‘triggers’ that could prompt such conversations to take place. This will be investigated further in Ipsos MORI’s qualitative research with GPs and practice/district nurses to explore how they think these ‘triggers’ could be identified and used to encourage planning for end of life care. However, as the research will be with generalist staff and not palliative care specialists, they may be less able to identify the potential ‘triggers’. Furthermore, it is understood that currently generalist staff in

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\(^{45}\) Same as above
the East of England are receiving training around discussions of end of life care and the perceived impact of this could be explored in the qualitative research.

Research has shown that attitudes towards advance care planning tend to be strongly influenced by past experience of illness and death in people’s own lives. Some studies suggest there is a more positive attitude towards advance directives and making statements about preferences of care, amongst those who are white, female and highly educated\textsuperscript{46}. Other potential factors could affect people’s attitudes towards advance care planning including religious and cultural beliefs, for example, around how death and dying should be prepared for and these will be explored further in the next stage of Ipsos MORI’s research. Advance care planning is viewed by some as an opportunity to consider not only their preferences for care but their spiritual, emotional and social needs when they are dying\textsuperscript{47}, e.g. whether they would like a priest to bless them and how this can be catered for.

\textbf{Preferences for End of Life care}

\begin{table}[h]
\begin{tabular}{|l|}
\hline
\textbf{Key Learnings} \\
\hline
\begin{itemize}
\item Most would prefer for a terminal prognosis to be disclosed and think this would, itself, act as a prompt for them to plan for their end of life care. However, some ethnic minorities would prefer for a terminal prognosis not to be disclosed, highlighting the need to ensure any intervention takes into account the specific needs of certain groups. Qualitative research conducted by Ipsos MORI will also seek to explore this further.
\item There is a strong consensus on what constitutes a ‘good death’ and it is important that end of life care planning takes into account the factors that contribute to this, e.g. being surrounded by family and friends and being pain-free.
\item Place of death is a key area of preference with most preferring to die at home, highlighting a need for planning to ensure this can become a reality.
\item Past experience of the death of someone close has a strong influence on people’s preferences in end of life care.
\item End of life care preferences are highly contextual and all influences need to be considered in any intervention encouraging people to plan for end of life care.
\end{itemize}
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\end{tabular}
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\textsuperscript{46} Seymour, 2009 \textit{Public Attitudes to death, dying and bereavement}  
\textsuperscript{47} Auger, 2007. \textit{Social Perspectives on Death and Dying}. 

© 2010 Ipsos MORI.
Further research will look to fully explore and examine influences in preferences in end of life care and how these can be addressed through an intervention.

While death is an inevitable part of life, for many, the need to plan for death is much more important when it is known death is near, e.g. in old age or if diagnosed with a terminal illness. Many people felt, that being diagnosed with a terminal illness would, itself, act as a prompt to make preparations and would therefore favour disclosure of such a prognosis. Indeed, eighty-eight percent of respondents in a NatCen survey\(^{48}\) favoured open disclosure and older people in Canada also stated a preference to allow them to plan for their death\(^{49}\). However, this is not always the case, a survey in the North East of England showed forty-seven percent favoured open disclosure; far lower than the national average, thus highlighting the importance of locality in end of life care\(^{50}\).

Further to this, some ethnic minority groups are less likely to want to be told of a terminal prognosis\(^{51}\). In some cultures, such as Southern European where religion is more orthodox, it is believed that talking about death will hasten its arrival. For others, such as some Asian cultures, it is inappropriate to discuss death with someone who is dying\(^{52}\). Recent work with Muslims in London showed that many felt only God can know when someone is going to die and that it is, therefore, not appropriate for healthcare professionals to discuss terminal prognoses in terms of time a person has left to live\(^{53}\). They felt, any terminal diagnosis should be given in more general terms without alluding to exact time-frames. There was also some suggestion that family should be told first to allow them to decide whether to inform an individual of their terminal prognosis. However, when challenged by healthcare professionals, most agreed this was not viable and therefore came to the same conclusion; that they should tell the individual themselves but in general terms rather than giving specific dates, then allowing an individual to probe for further detail if they desired.

