Attitudes Towards Death and Dying in the East of England - Qualitative Report

Research to Inform the Development of Social Marketing Interventions on Palliative and End of Life Care

27 August 2010
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Summary
Summary

While the majority of respondents in the quantitative survey across the East of England say they feel comfortable discussing death - both generally (73% are very or fairly comfortable) and with regard to their own mortality (69%) - this will not necessarily translate into action around discussing and planning for end of life. There are a range of external factors that influence an individual's ability to discuss end of life matters and plan accordingly.

Limited awareness of the plans that can be made (particularly those for the time leading up to death), why it might be important to plan, and who people can discuss plans with, are all issues preventing planning. Furthermore, the prospect of death is perceived as too distant for many to consider making plans. Even for people who feel comfortable discussing death and who are willing to discuss their preferences, this process can often be impeded by relatives who are unwilling to engage in the discussion.

Summary of key findings:

- **Perceived irrelevance is a key issue** as people are unlikely to plan if they do not think there is a need. The timing of when people are encouraged to plan is therefore extremely important as death needs to feel, in some way, relevant.

- It is also therefore important to provide **scenarios of real-life examples of how planning has helped individuals and families**. This may help to give people a sense of ‘agency’ over their end of life care – a feeling that they can have the death they choose – as well as making it more relevant to them. It could also help combat the **fatalistic view** held by some, that planning is futile as the NHS will not be able deliver it.

- **Relatives can be reluctant to discuss** plans with a close one as they do not want to consider a family member dying. Further to this, they sometimes prevent plans from being followed if they are not properly informed or supported.

- Having said this, **discussing plans or preferences with family members** is often the first step to making more definite plans, and **should be encouraged**. Informal discussions can often lead to more serious consideration of end of life planning.
• For those who feel that death is less relevant, or do not feel the need to plan, emphasising that planning can help reduce the burden on their loved ones may help to engage them with the subject.

• **Raising awareness** – both of what plans are available and why they are important - could encourage people to plan. Being targeted at all people, not just those approaching the end of their lives, is likely to help encourage wider-discussion and lessen the taboo around the subject.

• **Practice/District Nurses are seen (both by healthcare professionals and the public) as better placed than GPs to provide information** on a one-to-one basis. Written information provided in GP surgeries is also seen as suitable way to raise awareness.

• For those who feel death is less relevant to them, it may be more useful to concentrate on providing information around wills and funerals, rather than specific aspects of end of life care. The latter are seen as less relevant, out of context (it is deemed likely that they will change their mind regarding a preference) and morbid. It is also therefore important to make it clear that all decisions are reversible and plans can be updated.

• Experience of the death of a close one is often a key trigger as people consider what they would and would not like for themselves. They may then plan to ensure their own wishes are fulfilled.

• For people closer to the end of their lives, it is important to emphasise that making plans for end of life care is not giving up hope.

• Simply **starting a dialogue about death and dying across society** could help encourage people to plan. By ‘sowing the seed’, it would then become part of their consciousness so they would be aware of their options and plan accordingly.

• Bringing end of life matters into education is, generally, viewed as a good way to help break down the taboo around death, as well as build awareness. However, it is considered contentious by some.

• Presenting planning for end of life care as the **social norm** may encourage others to act. Anything which helps normalise it, is seen as positive.
• Examples of **good practice in information provision should be shared between GP surgeries.** This may also help ensure that information provided to patients is consistent.
Background
Background

End of Life Care

Over recent years, as the NHS has placed greater emphasis on patient choice, the profile of end of life care has become more prominent within the health service. In 2008 the Department of Health published an End of Life Care Strategy aiming to improve the provision of care to those approaching the end of life, as well as those who care for and support them. In addition, the Department has committed additional funding to end of life care services, over the next 2 years, to help implement the End of Care Pathway, represented below.

The End of Life Care Pathway

Department of Health End of Life Care Pathway

However, against this backdrop of increased patient choice, it has been recognised in recent years that there is a gap between people’s wishes for the care they receive at the end of their life and the reality that is experienced by much of the population. This gap is particularly noticeable when it comes to the location in which people die; currently between 56 and 74 per cent of people express a wish to die at home, yet 58% die in an acute hospital.

Previous research\(^2\) has shown that a key barrier preventing the fulfilment of people's wishes around end of life care is the societal taboo that exists around death and dying. This taboo can inhibit people from discussing the care that they would like to receive and making their needs and preferences known.

This lack of open discussion means it is very difficult for the NHS to plan services. To try to address this issue, the End of Life Strategy highlighted a need for increased awareness and discussion around the plans people can make, in order to make it easier for people to talk about their preferences.

The East of England Strategic Health Authority has put in place a clinical vision aimed at transforming NHS services in the area; *Towards the best, together*\(^3\). So far, a revised strategy has been published, a dedicated website has been launched and ten clinical programme boards, including one for Palliative and End of Life Care, have been set up. ‘*Towards the best, together*’ sets out several key areas of work for the Palliative and End of Life Care programme board, including:

- Delivering world class standards in meeting choice of place of death;
- Ensuring needs assessments and advance care planning for all identified as being in the last year of their life; and
- Working with the public and partners to raise awareness of end of life issues.

By addressing these actions, as well as others set out in the vision, the programme board aim to promote several key messages including:

- Helping people to talk about death more openly and understand the challenges faced by families and individuals at the end of life; and
- Enabling people to choose where they want to die.

Overall the East of England SHA have set in motion several actions to help tackle issues raised at end of life. The aims, set-out above, for the Palliative and End of Life Care programme board demonstrate the commitment of the SHA to ensuring high quality end of life care for all.

\(^2\) Examples can be found in the appendices of the Scoping Study Report completed as part of this research.

Aims and objectives

In light of the taboo around death, and the difficulties that this causes when trying to put appropriate care into place, the East of England Strategic Health Authority (SHA) has commissioned Ipsos MORI to undertake insight research to inform social marketing interventions. These interventions will be aimed at raising awareness of End of Life care and the plans which people can make, and at encouraging people to make these plans.

The research has been designed to engage both the general population and healthcare professionals to help inform the design and delivery of the intervention(s). It explores attitudes towards discussing and planning for death and provides insight as to what would encourage people to plan for the end of their life and the care they want to receive. The overall aim of the research is to:

- allow the population in the region to plan more effectively for the end of their lives;
- help increase the chance that the wishes of its residents can be fulfilled at the end of their lives (through greater documentation of them).

To meet these aims, the specific objectives of the research can be summarised as follows:

- To explore attitudes towards talking about and planning for death;
- To provide insight into why people do not make plans for their death and explore how this can be overcome;
- To inform the content and delivery of social marketing interventions targeting the general population and health professionals around the issues of talking about and planning for death; and
- To enable, to some extent, the evaluation of the interventions.

In order to meet these objectives, there were three distinct phases of the research. These included:

- A scoping study of the existing literature on the subject;
- A quantitative survey of East of England residents; and
- Qualitative discussion groups with the general public and healthcare professionals.
Interpreting this report

This report presents the findings of the qualitative element of the research with the general public and healthcare professionals. Separate reports have been produced for the scoping study and quantitative element. The final chapter of this report brings together findings from the quantitative and qualitative research to inform social marketing interventions.

Qualitative research is not by its nature designed to be statistically representative. It is intended to be illustrative, and claims cannot be made about the extent to which the conclusions may be applied in general to the population. As with any qualitative discussion groups, the aim was to facilitate deeper insight into and understanding of specific topic areas that go beyond 'top of the mind' responses.

Verbatim quotes are used throughout the report to illustrate particular bodies of opinion, but these should not be taken to define the opinions of whole discussion groups.

Exploring attitudes and behaviour to inform interventions

In order to develop a successful intervention it is vital to understand the attitudes and behaviours of the target population. Qualitative research allows us to fully explore people's attitudes and behaviours and to understand key influences on these. Furthermore, it allows us to investigate how people think these attitudes and behaviours can be changed. This means that any social marketing intervention is based on a clear and well understood starting point.

Specific objectives were therefore identified for the qualitative element of this research.

For the general population Ipsos MORI identified the key aims to be:

1. To explore participants’ views on death and planning for it, thinking both about their own death and their friends’ or family members, and to understand key influences on their views such as personal experience.

2. To determine levels of awareness of sources of information and knowledge about help and support available when approaching the end of life.

3. To identify barriers preventing people from talking about death or making plans for their own death and how these can be overcome.

4. To investigate how people make a decision to start discussing their wishes about their own death and the challenges they face in implementing this decision.
5. To examine what plans people think they should make to ensure their wishes will be fulfilled.

6. To identify factors that would encourage people to make plans for their own death, including making a will or completing a Preferred Priorities of Care document.

7. To identify the optimum channels of delivery for a social marketing intervention and whether they can be targeted to any key groups.

For the **healthcare professionals** Ipsos MORI identified the key aims to be:

1. To explore the experiences of healthcare professionals in helping patients make choices regarding their end of life care and what the key influences are.

2. To understand their motivation to help patients make choices about their end of life care.

3. To explore their views on which healthcare professionals are best placed to discuss end of life care and what they think should be expected of them in such situations.

4. To identify barriers that might prevent healthcare professionals from talking about death or discussing end of life care with patients and how to overcome these.

5. To identify what would better enable and encourage them to discuss end of life care with patients.

6. To identify the optimum channels of delivery for a social marketing intervention to maximise the impact.
Methodology
Methodology

By carrying out a thorough literature review, the research team was able to enter the qualitative stage with a more in depth understanding of the issues concerned, which was invaluable for designing the fieldwork materials (see appendices).

The qualitative research comprised of:

- Four face-to-face friendship discussion groups with the general public;
- Seven face-to-face or telephone individual follow-up depth interviews with participants from the discussion groups;
- Six face-to-face individual depth interviews with Asian Muslims;
- Six face-to-face or telephone individual depth interviews with GPs and practice nurses;
- Two face-to-face discussion groups with GPs and practice or district nurses.

Research participants were recruited from different Primary Care Trusts within the East of England SHA and it was aimed to recruit a mix of gender and age for the groups and depth interviews.

Discussion groups and depth interviews with the general public

The discussion groups with the general public were conducted with groups of friends; most of the participants knew each other before attending the group. This created a relaxed atmosphere and provided insight into the types of discussions people might have naturally with friends or family. Participants were recruited using ‘snowball’ sampling; a lead participant was recruited and asked to bring a group of friends either to a venue or their own house for the group. We set quotas on age and location to ensure we spoke to people from across the SHA and across a range of ages. Furthermore, we also set loose quotas on gender to aim to achieve a mix of men and women across the groups.
The following table sets out who we spoke to in the groups:

<table>
<thead>
<tr>
<th>Location</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watford</td>
<td>18-29</td>
</tr>
<tr>
<td>Cambridge</td>
<td>30-44</td>
</tr>
<tr>
<td>Peterborough</td>
<td>45-59</td>
</tr>
<tr>
<td>Norfolk</td>
<td>60+</td>
</tr>
</tbody>
</table>

At the end of the groups, we asked participants (across the groups) if they would be willing to take part in a follow-up depth interview either on the phone or face-to-face. Of those who volunteered to take part we selected seven, aiming to have a mix of age and gender. These were conducted two weeks after the initial groups to explore their thoughts on the topics discussed and whether any of their views had changed. Furthermore they were asked to talk to family and friends who had not attended the groups to explore any difficulties they encountered in doing so. During the interviews, participants were also asked their opinion regarding the ideas for interventions that came out of the initial group discussions.

The following table sets out who we interviewed after the discussion groups:

<table>
<thead>
<tr>
<th>Location</th>
<th>Participant 1</th>
<th>Participant 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watford</td>
<td>Male, 18-29</td>
<td>Female, 18-29</td>
</tr>
<tr>
<td>Cambridge</td>
<td>Male, 30-44</td>
<td>Female, 30-44</td>
</tr>
<tr>
<td>Peterborough</td>
<td>Male, 45-59</td>
<td>Female, 45-59</td>
</tr>
<tr>
<td>Norfolk</td>
<td>Female 60+</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**Interviews with Asian Muslims**

It was highlighted in the scoping report that there may be differences in attitudes towards death and dying across different cultures and religions and it was important to consider this in the research. Asian Muslims were identified as the largest ethnic minority group in the East of England so it was most relevant to include this group within the research.
Furthermore, we identified that there is a large population of Asian Muslims in Luton so six depth interviews were conducted in this area. In addition, it was decided to focus the research on those who were second-generation to explore the influence and interaction of both the Asian Muslim and local culture. Quotas were set on age and gender to ensure a mix of both. However, as the research focused on those who were second-generation, all the participants were under fifty.

The following table sets out who we spoke to from this ethnic minority background:

<table>
<thead>
<tr>
<th>Location</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luton</td>
<td>Male</td>
<td>18-29</td>
</tr>
<tr>
<td>Luton</td>
<td>Male</td>
<td>18-29</td>
</tr>
<tr>
<td>Luton</td>
<td>Male</td>
<td>30-44</td>
</tr>
<tr>
<td>Luton</td>
<td>Female</td>
<td>30-44</td>
</tr>
<tr>
<td>Luton</td>
<td>Female</td>
<td>30-44</td>
</tr>
<tr>
<td>Luton</td>
<td>Female</td>
<td>30-44</td>
</tr>
</tbody>
</table>

**Research with healthcare professionals**

The scoping report highlighted that people felt they would go to healthcare professionals in primary care settings for advice about end of life care. For this reason we chose to focus on GPs and nurses in the qualitative research. The research with healthcare professionals was conducted after research with the general public. This allowed healthcare professionals to respond to findings from the general public research and allowed us to gauge their opinion on views or suggestions of interventions.

Depth interviews were conducted, either face-to-face or by telephone with GPs and practice nurses. This ensured we could capture all views, even those that might contradict an ‘official’ line and that people may not feel comfortable voicing within a group setting. After the depth interviews, discussion groups were held; one with GPs and another with district and practice nurses. During the groups, participants were also presented with findings from the depth interviews with GPs and practice nurses to explore contrasting opinions.
Healthcare professionals were recruited from across the same Primary Care Trusts as the general public.

The following table sets out who we spoke to:

**Interviews**

<table>
<thead>
<tr>
<th>Location</th>
<th>Profession</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watford</td>
<td>GP</td>
<td>Male</td>
</tr>
<tr>
<td>Watford</td>
<td>Practice Nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Peterborough</td>
<td>GP</td>
<td>Male</td>
</tr>
<tr>
<td>Peterborough</td>
<td>Practice Nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Norfolk</td>
<td>GP</td>
<td>Female</td>
</tr>
<tr>
<td>Norfolk</td>
<td>Practice Nurse</td>
<td>Female</td>
</tr>
</tbody>
</table>

**Discussion groups**

<table>
<thead>
<tr>
<th>Location</th>
<th>Profession</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cambridge</td>
<td>6 Practice Nurses, 2 District Nurses</td>
</tr>
<tr>
<td>Mid Essex</td>
<td>GPs</td>
</tr>
</tbody>
</table>
Attitudes to death and dying
Attitudes to death and dying

This chapter will examine participants’ attitudes to death and dying. It will explore:

- Cultural influences on attitudes to death and dying;
- Changes in attitudes to death and dying over a lifetime;
- The influence of a person’s family and friends on attitudes to death and dying; and
- Differences in attitudes to various topics within death and dying.

Summary of key findings

- **Culture has a strong influence** on how comfortable people feel discussing death and dying. Participants felt, in Britain, these conversations were influenced by superstition and people were concerned that it would ‘tempt fate’ to discuss death and dying.

- **Death has become ‘hidden’** in today’s society. People tend to live longer and often die in hospitals or hospices, so it is removed from people’s every day lives.

- Attitudes to death and dying can change over the course of a person’s lifetime. As people grow older, **death becomes more relevant and people may become less comfortable discussing the issues**.

- A person’s ‘networks’ of family and friends can also influence how comfortable they are talking about death and dying. **Relatives can present a barrier** to talking about these topics, so people avoid these conversations.

- Participants tended to be **less comfortable talking about planning for the time leading up to their death compared to planning for what would happen after their death**. Healthcare professionals felt this could be due to a lack of familiarity with what actually happens when someone dies.

- Participants felt that people’s attitudes to death and dying are often **highly personal**. Their attitudes can be influenced by various factors, for example their age, culture and personal experience amongst others. The influence these have is explored in this report.
Overall it was found that **attitudes to death and dying are highly contextual and highly dependent on experience**. There are many factors influencing people’s attitudes towards death and dying, including culture and their own social networks. Attitudes can also **change over the course of a person’s lifetime**; as a person grows older or through experience. Further to this, attitudes may vary with regards to the different issues raised when discussing death and dying.

There was a general consensus that death and dying are taboo subjects in British society and participants identified a number of reasons as to why this might be. However, while participants thought society, in general, was not comfortable discussing death and dying, they themselves were comfortable discussing the topics. It should therefore be noted that participants were aware of the subject matter before they attended and an element of sample bias was therefore present, (i.e. many will have declined to take part if they felt they could not openly discuss the subject). Furthermore, participants thought that while they were comfortable discussing death and dying, other people may not be. This could be explored further to establish whether this perception is accurate.

The methodology is also relevant; in the research with the general public, all participants were friends with other members of their discussion group. This created a more relaxed environment in which to have the discussion and could also reflect how conversations might take place in real life.
1.1 Influences across society

There was a feeling, across all the groups, that a person’s culture has an effect on their attitudes to death and dying and their comfort in discussing such topics. Both the general public and healthcare professionals felt death and dying were not openly discussed in British society and identified some influences that they felt were part of British culture.

1.1.1 Fear and superstition

General Public

Across all the groups, several participants felt there was an element of fear that people feel when contemplating their own death. The discussion of death and dying is sometimes seen as ‘tempting fate’ and as being contrary to the ‘live for the moment’ attitude that is prevalent in contemporary society.

“Don’t want to tempt fate. We’re [society] superstitious, if you talk about it, it will happen”

Male, 60 plus, Norfolk

Asian Muslims

The Asian Muslims interviewed agreed that there is a fear of talking about death and dying. Most identified a similar notion of ‘tempting fate’ and felt that this was a factor influencing people’s attitudes to discussing the topics.

“It’s almost like it’s unlucky and you shouldn’t talk about it”

Female, 36, Asian Muslim, Luton

For those who regularly practised their faith, they felt there was less fear around death and dying as it was in Allah’s hands and not something they would worry about.