The diagnosis of a terminal illness is often viewed as a prompt for discussions of end of life care so any reluctance for open disclosure could prevent some people from making plans for their own death. This has been identified as a key barrier to discussing end of life care. Cultural preferences, such as the reluctance to disclose terminal prognosis within the

\(^{49}\) Auger, 2007. Social Perspectives on Death and Dying.
\(^{52}\) Library Index, The End of Life Ethical Considerations. http://www.libraryindex.com/pages/3104/End-Life-Ethical-Considerations-PATIENT-AUTONOMY.html
\(^{53}\) Social Action for Health, 2009, Engaging in Dialogue for St Joseph’s Hospice
Chinese community, need to be considered in order to successfully plan for end of life\textsuperscript{54}. Alongside this it would be interesting to explore other cultural factors, such as religion, with regard to preferences for end of life care in the next, qualitative, stage of the research.

There tends to be a strong consensus across society overall on what constitutes a ‘good death’. Some key factors include:

- Being around family and friends;
- Being free from pain;
- Dying in the place you want to die; and
- Not being a burden to others.

While there is agreement on these factors, there is some variation across demographic groups as to which factor is the most important in guaranteeing a ‘good death’. Women and older people, i.e. those aged 65-74, are more likely to show greater concern regarding becoming a burden to others\textsuperscript{55}, while those aged 16-24 are more likely to regard being with family and friends as most important\textsuperscript{56}. Recent work with Muslims in London indicated similar factors were important for them to experience a ‘good death’\textsuperscript{57}. However, in addition to these, they also highlighted the importance of being able to practice their faith at the end of their life\textsuperscript{58}.

A key area of preference is place of death, with most people expressing a preference for dying at home\textsuperscript{59}. Furthermore, many people would still prefer to die at home, even without sufficient support\textsuperscript{60}. There is some variation by demographic group, with women and older people more likely to report a preference for death in a hospice, potentially in part due to their concern over becoming a burden to friends or family. Similar to this, Muslims also reported a preference for dying at home but were keen to stress the need for sufficient care to be available\textsuperscript{61}. However, around fifty-eight percent of deaths in England occur in hospitals while surveys show up to seventy percent would prefer to die at home. This highlights a

\textsuperscript{54} Campbell Research & Consulting, 2006. Community Attitudes Towards Palliative Care
\textsuperscript{55} Seymour, 2009 Public Attitudes to death, dying and bereavement and National Centre for Social Research, 2009. Research for Dying Matters Coalition
\textsuperscript{56} National Centre for Social Research, 2009. Research for Dying Matters Coalition
\textsuperscript{57} Social Action for Health, 2009, Engaging in dialogue for St Joseph’s Hospice
\textsuperscript{58} Social Action for Health, 2009, Engaging in dialogue for St Joseph’s Hospice
\textsuperscript{59} National Centre for Social Research, 2009. Research for Dying Matters Coalition.
\textsuperscript{60} Same as above
\textsuperscript{61} Social Action for Health, 2009, Engaging in dialogue for St Joseph’s Hospice
discrepancy between peoples’ preferences and the reality they experience\(^{62}\). This has been identified by the National Council for Palliative Care as a key issue in end of life care.

There is sometimes a preoccupation with euthanasia and assisted dying when end of life care issues are raised. Indeed, there has been much research about views on euthanasia, with a recent survey showing around sixty percent felt euthanasia (allowing a person to deliberately end their life) should be legal\(^{63}\). People tend to think certain circumstances are more acceptable; there is less support for voluntary euthanasia carried out by a doctor where an illness is painful but not terminal with around fifty percent agreeing it is acceptable compared to eighty percent if the illness is terminal\(^{64}\). Further to this, support for euthanasia appears higher in fictional scenarios, where it relates to an ‘other’ and not the person themselves\(^{65}\).