Healthcare professionals

Both GPs and practice / district nurses were in agreement with the general public that there was a fear around death and dying. They felt this was often because people had little experience of death and therefore did not know what to expect. Similar to the general public, they also mentioned superstition as a reason why people do not discuss death, for fear of causing it to happen.

“That’s [death and dying] a bit of a taboo…it’s a fear of the unknown.”
Fear is seen as a key barrier to people discussing matters related to death and dying, in that it prevents open discussion. Furthermore, the lack of open discussion can add to the fear surrounding death and dying, thus leading to a vicious circle where people find it increasingly difficult to talk about the topics involved. There was a feeling that this could contribute to death becoming an ‘unknown’ as lack of discussion means people are unfamiliar with death.

1.1.2 Death is ‘hidden’ in society

General Public

As well as fear, participants thought there were other factors contributing to people’s lack of familiarity with death and dying. Longer life expectancies mean many people do not experience the death of a loved one until middle age. Further to this, participants felt that many people die ‘away from the home’, i.e. in hospices or hospitals and therefore it is not part of the everyday life of family and friends. They felt both these factors contributed to why people did not talk about death and dying.

“As death [is] mostly taking place in hospital, death has been removed from our lives. It isn’t often….any young family member witnesses death”
Female, 60 plus, Norfolk
Healthcare professionals

In line with the general public, both GPs and practice / district nurses also felt death had become removed from everyday life because of longer life expectancies and because it often takes place away from the family home.

“It used to be a lot better, in the old days you had families, three generations, all living within two feet of each other….now families are more widespread that the younger generations don’t see severely ill people unless they visit them in hospital”

GP, Peterborough

In addition, some thought death and dying were ‘hidden’ from children to ‘protect’ them so death and dying were not openly discussed. This could then lead to a vicious cycle where children are less comfortable discussing it in their own lives as they have no experience to draw upon.

“People previously always died at home so there was a lot of acceptance of death and you saw death”

District Nurse, Peterborough

Overall, culture was seen to have a strong influence on whether or not people discuss death and dying. Across all the groups, participants felt death had become something that was not discussed and that this contributed to death becoming a topic that became ‘hidden’. This indicates a need to encourage a more open dialogue, generally, across society to increase people’s familiarity with the issues involved. This could then break down some of the fear of the ‘unknown’.
1.2 Changes in attitudes over a lifetime

Participants thought that people’s attitudes could change over the course of their lifetime. As people grow older, death may feel more relevant as it becomes more proximate. Further to this, people’s experiences of death throughout their lives could also be a key influence on their attitudes.

1.2.1 Differences in attitudes by age

General public

Across the groups, it was felt that attitudes towards death and dying would differ according to a person’s age. Participants thought their own views would change as they grew older but also speculated that people who were older or younger would have different attitudes according to their age. Some participants in the eldest group (those aged 60 and over) stated that the increasing relevance of death as they aged meant that the topic was becoming increasingly difficult for them to discuss. This contrasts with research conducted in Canada[^4] noted in the scoping report, where it was found old people were more willing to discuss death and dying.

> “But you do find talking about it…traumatic is the wrong word, but I think perhaps the older we get and the nearer we get to that date, the more we think ‘well I’m not going to talk that one up’.”

**Female, 60 plus, Norfolk**

While participants in the eldest group (those aged 60 plus) expressed some discomfort discussing death and dying, they were more concerned with the years leading up to their death. They were anxious over the care they would receive and how they could guarantee they were looked after. This was more worrying for them, than issues around the care they would receive at the very end of their life.

In contrast, the participants in the youngest group (those aged 18-29) were happy to discuss nursing homes and end of life care. However they did feel that, at their age it was not an issue that they felt was relevant to them and tended to discuss the issues in relation to older relatives. Their younger age could be a key influence in them feeling more comfortable discussing these issues as death felt ‘far off’ and, therefore, less relevant.

[^4]: Auger, 2007, *Social Perspectives on Death and Dying*
Age can also influence how comfortable other people, e.g. relatives, feel discussing death and dying with a person. Some younger participants said they did not want to discuss death and dying with family members who they perceived as being closer to death because they felt the subject would be uncomfortable. This, again, shows proximity of death is a key factor affecting how comfortable people feel discussing it.

“I might talk to my parents about dying, it’s far enough off for them, but I wouldn’t want to upset someone who is old.”

Female, 18-29, Watford

Healthcare professionals

Healthcare professionals drew on their own experience of treating patients and felt older people were more likely to have contemplated their own death. Further to this, they thought elderly people were more likely to feel comfortable and want to discuss death and dying. However, this is in contrast with the views of the general public, where the eldest group (those aged 60 and over) tended to feel more anxious about the time leading up to their death. This could, in part, be due to participants in the eldest group focusing on the years leading up to their death, not just the care at the very end of life, which was an issue some felt very concerned about.

Further to this GPs and practice / district nurses said they were far more likely to discuss death and dying with patients who are nearing death, for example, patients who are very old or terminally ill. This may have influenced their opinion on who would be more comfortable discussing death and dying. Finally, it is important to note the eldest group was with those aged 60 or over, who felt that death was still a ‘long way off’ whereas GPs and practice / district nurses were often referring to patients who were more than 70 or 80 years old.

“It’s interesting talking to elderly people about death in that they’re prepared for it and they sort of get to a point where they almost welcome it.”

Practice Nurse, Peterborough

Practice / district nurses and GPs felt younger people would be less likely to discuss death and dying as it was not relevant to them. This was in line with comments in the youngest group (those aged 18-29) where participants said they were happy to discuss the issues but did not do so in relation to their own death. Healthcare professionals also felt younger patients would be less willing to discuss their own death as it is not something they want to contemplate happening at their age.
Overall, participants were divided on whether increasing age and proximity to death would mean they were more or less comfortable discussing death and dying. For some, the increasing proximity to death increases discomfort as it becomes more relevant and they avoid discussing it. However, for others the increased relevance means they feel more ‘need’ to talk about the issues and therefore are more likely to do so. This highlights the importance of timing with regards to the success of an intervention if it is to encourage people to discuss death and dying. This will be discussed further in the later chapter on barriers and triggers.
1.3 Who people talk to matters

Across the groups, participants thought a person’s attitudes could be influenced by the attitudes of people around them. Participants felt that, as death and dying affect not just an individual but also their family and friends, it was important to consider the attitudes of the people who they might discuss these matters with.

1.3.1 Relatives can act as a barrier to discussion

General public

Many participants said they found it difficult to raise issues relating to their own death, or the death of family members, with loved ones.

“I can’t just; if we’re watching the telly, The Simpsons for example, I can’t just from the blue, say out of the blue about me not being around.”

Male, 30-44, Cambridge

This reluctance stemmed, in part, from a desire not to frighten or upset their families. This attitude was expressed both by parents in relation to their children and by participants in the youngest group (those aged 18-29) who did not want to upset older relatives.

Many participants reported that the degree to which they felt comfortable discussing these issues depended greatly on who they were talking to. Most felt they would rather talk about these topics with their family and friends than with healthcare professionals. However, those participants who were parents in the eldest group (those aged 60 plus) said that sometimes their grown-up children could make conversations about death difficult. There was a perception that people may not wish to discuss plans for the end of life care or death of their own parents because it makes them uncomfortable so, therefore, they avoid it. This was also felt in the middle-age groups (those aged 30-44 and 45-59) where they said they often did not like discussing death and dying with their parents.

“Children [grown-up children] don’t actually like talking; they say they don’t want to talk about it.”

Female, 60 plus, Norfolk
Asian Muslims

The Asian Muslims interviewed did not think their relatives would be reluctant to discuss death and dying, but there was a feeling that it needed to be relevant at the time, i.e. when someone was older or ill. The younger participants, in particular, felt that discussing death and dying was not relevant to them but that they would be happy to discuss it with other relatives who were older.

“If my parents were ill and said ‘make sure this happens’, I would definitely talk to them. I know they talked to their grand-parents because they had to go back home.”

Male, 18, Asian Muslim, Luton

Healthcare professionals

Healthcare professionals also highlighted the potential issues around discussions with relatives. It was mentioned that while a dying or older patient may wish to start discussions around their own death, relatives were often unable to have these conversations as it was upsetting and they did not want to contemplate the death of a loved one.

“So the person themselves may be ready to talk about dying and how they, where they want to be and what they’d like to happen, but I’m not always so sure that the family are, are the close ones [family members] ready to manage that?”

Practice Nurse, Norfolk

Both GPs and practice / district nurses agreed that people were more likely to have general discussions about death and dying with family or friends, rather than healthcare professionals. However, although many people may have contemplated their own death, conversations around death and dying may be very difficult to have as many would not feel comfortable or able to discuss the issues with their family or friends.

This reluctance amongst friends and family highlights the need to encourage relatives to be open to talking about another family member’s death.

1.3.2 The gender divide

Across the groups, participants felt there was a difference between men and women with regards to their attitudes to talking about these issues.
General public

Many participants felt men were particularly resistant to discussions about death. There were fewer men in all the groups and one participant said many of his male friends were unwilling to take part. Throughout discussions, men appeared less comfortable than women discussing emotional issues related to death and dying. They tended to focus on more practical arrangements that could be made, such as drafting wills, making funeral plans.