Similarly, preference for life-sustaining medical support is also higher in relation to a fictional, hypothetical situation. This means it is hard to transfer what people say in research to their actual decision-making as their views on hypothetical situations seem to differ to when asked what they wish for themselves. With regards to life-sustaining treatments, women are less likely to be in favour, while members of black or ethnic minority groups and those with strong religious beliefs are more likely to state a preference for these\(^{66}\).

Overall, research shows preferences in end of life care are highly contextual and highly dependent on past experience as well as culture. This means any planning for end of life care needs to take into account a wide-range of factors to ensure it meets the needs of individual people.

\(^{63}\) ComRes, 2009, Death Poll with 1000 UK residents, for Theos
\(^{64}\) National Centre for Social Research, 2005. British Social Attitudes Survey
\(^{65}\) Seymour, 2009 Public Attitudes to death, dying and bereavement
\(^{66}\) Same as above
Interventions
Interventions

Introduction

Whilst the body of existing literature is beginning to form a picture of the issues related to end of life care, many of the articles reviewed highlight the scarcity of research in this area. In particular there is a lack of coordinated research showing what can be done to address the deficit in planning for end of life care and more generally the notion of death as a taboo subject in society. This is an important finding itself which further legitimises the need for this research.

Interventions can be aimed at an entire community or different groups within the community, depending on what the aims are. Some interventions, for example, are targeted specifically at healthcare professionals to help them address some of the key issues they encounter related to end of life care. We have identified four key target audiences for interventions:

- General public;
- Carers;
- Patients; and
- Healthcare professionals including generalist staff and palliative care specialists.

Further to this, the aims of interventions vary greatly, from a desire to raise general awareness of end of life issues to specifically enabling GPs to identify the needs of patients to discuss end of life care plans. We have identified two key themes which we will explore in more detail in this chapter:

1. Raising public awareness and changing attitudes to death, dying and end of life care.
   - The response of healthcare providers
   - Community based interventions
   - General interventions

2. Enabling planning for end of life care.
   - Enabling the general public to plan for end of life care
   - Enabling and encouraging healthcare professionals to help patients plan for end of life care

It is important to note that many interventions may encompass more than one of these themes as they address several issues. In some cases, this is an unintended consequence.
of the intervention but a welcome one none the less, for example where a community based event may aim to broadly raise awareness of death, it may also lead to specific plans being made by those participating.

A key issue with most of the interventions that have been reviewed is a lack of evaluation. This means it is hard to assess any impact the interventions may have had on people’s attitudes to end of life care or their likelihood to make plans for their own death. In some cases, informal feedback from participants was collected by speaking with them throughout an event or by collecting feedback forms afterwards. However, little has been done to look at the effects any interventions have had on people’s behaviour in relation to end of life issues and end of life care.

Raising public awareness

A key focus for many interventions surrounds raising public awareness of end of life care to help ensure people are conscious of the prospective range of decisions and are confident in where to go for help and advice. In doing so, these interventions also add to an over-arching aim to tackle the issue of death as a taboo subject. As a result, it is hoped more people will be prepared to plan for the end of their life, including plans for preferences in care.

Interventions of this nature have been initiated by many different sources, from healthcare providers to local hospices and charities as well as individuals.

The response of healthcare providers

Both at national and local levels, healthcare providers have sought to raise awareness of end of life care. In 2008, the Department of Health published its End of Life Care Strategy aiming to ensure high quality end of life care for all, including enabling patients to make informed choices. As part of this, it recognised the need to shift public perceptions and the National Council for Palliative Care were assigned to take on this challenge. The Dying Matters Coalition was established to help address the issue of reluctance to discuss and plan for death.

- **Dying Matters Awareness Week** took place in March 2010 organised by The Dying Matters Coalition. Various events and conferences took place across the country to raise the profile of the coalition as well as to raise awareness of the issues surrounding end of life care.

- The Dying Matters Coalition has more than 7,000 members and encourages them to help raise awareness of planning for death. The website has resource packs that
can be downloaded, including one with suggestions for activities such as distributing leaflets in GP surgeries, at libraries as well as holding events and more generally starting conversations themselves. Any activity is encouraged to be reported to the coalition so it can be accounted for and reported on.

**CASE STUDY – Dying Matters Coalition Booklets.**

The Dying Matters Coalition has produced a series of booklets focused on death, dying and bereavement to help encourage people to discuss and plan for death. These are available, alongside the resource packs, on the website.

The booklets were recently evaluated in focus groups and depth interviews and were met with varied reactions. People thought the main messages were very clear and they were positive about the non-prescriptive approach. The light-hearted tone was appreciated as it makes it seem ‘everyday’. However, a key issue highlighted was a tendency for people to ignore information in this format, simply disregarding it if it were to come through their door, or not picking it up if left in a GP surgery, for example. People thought the leaflets should be available in libraries and Citizens Advice Bureaus but were more divided on GP surgeries and at funeral homes. Some felt they would be more receptive in these environments as it might be on their mind but others felt it was invasive and may cause distress. Many felt it was important that these were linked with making a will so they could be available alongside information on that, e.g. in post offices. The leaflets were a source of interest for many and they reported it would make them consider the issues. Moreover, some took the leaflets away with them to consider their own plans. Finally, there were some suggestions that other mediums of delivery would be more effective, such as television.
- **NHS Sutton and Merton** held two local events in the community during “Dying Awareness Week”. These were held in local venues and members of the public were invited to “drop-in” to find out more about end of life care. The events offered information and guidance.

- **NHS Bradford and Airedale** offered members of the public the chance to share their views and personal experiences in a video campervan. They were also invited to talk about their own choices in end of life care.

- **NHS North West** produced a **guide for raising awareness**. It was **aimed at health and social care organisations**. It was produced in collaboration with the Dying Matters Coalition. The guide outlines what they plan to do, who will be involved and has links to research and best practice to help ensure success. There are also suggestions on how they can help raise awareness of end of life care. It was aimed at providing information and advice to health and social care partners to encourage them to get involved and help raise awareness in the North West.

- **NHS West Essex** alongside colleagues from the Preferred Priorities of Care National Team designed a **promotional poster and leaflet** that aimed to introduce Advanced Care Planning to individuals and carers. They wanted to encourage families and individuals to have more control and not be dependent on healthcare professionals raising the issue of Advanced Care Planning. They piloted the poster and leaflet in care settings across the UK and within the PCT. They undertook **qualitative and quantitative evaluation** of the pilot including assessing the number of leaflets distributed, the number of hits on the website, any increase in the uptake of Preferred Priorities of Care as well as feedback from professionals and patient groups.

- **NHS South West Essex** initiated a partnership led by a Hospital Macmillan Team Leader and Head of Care Services from a local hospice. The group, consisting of professionals, community groups and members of the public, first met in September 2009. They then held a **‘drop-in’ style workshop** to prompt discussions of End of Life care: Services, choice and planning. This workshop explored the public’s priorities, for example asking them to vote on which services were most important to them. Those who attended were shown four different designs of a leaflet outlining local palliative care services. The public tended to prefer wording that may be deemed insensitive and even avoided by healthcare professionals. This choice was then taken forward and leaflets printed. Further to this, **two road show events** were held at two sites within the PCT. These aimed to raise awareness and provide information to the public. In recognising the different aims of members of the group, for example the aim...
of professionals to raise the profile of their services, they were able to work together towards a collaborative aim. Those attending the road shows were asked to complete questionnaires relating to End of Life care planning, for example preferred place of care/death. In order to encourage people to complete these, the group found providing free promotional resources, such as pens or canvas bags, acted as good incentives. The preliminary results of these roadshows found discrepancies between people’s needs and professional’s assumptions.

Community based interventions

- The Peer Education Project Group was set up by The Health Foundation in collaboration with Help the Aged in 2006. It was a development study with older people to raise awareness of advance end of life care planning among older adults and community groups representing them. Training sessions were developed for peer educators to talk through these issues with other older people and an education guide was developed to be used and discussed in small groups. Evaluation of the programme was carried out alongside the project using face-to-face and telephone interviews as well as questionnaires completed by those who took part in group discussions. These discussions and the booklet produced were viewed positively as an acceptable approach to providing information on this sensitive topic. The approach also received positive feedback; the training course was perceived to fully prepare the peer educators to carry out their role. This project also showed that older people had a desire to discuss the issues surrounding end of life care and this enabled them to do so.