Healthcare professionals

Practice / district nurses agreed with the general public that men tended to be less forthcoming on matters of death and dying. They felt women were more likely to discuss emotional matters and therefore more likely to talk about the issues related to death and dying. However, GPs did not raise this issue although this could be because the nurses we spoke to were female while the GPs tended to be male. It was hard to separate out what role gender had in their approach.

“I do think women will talk, they’ll talk amongst themselves. Men don’t.”

District Nurse, Peterborough

These indications that men may be less likely than women to discuss death and dying could highlight a need to adopt a tailored approach to encouraging men to talk about the issues.

1.3.3 Death as a personal issue

While potential factors were identified that could influence how comfortable someone is discussing death and dying, it was impossible to know which factors had the strongest influence. These factors could affect people differently, as well as have a varying influence at different times in their lives.

General public

While participants felt relatives can represent a barrier to conversations about death and dying which needed to be addressed, it was also felt that this might not be possible. Some participants felt that certain family members simply would never want to discuss such issues, regardless of the circumstances.

“I know my Dad thinks it’s a horrible thing to talk about. He doesn’t like talking about his Mum, who’s sick.”

Female, 18-29, Watford
Some individuals said they had already tried to express their wishes to relatives and these had provoked negative reactions because their requests were unusual, for example, not wishing to be buried or cremated. Once an initial discussion had gone badly it was even more difficult to embark on subsequent discussions. These individuals then became still more reluctant to state their plans for the end of their life. For one woman, her fear of being in enclosed spaces had resulted in her expressing a desire to be left above ground after death. However, following a strong, negative reaction from both her husband and her children, she no longer felt able to discuss her wishes with them.

“There are people who can actually be left to decompose…that, for me would be my choice. But for my family they’re heartbroken when I say that…Now I think I would be reluctant to talk about other stuff now…because I don’t want to hurt them.”

Female, 45-59, Peterborough

Healthcare professionals

Healthcare professionals agreed with the general public that death and dying were personal matters that differed from person to person. They felt, in their roles, they had to gauge the comfort level of an individual patient with regards to opening a discussion about death and dying. They also added that some patients would never want to discuss the topics, regardless of their situation.

As some people may never be willing to discuss death and dying, this raises obvious difficulties for the NHS as, in this situation, encouraging an individual to plan for their death and ascertaining their wishes becomes exceptionally difficult.
1.4 The many aspects of death and dying

1.4.1 Discussing the time leading up to death

As well as age, gender and relatives affecting peoples’ attitudes towards discussing death and dying, people felt their attitudes differed depending on whether they were discussing the time leading up to death or the time after death.

General public

Although participants were comfortable throughout the discussion, many felt they were more comfortable discussing plans that could be made for after death, e.g. funeral plans and wills, compared to issues related to the time leading up to death, e.g. care preferences at the end of life. Across all the groups, they expressed greater discomfort discussing the time leading up to death and felt this was due to concerns around dying in pain, how they would die and so forth. This was especially true of the older groups (those aged 45 and over) who felt death was moving ever closer. This suggests participants felt they had less control over what would happen in the time leading up to death.

“I don’t think it’s the [prospect of] death, I think it’s the dying [that we’re afraid of].”

Female, 45-59, Peterborough

As has been noted, those in the eldest group (aged 60 or over), in particular, were uncomfortable contemplating the last few years of their life and expressed a high level of concern about the quality of life that they could expect during these years.

Asian Muslims

The Asian Muslims interviewed did not express any greater concern or discomfort regarding issues related to the time leading up to death compared to what would happen after death. They were equally comfortable discussing both issues.

Healthcare professionals

This feeling that people may be less comfortable discussing plans for the time leading up to death compared to the plans for what would happen after death was echoed by the healthcare professionals. Both GPs and practice / district nurses felt people were often less comfortable contemplating the dying process itself because they were afraid of how they will
die, e.g. being in pain. They felt these were understandable concerns. In part, it was felt this could be due to a lack of familiarity with death and the dying process, i.e. lack of experience and lack of open discussion of death and dying across society.

“I suppose people don’t know whether you’re going to die in pain. Is it going to be managed? Are you going to die with family? Are you going to die alone? But I’m sure people worry and I would too about all those different things really.”

Practice Nurse, Peterborough

This discomfort towards discussing the time leading up to death presents a barrier to planning for end of life care. However, this discomfort could be linked to other influences on people’s attitudes such as the cultural factors discussed above. The healthcare professionals felt a lack of familiarity was a key factor behind people’s fear of the dying process and so this could be addressed by raising awareness and encouraging people to talk more openly about death and dying. Further to this, a lack of control may add to this fear of the dying process. Planning for end of life care could be encouraged as a way of increasing control over this process.

1.4.2 Terminal disclosure

Across all the groups, participants discussed their views on the disclosure of a terminal illness.

General public

While it has been seen that participants thought it was harder to discuss matters relating to the time leading up to their death, there was agreement across the groups that participants would want to know if they had a terminal illness. They felt this would give them the opportunity to put plans into place. The exception to this was the eldest group (those aged 60 plus) who were split on the issue.

“If I knew I had a terminal illness….I’d write one of these living wills.”

Female, 45-59, Peterborough

“I know lung cancer, you could live for two years but don’t tell me, that’s how I feel, I don’t want to know.”

Male, 60 plus, Norfolk
Whilst wishing to know if they were terminally ill, participants also stated that such information had to be delivered sensitively and in a way that did not unduly distress the patient.

“A friend of mine is terminal at the moment, she saw a consultant who is not her consultant and came back from the hospital really stressed out, because they said they didn’t inform her nicely.”

Female, 60 plus, Norfolk

Asian Muslims

The Asian Muslims interviewed were divided on the issue of terminal disclosure. Whilst some felt that they would like to have the time to plan their deaths, others questioned the ability of the medical profession to accurately determine how long anyone had left to live. They felt only Allah can know when an individual will die. Those who said they practised their religion regularly tended to feel less comfortable with a terminal prognosis that gave definite timeframes.

Healthcare professionals

There was a general consensus amongst the healthcare professionals that disclosure of a terminal illness should take place and felt, generally, patients would want to know.

However, a few of the healthcare professionals did mention that it does become an issue particularly with regards to younger people. Some nurses mentioned parents’ reluctance to giving their child a terminal diagnosis but said that they felt the patient themselves would often welcome disclosure.

Further to this, there were also experiences of concealing a terminal diagnosis from children within a family. One nurse spoke of a patient who had received a terminal diagnosis years before she died and the children were only told at the end.

“They’re [the teenagers] fairly frank and you’re like well yeah [you are going to die]. But then you’ve got the parents going ‘no don’t tell them that’…everybody shies away from youngsters, but they tend to be the ones that are up front and want to know.”

Practice Nurse, Watford
It was also highlighted that there may be additional issues to consider when delivering a terminal prognosis to patients from different cultures. Healthcare professionals tended to think it was an individual choice and that they would take this into consideration. However, generally they, themselves, felt it was important for people to know so the patient and their families could prepare.

Overall, most participants across both the general public and the healthcare professionals felt it was preferable for a terminal illness to be disclosed to enable people to plan and prepare. However, it was important to healthcare professionals to consider each patient individually before informing them.
Planning for death and dying
Planning for death and dying

This chapter will explore the plans participants had made or plan to make for both what will happen after they die and the time leading up to death. It will examine:

- Awareness of plans for end of life care and what plans participants had made;
- Participant’s views on the importance of such planning;
- What motivations lie behind why people make plans; and
- What prevents people from planning for death and dying.

Summary of key findings:

Why people do not plan for end of life care

- The fact death does not feel relevant is a key reason why many people have not put any plans in place as it feels like it is ‘a long way off’. Participants felt there was no need to plan until death became highly relevant, e.g. in old age.
- Some participants took a fatalistic view, that there was no need to plan as they had no control over their own death.
- Healthcare professionals were concerned with managing expectations to ensure patients were fully aware of the choices.

What encourages people to plan for end of life care

- Raising awareness is vital in order to encourage people to plan. Participants were more aware of plans that could be made for after they die than plans for the time leading up to death. This, in turn, meant they were more likely to have made plans for after their death such as wills or funeral arrangements.
- Experience of the death of a friend or relative was seen as a key trigger for conversations around death and dying. It also prompted people to contemplate what they would or would not like for themselves.
- Having children could also prompt people to plan for what will happen after their death but may not prompt planning for end of life care.
- Avoiding placing a burden on relatives was a key reason as to why people felt it was important to plan for end of life care.
- Many felt it was necessary to start a dialogue about death and dying by providing people with forums to discuss the topics, similar to the groups themselves.
2.1 Awareness of plans for death and dying

Overall, participants had greater awareness of plans that could be made for after one’s death, for example wills and funeral plans. Further to this, they were more likely to have discussed plans for the time after death compared to plans for the time leading up to death. This is in line with findings from the previous chapter which suggested participants felt more comfortable discussing plans for after death compared to plans for the time leading up to death.

2.1.1 Greater awareness of plans for after death

General public

Most participants were aware of plans that can be made for after one’s death such as wills or funeral arrangements. As has been seen in the previous chapter, they also tended to feel fairly comfortable discussing these types of plans.