- In Edmonton, Canada, a hospice regularly goes out into the community to give presentations on the services it provides and the arrangements that can be made for end of life care. It does this in local service clubs, churches and community groups to raise the profile of the hospice and end of life care generally. They have also established a speakers’ bureau which asks volunteers to present to the community.

- A collaborative event was held in Warrington during the Dying Matters Awareness week encompassing support from a variety of sources including, Warrington Macmillan Nursing, Warrington Borough Council, Age Concern and a local hospice. Advisers were available in a shopping centre, at a branch of HMV, to provide information and advice on support, financial issues and end of life care.
CASE STUDY: ‘Saying the Unsayable Exhibition’ Birmingham

‘Saying the Unsayable’ was an exhibition held in Birmingham to try and generate an ‘open dialogue’ about living, death and dying. It was funded by NHS West Midlands and organised by Well Being in Dying which is a website set up to try and encourage people to consider their own plans for death and dying. The exhibition included images centred around 6 key themes: decay, regeneration and renewal / being alive, hope and death / compassion, attachments, hope and death / remembrance and continuity / living life well, life as a journey metaphors and symbols. The images were provided by members of community groups who the team had asked to be involved.

As well as this there were ‘performances’ centred around a kitchen table with actors performing rehearsed scenes, such as planning their own funerals, discussing someone’s death. Members of the public were invited to participate, sharing their own thoughts and experiences. There were also narratives and a DVD piece from a Masters student. There were various ways to interact with the exhibitions, such as by writing the name of someone who has died in water.

Views and experiences were collected on the day and participants were observed as they took in the exhibition. There was a book where people could record their comments. Members of the public were often pleased to be able to share their experiences with others and many were surprised at the level of interest. During the exhibition, and in particular the performance, many people were discussing their own plans for their end of life and one family discovered a wish of their mothers which they felt they would not have anticipated and were happy to uphold. It was clear from levels of involvement how engaged people felt at the event. However, it is important to note that there was no formal evaluation of the event.
and no way of measuring the longer-term impact of the exhibition.

General interventions

- **IfICouldDie.co.uk** is a website dedicated to arrangements for death and dying. It was set up by one individual after the death of her father as she realised it was important to ensure the wishes of an individual are upheld. It provides a **source of information** on all plans that could be made before death, including funeral care, making a will, as well as preferences for end of life care.

- **A Good Death** was a **documentary television programme** screened in Australia for Four Corners, following the lives of four terminally ill patients at the end of their life. Those participating hoped that in documenting their last days they could help others in handling the experience. The programme showed how patients came to terms with their terminal prognosis, made plans for their own death, including place of preference and included interviews with their family and carers in a hospice setting. A **forum on the website** for the programme allowed the public to express their reactions to the programme and many positive comments were left. Many felt the documentary portrayed a strong message and was helping to raise awareness of the process of dying in a positive light.
Enabling planning for end of life care

Research has highlighted the importance of raising awareness of end of life care amongst the general public to ensure better end of life care for all. However, alongside this it is vital to provide patients with the tools to plan for the end of their life and to ensure these are easily accessible and that patients are aware of them. In addition, it has been highlighted that certain healthcare professionals, such as GPs, are preferred sources of information and initiators of discussions of end of life care. For this reason it is important to enable these healthcare professionals to provide the support and guidance that people want in order to enable them to make an informed choice. This section will explore initiatives that have been developed to address the needs of the public and the needs of healthcare professionals.