Familiarity with plans that can be made for end of life care was a lot lower across all the groups compared with plans such as wills or funeral arrangements. Indeed, hardly any participants spontaneously discussed any plans for the time leading up to death and had to be prompted on these issues by moderators. While some had heard of terms such as a ‘Living Will’, they tended not to have a detailed understanding of what it would involve.

“No, I was trying to think of the word, I knew there was something… something like a living will, but I don’t think many people are aware of it.”

Female, 30-44, Peterborough

Whilst awareness of plans regarding end of life care was low, all groups had some, albeit limited, level of understanding of what palliative care is, although this was slightly lower in the youngest group (those aged 18-29).

“I do know for Sue Ryder palliative care they do absolutely everything and anything to accommodate your wishes. And if you want to die at home they’ll put everything in place if they can.”

Female, 30-44, Peterborough

Asian Muslims

Reflecting the findings from the discussion groups with the general public, those Asian Muslims interviewed expressed high levels of familiarity with wills and funeral
arrangements. However, again, in line with the groups, familiarity with the plans that could be made for end of life care was far lower.

“I’m not sure about planning for before you die, there probably are plans but I’ve never thought of it.”
Female, 36, Asian Muslim, Luton

Furthermore, palliative care was rarely mentioned by these participants, potentially indicating lower levels of awareness of the services available.

Healthcare professionals

Familiarity with specific plans for end of life care mirrored that of the general public as it was lower than familiarity with other types of plans, such as wills or funeral arrangements. However, as would be expected from their professional background, the healthcare professionals were more familiar than the general public with the plans that could be made for end of life care.

All were aware that plans could be made but some did not know exactly what these were. Further to this, they expressed concern regarding their lack of knowledge of what exactly could be provided for patients and therefore what plans could be made. Many participants spoke about the Gold Standards Framework⁵ although a few were not aware of what this actually meant for the patient in terms of planning. In particular, some were not aware of how a patient’s plans were translated into action, i.e. how to ensure that a patient received the care they wanted.

“I assume that there’s a bit of paper somewhere round the patient’s neck or by their bed that says ‘this is what I want’.”
GP, Mid Essex

“I think our practice does Gold Standards Framework, although I don’t completely understand what that’s all about.”
Practice Nurse, Watford

⁵ Gold Standards Framework Website http://www.goldstandardsframework.nhs.uk
In line with findings from the general public, healthcare professionals had some awareness of ‘Living Wills’. However, many were not sure exactly what these would cover or what authority they would have.

“The big thing I think is giving information and [letting people know] where to go. I personally don’t even know where to go for a will, living will, I don’t even know where to send them. I tell them to look it up on the internet.”

GP, Peterborough

In addition, GPs and practice / district nurses did not think patients were aware of their options regarding end of life care. They said it was rare for patients to initiate discussions around planning for end of life care.

“Well people aren’t aware at the moment, not enough people are aware of end of life choices.”

GP, Peterborough

This lack of awareness of planning demonstrates a need to increase the public’s knowledge and understanding of the plans that can be made for end of life care. Furthermore, there is a need to clarify, to healthcare professionals, the options that are available for patients, what these entail and where people can go for more information.

“It’d have to be very clear about what they wanted and who we shared it with.”

GP, Mid Essex

2.1.2 Discussing and making plans

General public

Participants were more likely to have discussed their own or a loved one’s wishes for after their death, than they were to have discussed plans for the time leading up to their death. Consequently, wills, funeral arrangements and wishes relating to burials or cremations were the most common topics participants mentioned discussing with their families.

However few participants had actually made plans themselves, with just a few participants in the older groups (those aged 30 and over) saying they had wills. Only one or two had thought about any formal planning for their end of life care.
A small number of participants had talked about where they or their parents would want to die. Most participants said they would prefer to die at home.

“I would rather stay in my own home…I have already told [my children] that they will have to drag me out.”
Male, 60 plus, Norfolk

Asian Muslims

The Asian Muslims interviewed stated that most conversations they had about planning focused heavily on plans for after death, such as funeral arrangements. In particular, many said these discussions focused on whether or not they wanted their bodies to be repatriated to Pakistan.

Nearly all the Asian Muslims we interviewed had made wills, with the exception of two participants who were eighteen years old. Those who had wills said they had put these in place to ensure they were in control of who their estate went to when they died. None had discussed plans for their end of life care. They said they simply had not thought about these issues because they did not feel relevant yet. However, during the course of the interviews, most of the participants felt they would rather die at home than in hospital.

Healthcare professionals

Similarly, most of the healthcare professionals had not made any formal plans for either after their death or their end of life care. However, a few said they had discussed the subject with their friends or family but that these conversations tended to focus on plans for what will happen after their death.

People might say, ‘oh well I want an eco funeral’ and some will say, ‘oh I don’t want to be cremated because it wastes too much energy’. But I think there isn’t a lot of planning, really, apart from, hopefully people will write a will. But beyond that people don’t want to think about it.

Practice Nurse, Watford

GPs and practice / district nurses also felt it was unlikely for people to plan for their end of life care. They evidenced this by drawing on their own experience, stating that very few of their patients had done so.
“Well it’s not common, we’ve got 4,500 odd people [at our practice] and we’ve probably got about 6 people who have written what they want [in end of life care].”

GP, Peterborough

Our findings suggest that people are not inclined to plan with regards to death and dying. In particular, people are less likely to plan for the time leading up to their death, i.e. their end of life care. This could be, in part, due to a lack of awareness of the plans they could put into place, highlighting a need to raise awareness if people are to be encouraged to plan.
2.2 Why don’t people plan?

There were many factors identified behind why people do not plan for death and dying.

2.2.1 Lack of awareness

General public

As discussed in the sections above, there is a lack of awareness and knowledge around planning for end of life care. This presents a key barrier since people do not know what they can do to plan or even that it is possible to plan for end of life care.

However, participants believed it is important to raise awareness of end of life care and the options available, to highlight to people why they might need to make plans.

“I don’t think people realise they might need to plan. Now you’ve said ‘what about planning for how you want to die?’ I’m thinking, well why not? It seems silly that people don’t think about it.”

Female, 18-29, Watford

Healthcare professionals

In line with findings from the general public, GPs and practice / district nurses felt it was important to raise awareness of planning and why it is important to think about this. They thought that increased awareness and knowledge could lead to more patients making plans as they would know what choices and options were available to them.

“So you can, at that point [when someone is closer to death], and say, ‘look, you’re old and infirm what would you like?’ And it would make sense to.”

GP, Peterborough

2.2.2 The issue of relevance

General public

The main reason given for a lack of planning, across all the discussion groups, was that death seemed a long way off and therefore planning for it seemed less relevant.

“I am 65, it is hopefully a long way away, I am not sitting there and worrying myself to death about it. Whatever will happen, what will be will be.”
This perceived lack of relevance (or immediacy), even amongst the older participants, indicates that age is not always a key influencer in making plans for death and dying and that other factors may be more influential. However, as participants discussed hypothetical situations, they did feel there would be ‘an age’ where planning would seem increasingly relevant and necessary. Across all groups this tended to be in an individual’s sixties or seventies, after retirement.

Although most participants in the eldest group (those aged 60 and above) had not made any plans themselves, they felt that older age could be a good time for people to be ‘prompted’ to make plans.

**Asian Muslims**

Most of the Asian Muslims we spoke to also felt that, since death felt a long way off, planning for end of life care is therefore not relevant to them. This was particularly true of the younger participants who felt they would only plan if they were diagnosed with a terminal illness as it would only seem necessary then.

“I wouldn’t think about it unless I knew I was going to die. If I knew my parents were going to die I’d want to know what they want.”

Male, 18, Asian Muslim, Luton

However, when participants discussed planning for end of life care in relation to older relatives they said they would be happy to talk about these plans. They felt it was important to know what a person wanted in the time leading up to their death and to uphold these wishes.

**Healthcare professionals**

In line with findings from the general public, both GPs and practice / district nurses thought people were more likely to feel it was necessary to make plans if they were nearing death, i.e. if they were diagnosed with a terminal illness. They felt it would seem both relevant and necessary for them to plan for their end of life care at this time.

As highlighted in the previous chapter (section 1.2), healthcare professionals felt older people (those in their seventies) were at an age when they are more likely to have thought
about death and dying. They, therefore, felt it was more relevant to target them with regards to encouraging them to plan for their end of life care.

Perceived irrelevance is a key barrier to discussing death and dying as most people, particularly those who are younger, do not identify a need for themselves to plan. This suggests there is a need to consider carefully the timing of any intervention to ensure people engage with it. It also highlights that interventions could help people understand why there might be a need to plan for end of life care.

2.2.3 A fatalistic view

Across the groups, many participants adopted a fatalistic attitude towards death and dying. Since they felt that their death was beyond their control, they could not see a need for planning for end of life care.

**General public**

In particular, participants in the eldest group (those aged 60 and over) tended to be more fatalistic than in the other groups. These participants felt there was little need to plan for the time leading up to their death as they could not control when it would happen. This view was influenced by their experience of the death of friends or family where they might have died suddenly.

“Sometimes you don’t have a choice where you can die because my sister got out of bed and just dropped dead.”

Male, 60 plus, Norfolk

**Asian Muslims**

For some Asian Muslims, there was a lower sense of need to plan for end of life care. Religious beliefs did have some part to play in the views of a few participants who were more fatalistic about their end of life. They said they felt it was the will of Allah and that one could not predict when they would die. Consequently, these individuals felt that there was little point in planning for their death, although they still felt they would discuss their wishes with family and friends.
“I believe only God can know when you will go, I would just want to go on pilgrimage if I could. My family know that.”
Male, 44, Asian Muslim, Luton

Healthcare professionals

To some extent, healthcare professionals also believe that death and dying cannot always be planned for. However, they still felt people needed to be made aware of the choices they can make with regards to death and dying when there is time and opportunity to plan.

Overall this suggests there is a need to highlight the reasons why there is a need to plan, as well as raising awareness of the plans available for end of life care. Further to this, the NHS could demonstrate how people can exert greater control over their end of life care to help challenge this fatalistic view.

2.2.4 Assumption of care

General public

Many participants thought the palliative care that people receive would be of a high standard. This was mainly due to word of mouth or people’s own experiences of relatives who had died, but many could not explain exactly why they thought palliative care would be of a high standard. This could allude to a degree of confidence that participants felt they would be able receive the end of life care they want. This may also be a factor behind a lack of planning, as it indicates an assumption that everyone can receive high quality end of life care as standard. People assume this will be taken care of, automatically, as part of the NHS care they receive.

Healthcare professionals

When presented with the view that some people think there is less necessity to plan as the NHS 'will take care of it', healthcare professionals were concerned that this could mean people not being able to die where or how they want to, due to a lack of preparation.

These findings suggest there is a need to highlight the need to plan to ensure wishes are upheld and people receive the end of life care they want.
2.2.5 Cynicism amongst healthcare professionals

In keeping with the fatalistic view that some participants held, some healthcare professionals believed that any plans made may not be upheld, due to lack of resources within the NHS.

Healthcare professionals

Many GPs and practice / district nurses thought that while it was important to encourage people to plan and prepare, patient’s expectations should not be raised too high that their plans would be unachievable.

“I think it is [important to plan] and I think it’s very difficult to do in advance. I don’t think at the moment there’s the care structure, and some people who might want to die at home might only have one other elderly relative, a spouse or something, and that’s pretty tough on them isn’t it?”

Practice Nurse, Watford

Indeed, there was a certain level of cynicism that not all plans could be upheld.

“It’s almost cruel to give people a choice when there isn’t one. Because for example they say ‘yes you can have a home delivery’ so you plan that and then there are no midwives….I think you’ve got to marry up facilities with demand, because there’s no point creating expectations and not being able to fulfil them.”

Practice Nurse, Watford

However, GPs and practice / district nurses felt it was important to raise awareness of the options available for end of life care amongst the general public to enable them to make decisions and plan. This was tempered by concerns that not all choices would actually be available for patients at the time so there is a need to manage expectations as well.

Nurses, in particular, were concerned about giving patients a choice that could then not be fulfilled due to, for example, a lack of space in hospices. They thought it was important to make healthcare professionals aware of exactly what was on offer to ensure they could advise and help patients plan, while managing their expectations.

“I think the big thing is what choices the patient has and that there are things available to them to make choices. And just empowering and knowing that they can be empowered when and if this were to happen to them, or any main member of their family.”

GP, Norfolk
“I think you have to be really honest about them. You need to make sure that everyone knows what people can expect.”

District Nurse, Peterborough

2.2.6 Fear and superstition

As discussed in the previous chapter, participants expressed a greater fear of the dying process than death itself, (section 1.4), and this is potentially a key reason for a lack of planning. This became clear where participants seemed less comfortable entering into discussions surrounding plans that could be made for end of life care compared with discussions of wills. This distinction between attitudes towards planning for the time after death and planning for the time leading up to death could impact on the design of any intervention aimed at encouraging people to plan.

2.2.7 Relatives not wishing to discuss death and dying with a loved one

As highlighted in the previous chapter (section 1.3), participants felt it could be difficult to raise the topics of death and dying with relatives which presents a barrier to planning. Participants in the eldest group (those aged 60 and over), in particular, felt they could not have serious conversations with their own children about their desires for when they die, due to the reluctance of children to discuss their parents’ deaths.
2.3 What encourages people to plan?

Despite few participants having made wills or any plans for their own death and dying, most felt it was important to do so. This was, in part, because the discussion group itself had highlighted why it was important. For example, the youngest participants (those aged 18-29) were concerned to hear that around sixty percent of people die in hospital.

“When you come to think of yourself, you’re so certain about where you want to be afterwards, actually, are there certain things you don’t want to happen to you when you come to the end.”

Female, 45-59 Peterborough

“I think it’s important now, you want to know you’ll get what you want and if you have to plan to make that happen, you should.”

Female, 18-29, Watford

Healthcare professionals

Both GPs and practice / district nurses thought it was important for people to plan for their end of life care. They felt it would better enable healthcare professionals to provide the necessary care and to do so in a way that is in line with a patient’s own preferences.

Across the groups, there were various reasons behind participants already having discussed certain plans (and in some cases having already put plans into place). Further to this, they mentioned other factors that could help highlight a need for planning and encourage them to discuss the issues. We set out these factors in the following section.

2.3.1 Experience

General public

Across all groups, participants identified the experience of the death of a close one as a prompt for discussions about death and dying.

Participants spoke of ‘light-hearted’ conversations they had had with family members discussing song choices or celebrations they would like at their funerals. As has already
been observed, such conversations were often said to have arisen after participants had attended funerals of friends or relatives which prompted them to express a desire for similar or different plans for themselves.

“My dad talks about the songs he wants at his funeral but just in a jokey sort of way, like it’s not serious so it’s easy to talk about stuff like that.”

Female, 18-29, Watford

Often those who had discussed or made plans had done so as a reaction to their own experience of someone close to them dying. Those in the youngest group (those aged 18-29) tended to refer to the experience of their parents and how this had prompted their parents to initiate conversations with them.

“My dad says he doesn’t want the same thing as his dad, that he wants it to be more fun for everyone.”

Male, 18-29, Watford

In particular, participants in older groups (those aged 45 and over) often referred to their own experiences, or to those of friends and family, as a measure of why it was important to make plans. They often felt their wishes for their end of life care might be different from those that they had seen others experience, and felt it was important for them to plan to ensure that their desires were upheld.

“You need to know what a bad death is though if you can’t explain what a good death is. Because a bad death would be something that actually happened that you had no control of and it really shouldn’t have happened.”

Female, 45-59, Peterborough

This kind of formal planning was discussed in more detail in the older groups (those aged 30 and over) compared to the youngest group. This seemed mainly due to the younger participants being less likely to have experienced the death of someone close to them. Those who felt it was important to have this kind of formal plan in place wanted to ensure their lives were not ‘dragged out’ at the end. They often drew upon their own experience of the death of a friend or relative where they felt life had been prolonged and it was sometimes

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a negative experience. Some felt it was necessary to put plans into place to ensure death was dignified and life not prolonged when they would not wish it to be.

“If that was on a form, you could put that on a form…that you didn’t want to be resuscitated if your life weren’t going to be of any quality.”
Female, 60 plus, Norfolk

“She [my mother] was 100% sedated and I wouldn’t want to be.”
Male, 30-44, Cambridge

Healthcare professionals

In line with findings from the general public, GPs and practice / district nurses thought, often, the importance of end of life planning was highlighted when people experienced the death of a close loved one.

“If they’ve witnessed a friend or a close relative that’s died, they then they feel very strongly that they didn’t like the way they died in hospital or they didn’t like the way they were treated or they didn’t like this or that or the next, they want to make sure that this doesn’t happen to them.”
GP, Norfolk

Healthcare professionals believed this experience can lead to people considering their own end of life care and highlighted the importance of planning.

Both GPs and practice / district nurses tended to link older age to the experience of friends or family dying as a key trigger for discussions to take place. They felt that people draw upon their own experiences to compare what they want for themselves so, if they have experienced the death of a close friend or relative, they may have considered the issues involved when someone dies.

“I think it depends on age…I think probably over 50 most people then have experiences of their contemporaries dying and having illnesses and they actually would think about it and they’ll also have parents who have been elderly and had something to do with it. So that might be a good time. In your 30s, you just don’t want to think about it.”
Practice Nurse, Watford
Overall, the experience of the death of a close friend or relative seems to be central to people considering their own end of life care. This could indicate a potential target audience for any intervention of people who are likely to have experienced the death of a friend or relative. This is often people who are older (middle aged and above).

2.3.2 The influence of parenthood

General public

Participants felt that having children was a key reason for making a will so they could ensure their families will be taken care of in the event of their death. In particular those in the older groups (those aged 30 and above) felt it was important to ensure that their estates will be inherited by their children. These participants also wished to prevent any family arguments after their deaths. Further to this, men, in particular, were keen to make sure their families would be financially secure while the women were also concerned with the emotional well-being of those left behind.

“I want to leave my estate to my daughters. I don’t want anyone jumping in.”

Male, 30-44, Cambridge

Family, and in particular children, were also identified as a key reason for the need to plan for end of life care. Many participants in the older groups (those aged 30 and above) felt it would be easier for their children if they had plans in place as this would prevent them from having to make decisions surrounding their care. These feelings were echoed in the youngest group (those aged 18-29) where participants felt it would be easier for them if their parents had plans.