Enabling the public

- **NHS North East** is producing a charter entitled ‘A Good Death Charter’ with help from partners across health, social care and voluntary sectors and patients and carers. It aims to provide information and advice for those planning and providing end of life care. Furthermore it will act as a guide for the public, to give them an idea of what they can expect should they, or someone close to them, require this care or other services. Once it is finalised, carers and providers across the North East will be encouraged to use it when planning and delivering services. As part of this, there have been consultations with the public, through online surveys and in-street interviews, to explore their views on the charter. Care providers, partners and patients were also consulted on the charter. As noted, it is important to ensure there is some consensus between all interested parties in the design of an intervention to ensure any discrepancies between perceptions are addressed. For this intervention, the consultation aimed to address this issue. Further research using alternative methodologies to ensure it is as wide-reaching as possible (e.g. using postal rather than online surveys) could be useful to gain further insight on the public’s views on an intervention.

- **Weston Hospicecare** developed a guide to help facilitate discussions regarding end of life care. The guide was developed with collaboration between healthcare professionals and patients. Healthcare professionals reported that there was a sense of relief when discussions were initiated and patients were pleased to put advance plans into place. In addition, leaflets related to end planning for the end of life were produced by palliative care professionals, targeting 4 key areas: Advanced Care Planning, Making a will, appointing someone to make decisions and the writing of an
Advanced Care Decision. The leaflets were designed to provide patients with the information they would need to make decisions about their end of life care.

- **A Citizens Advice Bureau service** has been developed in Worcestershire as a result of partnerships between CAB, hospices, social services and the PCT. It aims to provide people with **quick access to advice and information** regarding palliative care. As the project involved a partnership of a number of different organisations, clinical staff are confident people are getting relevant and suitable advice. The scheme was set up after a successful pilot and a project group has been created to monitor the success of the service. The group identifies potential issues and discusses these with stakeholders and CAB staff to resolve them before they become a problem.

- **Tower Hamlets PCT** has produced **two complimentary directories**; one for patients or carers and one for healthcare professionals. There are personalised reference sheets for people to use at home, guidance for emergencies, explanations of terminology and a **full directory of resources**. Both directories were produced in collaboration with St Joseph’s Hospice and an information management company and were launched in 2009. In producing the directories the team engaged with local people, professionals and various representatives to identify gaps in information. Feedback is currently being collected from users of the directories and once this is complete they will be reviewed. It is hoped the directories will soon be included on the PCT website.

**Enabling healthcare professionals**

- **St Benedict’s Hospice** held a **communications study day** for health and social care workers. It reviewed the key principles of communication looking specifically at **how to deal with difficult questions** that can be raised. The participants were offered the chance to **practice their skills with ‘actor patients’**. After the study day, participants reported an increased awareness of the questions which might be raised and felt they were better at listening, showing compassion and picking up on cues from patients to discuss end of life care

- **St Christopher’s Hospice** runs a two-day training course for social and healthcare professionals contributing to the care of people approaching end of life. The course aims to enable staff to listen sensitively and explore needs and preferences in issues of care. Theoretical principles of communication are explored, as well as the aspects of advance care planning through workshops. Participants are encouraged to **reflect**
on their own barriers to develop means to break these down and enable them to help patients plan for the end of their life.

- **A Sussex Care Home** implemented a **coding system** to help identify patients who were near the end of their life. They used a system of A to D and those coded as C or D were reviewed weekly while those in A or B were reviewed monthly. Staff praised the system as it helped them to identify patients needs and, where necessary, to initiate advance care planning.

- **A palliative care information website** was set up in Manchester by the PCT and the city’s palliative care forum offering, information and educational resources to community and hospital staff. It was aimed at all nurses, GPs and allied healthcare professionals. The site includes tutorials, local contact details and referral forms as well as a bulletin board for news. It is available on an intranet but there are plans to increase the usage by rolling it out on the internet. There is an annual review of the content to ensure it is up to date and relevant.

- In Cumbria, palliative care professionals developed a **palliative care website** aimed at GPs to enable them to help isolated people die at home, in their preferred place of care. The website provides advice and guidance on what they can do to make this possible and helps enable them to provide the care and support needed. It provides simple information on palliative care topics as well as links to local or national events on the subject. Feedback received from users has been positive and GPs have felt they are better able to meet the needs of these patients using the guidance.