“It would be good because then we’d know if they wanted this or that and make sure we didn’t do something they would really hate.”

Female, 18-29, Watford

Nevertheless, it is important to note that while most of the participants in the older groups (those aged 30 and above) did have children and thought it was important to plan with them in mind, one female participant stated that her single status placed more of an onus on her to plan. She felt that, as there was no-one to ‘just know’, through informal discussions, what
she wanted, there was a greater need to put plans into place to ensure she received the end of life care she wanted.

“If they were to contact me, I’m very much on my own, so for single people who’ve got no family around, no children, it’s very important really for them to be signposted somewhere.”

Female, 45-59, Peterborough

Asian Muslims

As discussed earlier in this section, many of the Asian Muslims interviewed had put plans into place for after their death, i.e. wills and funeral arrangements. They agreed with those in the discussion groups, that having children had prompted them to think about a time when they might not be around. The main reason for having done so was to ensure their children received their money after they died. This was a particular issue for female participants as they were concerned their estate would go to their husbands, in line with usual cultural practice. For this reason, they felt it was particularly necessary to plan, as they did not want to follow the traditional custom.

“I wrote a will purely in my children’s name. Their dad, if I died before him, would be the guardian of it but he’s got no right to sell or do anything with my property.”

Female, 41, Asian Muslim, Luton

Participants tended to think it was important to ensure their family is aware of what they would like, for example whether they wanted to be repatriated or to be buried in the UK.

Healthcare professionals

Healthcare professionals also identified the importance of end of life planning for relatives, including the children, of a patient. Having children prompted people to ensure they would be taken care of in the event of their death. They often linked this to making a will and thought this could provide an opportune moment to encourage people to plan more widely as well. However, they still felt age was an important factor and that many would still find it irrelevant to think about planning for end of life care at the age at which they have children.

“When you have children that usually prompts you to make a will because you want to make allowances for them and you might think of guardianship and those sorts of things as well as children, in case you die while they’re still under the age of consent or whatever.”
Further to this, both GPs and practice / district nurses felt it was important to plan so relatives would know what a person’s final wishes were.

“You have tales of a 95 year old who is double incontinent, who is blind, riddled with cancer, and the family says, if their heart stops, to jump on their chest, and you think well, is it for them or for the patient?”

GP, Peterborough

This section highlights that having children could be a key point in people’s lives when an intervention to encourage people to plan could be effective. In particular, this could be a key opportunity to encourage people to make wills, as they want to ensure their children will be looked after in the event of their death. Although, some might feel it is irrelevant to plan for their end of life care as they are fairly young, it could still provide an opportunity for raising awareness of the issues and help to generate discussions around end of life care issues.

2.3.3 The sense of burden

General public

As discussed above, family and children are a key factor behind why people felt it was important to plan for end of life care. Further to this, the wish to avoid being a burden was keenly felt across all groups and, in particular, by female participants. This was a key reason why some participants in the eldest group (those aged 60 and above) felt it would be better to die in a hospice or hospital so that their family would not have the ‘burden’ of looking after them. They also tended to feel dying at home was not possible if they did not have family nearby, since they would not have the care they would need.

“They [children] are off doing their own thing, careers and what have you, so it is putting a burden on them, for them to have to look after you in your own home. It is different if you are in residential care or you are in hospital, they can then visit and not feel so bad about it, but it is a bit of a drag if they have got to come and sort you out at home.”

Female, 60 plus, Norfolk

In addition to not wanting to be a burden on family and friends, participants also felt that they did not want to be a drain on resources within the NHS. This was particularly true across
the three older groups (those aged 30 and above). These participants did not want money to be taken away from other NHS services to provide additional end of life care. These participants tended to think that dying in a hospital or hospice would require more NHS resources and that dying at home would mean they were less of a burden on the NHS. It is important to note, this sense of burdening the NHS may have been influenced by the media narrative at the time of fieldwork (June-July 2010) surrounding budget cuts and cost savings for the NHS.

“I don’t want to put too much burden on the NHS doing this that or the other.”

Male, 30-44, Cambridge

Decisions regarding where individuals would prefer to die are complex since some are torn between not wanting to burden their family and not wanting to burden the NHS. This highlights a potential factor that could motivate people to plan for end of life care as it could alleviate this sense of burden but also raise awareness of the issues related to planning for death and dying.

Asian Muslims

This sense of burden was a key issue for all Asian Muslims interviewed. Every participant spoke of a desire not to be a burden to their family and, further to this, many also mentioned the idea of not being a burden on NHS resources. This seemed to be a sticking point for many who felt any plans they would make would need to ensure they did not burden anyone.

“I don’t want to burden my family and make them look after me, especially my children. It’s hard enough to lose someone but to create more fuss than needed is wrong.”

Female, 43, Asian Muslim, Luton

“I think the NHS is wonderful, I don’t want to burden them.”

Male, 44, Asian Muslim, Luton

This contrasts slightly with the general public discussion groups whereby the younger participants (those aged 18-29) tended to focus less on the sense of burden; among the Asian Muslims interviewed even the two youngest participants (aged 18) mentioned this as a key factor. This indicates that, amongst Asian Muslims, alleviating concern around being
a burden could be a key motivational factor in encouraging people to plan for end of life care.

Furthermore, participants highlighted the need to plan to ensure all family and friends could come and visit the dying person before they died. This is an important cultural consideration that could influence a need to plan for end of life care. Many participants felt hospitals or hospices would need to be able to accommodate this and felt they, themselves, would have to plan for this. Indeed, one female participant said that she would rather die in a hospital or hospice so she would not have to cater for large numbers of visitors coming to her house. This indicates that, amongst Asian Muslims, planning for end of life care could also alleviate the burden the person themselves might feel.

“You’d have everyone visiting and they’d expect big nine-course meals. That’s a lot when someone is dying, so it would be easier to go in a hospital or something.”
Female, 36, Asian Muslim, Luton

Healthcare professionals

Reflecting findings from the general public, healthcare professionals also felt that some people are concerned about becoming a burden to relatives at the end of their life. They felt this added to the need to plan to ensure there was full support for their families at the time. GPs and practice /district nurses also spoke about the burden that relatives feel when caring for someone who is dying. Thus they thought it was important to ensure relatives are fully prepared, another key reason to put plans in place.

“They might like to die in their own bed, but only if their family will be supported, because they’re terrified about what their family might see.”
Practice Nurse, Peterborough

Healthcare professionals, particularly GPs, stressed the importance of planning since relatives would not have a final say regarding treatment (unless they have power of attorney). As it is often up to clinicians to make decisions on treatment, they believe that it would help to have some understanding of what a patient wants.

“I don’t think the general public is aware that relatives can’t make decisions. I think people assume that their next of kin can say, ‘well I want this and I want this and I want him to have the flu injection or I don’t’, I think people don’t realise that that’s changed.”
This sense of burden could demonstrate why there is a need to plan for death and dying. Offering people the chance to avoid becoming a burden could encourage people to plan for their end of life care.

2.3.4 The impact of culture for Asian Muslims

As discussed, culture can affect people’s attitudes towards death and dying (see chapter 1). In particular, the Asian Muslims interviewed, made references to their culture as a key influence on their views and behaviours.

For many Asian Muslims, strong cultural influences had made it easier to discuss their parent’s wishes with regards to death, for example discussing whether or not they wanted to be repatriated. They realised the importance of planning for ensuring one’s wishes are met, although the focus was very much on planning for what happens after death. This, in turn, had prompted them to consider how and where they would like to be buried and they had expressed their desires to their siblings, children or partners.

“Both my mum and dad wanted to be flown back to Pakistan, to be buried with their family but I don’t want that. I want to be here so my girls can visit my grave. I’ve told my sisters that and I’ve put it in my will, I want to make sure this is where I am.”

Female, 36, Asian Muslim, Luton

While it was felt that culture, rather than religion, often exerted a stronger influence on people’s wishes for after their deaths, it is important to note that the participants’ culture was also often influenced by their religion. Some of the Asian Muslim participants said that while many Muslims do not strictly follow Islam, they could still be strongly influenced by the Islamic culture that their parents or grand-parents follow. Western culture was also included in this blend of influences, with participants saying that it had affected their views.

“I was born here and all my friends were so I think that influences me. I don’t feel any ties to Pakistan but I know my parents really do.”

Male, 18, Asian Muslim, Luton
However, not all participants were equally susceptible to this variety of influences, with one stating that he felt his faith was the strongest influence over all aspects of his life, and that this would have a significant impact in his approach to planning for death.

“For me, following Islam is the most important thing. So I have to be buried here within 24 hours if that’s where I die, a lot of people here now are flown back to Pakistan but that is not following Islam.”

Male, 44, Asian Muslim, Luton

Some participants mentioned their faith and its role in plans they would make for their own death. The importance of prayer during the end of life was raised, often in relation to older relatives, and it was felt that hospices or hospitals should be able to cater for this whilst also stating they felt it was their own responsibility to ensure this would happen for them.

“They [my parents] would want to be able to pray and so I guess the hospital would have to help with this.”

Male, 18, Asian Muslim, Luton

Still, the focus tended to be on plans for what would happen after death and it was often difficult to focus participants on end of life care issues. This could, in part, be due to strong cultural factors influencing the plans of their parents or generations before them. Many did not want the same as their parents, for example to be buried in Pakistan, and therefore were far more focused on these types of plans as opposed to planning for their own death.