- **Barts and The London Trust** have appointed a **bereavement co-ordinator** to help address issues of raising awareness of end of life support amongst staff to better meet patient/carer needs. Staff received training from the co-ordinator and, in addition to this there is an intranet website, a ward based resource folder and a last offices (procedures performed by healthcare professionals immediately after death) check list. The website includes information, guidance and checklists for staff dealing with end of life care issues. It is hoped that by providing this support for staff, the number of complaints surrounding the experience of the death of a loved one will be reduced. Feedback from staff has been extremely positive, with particular praise for the check-lists. While this intervention is mainly aimed at bereavement issues, the method is one that could be more widely introduced.

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67 Summary of the Bereavement Co-ordinator intervention at London and St Barts
http://www.endoflifecare.nhs.uk/eolc/CS267.htm
Waltham Hall Nursing Home in Leicestershire has set up a ‘support group’ for staff who have attended training on end of life care. The group meets to discuss any issues or successes they have in their work related to end of life care. It allows staff to exchange ideas and experiences. The feedback from participants has been good with staff reporting that they feel better able to help families and patients plan for end of life, as well as better at recognising when someone’s life is drawing to a close and therefore putting into place advance care planning.

Learnings and Recommendations of interventions

It has been identified in the research that more needs to be done to encourage people to plan for their end of life care. By better enabling people to make plans for the end of their life, it is hoped the issue of death as a taboo subject will be addressed as well. The literature reviewed has uncovered many recommendations which we have listed here for consideration and elaboration throughout the course of this research:

- Several initiatives have been set up in response to the need for better planning for end of life care amongst the general public but most have not been formally evaluated to assess their impact. Evaluation of any intervention is vital to monitor whether the desired outcome is being achieved.

- Any intervention aimed at increasing awareness and encouraging people to make plans for the end of their life needs to be implemented in conjunction with better education of healthcare professionals, particularly generalist staff (e.g. GPs and Practice Nurses) as they are often the first port of call for help with end of life care plans. This will enable them to better meet their patient’s needs in this area.

- Peer education programmes are viewed as highly relevant models in educating and encouraging people to plan for their end of life care.

- Using community groups and clubs is a helpful way of targeting the general public.

- Using art and exhibitions can help make planning for the end of life more accessible to a wider audience as was seen at the exhibition in Birmingham.

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68 Seymour et al, 2006. *Planning for Choice in End of Life Care, The Peer Education Programme Help the Aged*


70 Website for the ‘Saying the Unsayable’ event in Birmingham: [http://www.wellbeingindying.org.uk/stories-introduction.htm](http://www.wellbeingindying.org.uk/stories-introduction.htm)
• Partnerships and collaborations with community-based services, such as hospices, enable better informed interventions and should be encouraged in the development of initiatives surrounding end of life care.

• It is important to consider different cultural views on discussing death and the disclosure of terminal illness as these could present barriers in planning for end of life care71.

• Palliative care providers have advocated a health promotion approach, similar to that taken in raising awareness of HIV with suggestions of incorporating end of life care issues into popular culture through television programmes72. It is felt this would make end of life care and planning for it seem like part of ‘everyday life’ and something which everyone has to deal with. Further to this, when Ipsos MORI conducted groups at the Dying Matters in the East of England conference this year, this was also suggested as a way to raise awareness of end of life care.

72 Campbell Research & Consulting, 2006. Community Attitudes Towards Palliative Care
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**Websites**

Australian Palliative Care Programme Website: http://www.palliativecare.org.au/

Dying Matters Coalition Website: www.dyingmatters.org.uk

Library Index Website, The End of Life Ethical Considerations: http://www.libraryindex.com/pages/3104/End-Life-Ethical-Considerations-PATIENT-AUTONOMY.html

NHS End of Life Care Programme Website: http://www.endoflifecare.nhs.uk/eolc/

NHS Library Website: http://www.library.nhs.uk/default.aspx

NHS North East Good Death Charter Website: www.agooddeath.co.uk

Weston Hospice Care Website: https://www.westonhospicecare.org.uk