This examination of the influence of culture on Asian Muslims’ attitudes towards planning for end of life care highlights the need for the NHS to consider these differences. It shows the importance of considering the population of the target area for any intervention to ensure it takes into account diverse needs. Further to this, it is important for healthcare professionals to be aware of these influences when treating patients or encouraging them to plan for their end of life care.

2.3.5 Starting a discussion

General public

Many participants felt that the discussion groups themselves had prompted them to think about the issues related to planning for end of life care. They felt the group had
highlighted to them the need for planning and had raised their levels of awareness of the plans they could make.

Participants also felt the format of an open, informal discussion would help people discuss the topics in a non-threatening way and also allow them to consider the options that were available.

“I think it was almost like a counselling session. She [another participant] was saying it was helpful because she can't really talk to her family. It made me think about whether I would want to write down something that I hope would happen at the end.”

Female, 45-59, Peterborough

Further to this, upon reflection, after the discussion group, some participants said they were more likely to make plans for death and dying. When participants spoke to family members and friends after the groups they said they were happy to discuss the issues and many felt taking part in the discussion group had prompted them and their families to begin planning.

“When I told her about the things we talked about my mum started to tell me what she would like for her funeral, like songs and stuff.”

Female, 18-29, Watford

“We spoke about the will and so we’re going to sort that out.”

Male, 30-44, Cambridge

Healthcare professionals

GPs and practice / district nurses also felt that by starting discussions with people about death and dying, people could be encouraged to consider the issues and their options for end of life care. Simply by starting a dialogue people would start to contemplate the topics. This could help raise awareness and therefore potentially increase people’s willingness to plan. Practice / district nurses, in particular, felt more open discussions were vital for both healthcare professionals and the general public to ensure more people planned for their end of life care.

“It’s just sowing the seed isn’t it? After this [interview] I shall probably just go and talk to my husband. It’s just getting people to talk about it.”

Practice Nurse, Norfolk
Encouraging open discussion of the topics related to death and dying and potentially providing a forum for such a discussion, could help encourage people to plan for their end of life care.
Sources of information
Sources of information

This chapter will explore who participants felt they would be likely to discuss matters relating to death and dying with. It will examine:

- The role of friends and family in discussions around death and dying; and
- The role of healthcare professionals in discussions around death and dying.

Summary of key findings:
- Overall, participants felt there was a clear distinction between the role of the healthcare professionals and the role of friends and family in planning for death and dying.
- Family and friends were seen as the first port of call for discussions around death and dying. Many felt these conversations would be sufficient to ensure they received the end of life care they wanted.
- There is a need to raise awareness of the importance of formal planning to ensure people’s wishes are upheld.
- Healthcare professionals felt they were best placed to discuss formal planning when death became highly relevant to their patients, i.e. if they were terminally ill.

3.1 Role of friends and families

General public

Conversations with family members were often mentioned as the most common method of planning for end of life care; these conversations are used to ensure awareness of individuals’ wishes and to entrust family members with upholding them.

When discussing who to go to in order to discuss their end of life care, most felt friends and family would be their first port of call. Discussions with friends and relatives were felt to be sufficient to ensure their wishes were upheld and this was reflected in the fact the plans people had made were usually informal.

“I think maybe the closest person in your family.”

Female, 30-44, Cambridge
Participants felt they would not go to healthcare professionals in the first instance. This was in part because they felt plans for end of life care are highly individual and liable to change and so many were reluctant to formalise these until they were closer to death, e.g. if they were diagnosed with a terminal illness.

“You could go to your GP but that would feel quite serious, it would be easier to talk to your family and tell them what you want.”
Female, 18-29, Watford

Asian Muslims

Reflecting findings from the general public discussion groups, Asian Muslims also said they felt it was more appropriate to discuss end of life care planning with family and friends. In line with the plans they discussed regarding funeral arrangements and so forth, they felt they could tell their family what their wishes would be for end of life care and that these would be upheld.

“I’d tell my family like I have that I don’t want to go back to Pakistan.”
Female, 36, Asian Muslim, Luton

Healthcare professionals

Both GPs and practice / district nurses felt that people would be most likely to discuss plans for death and dying with family and friends. Further to this, they felt their role was more concentrated on those for whom end of life care was more relevant, i.e. older people or those with a terminal illness. While they believe that, initially, conversations would take place with family and friends, they did think it was important for these plans to be more formally discussed and agreed with healthcare professionals when end of life care is anticipated.

It was felt, across all the groups, that family and friends provide a first port of call for discussions around death and dying and an initial planning stage. Many felt these conversations would be enough to ensure they received the care they wanted at the end of their life. However, healthcare professionals thought it was important to also make some formal plans to ensure their wishes were upheld.
3.2 Role of healthcare professionals

General public

Participants tended to think it would become more important to discuss their end of life care plans with healthcare professionals if they were seriously or terminally ill. In particular, when it was highlighted that while between sixty and seventy percent of people would rather die at home, around sixty percent die in hospital, participants felt it would be necessary to share their wishes for end of life care with healthcare professionals. They also felt that they would find it easier to make clear plans for their end of life care if they were terminally ill and would feel more comfortable formalising them at that point.

“I think I’d want that, I’d want kind of notes about the discussion, but I don’t think at that point [when I knew I was going to die] until I really had kind of, made up my mind, I wouldn’t want anybody else to have it.”

Female, 45-59, Peterborough

This suggests people do not feel the need to put formal plans into place until they believe it is appropriate and necessary, for instance if terminally ill. However, there is still a need to raise awareness of the importance of planning for end of life care to encourage people to discuss the matter with their family and friends. Encouraging people to have these initial informal discussions could make it easier for people to put formal plans into place when they feel it is necessary.

Asian Muslims

Again, in line with the findings from the general public, participants tended to feel it was only necessary to go to a healthcare professional to discuss end of life care once they have been diagnosed with a terminal illness. In this case, they would expect their GP or consultant to raise the issues with them and invite them to discuss plans with them. Participants wanted medical professionals to be suitably trained and initiate conversations regarding end of life care in a friendly and compassionate way.

“If I was told there’s nothing more they can do, then I suppose they’d ask me what I wanted.”

Male, 18, Asian Muslim, Luton

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Healthcare professionals

Healthcare professionals agreed with the general public in thinking their role in helping people to plan for end of life care was more relevant for older people or those with a serious or terminal illness. GPs and practice / district nurses tended to think they were not best placed to initiate conversations around death and dying with young or healthy patients, since it may feel inappropriate to raise the matter.

“It wouldn’t be right for me to talk to a 30 year old patient with no health issues who came in for whatever. I’m not the right person to speak to at that point.”

GP, Watford

GPs and practice / district nurses tended to think they were only likely to have discussions about death and dying with patients who were seriously ill or elderly. They felt it was likely these patients would be planning their end of life care because they are referred to the Gold Standards Framework or to Macmillan services.

“I think the trouble with planning is it needs to come at the right time, and that’s inevitably going to be closer to the death.”

Practice Nurse, Watford

“Put them [patients] on the gold standards list and you have to think, ‘do you think this person’s got six months to live?’ and I’d say, ‘well maybe, that’s why I put them on the list’ and they’ll say, ‘well let’s discuss it more’.”

GP Mid Essex

Referrals to Macmillan and use of the Gold Standards Framework then enable discussions to take place and plans to be drawn up for end of life care. However, it was felt that there could be disparities across different areas or GP practices as to the levels of planning that were carried out. This means not all patients identified as terminally ill will have the same access to means for making plans. Practice / district nurses, in particular, felt this was an issue that needs to be addressed to ensure that all patients can make plans to receive the end of life care they want.

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9 Macmillan Website, www.macmillan.org.uk
10 See above
“The trouble is you don’t get the doctors necessarily engaging with them [the Gold Standards Framework]. Some practices are brilliant and they take up actually case histories, and if they had a patient that died they’d ask how did they [everyone medically involved] all feel about it and it was brilliant.”

District Nurse, Peterborough

While the healthcare professionals felt they had a key role to play in helping patients plan when they were ill, they did not always feel they were fully able to carry out this role. They identified a lack of awareness of some options that are available or with regards to what these plans involve and how to make them.

Further to this they felt a lack of communication between different healthcare services sometimes hindered their being able to encourage a patient to plan for end of life care. This was particularly relevant with regards to the diagnosis of a terminal illness where GPs felt it was vital for them to know as soon as this occurred to enable them to provide relevant care for their patient. However, they also argued that it was the role of the specialist to make the initial referral to palliative care services for planning to take place. In addition to this, GPs felt that patients were not always made fully aware, by the specialist, that their diagnosis was terminal and this left them in a difficult position to discuss plans for end of life care.

“I think the right person to start the conversation initially is for example the oncology consultant, they are the most appropriate people, because they have a rough idea how long they have got [left to live]. So if they have given a little bit of initiation, if they want to discuss further, then they can approach GPs or the practices, or whoever appropriate.”

GP, Mid Essex

Overall the GPs and practice / district nurses felt they, and other healthcare professionals, were in a good position to discuss end of life care plans but only once it was appropriate to the patient i.e. when patients were older or terminally ill.
Overall, participants, including the GPs and practice / district nurses themselves, felt the role of healthcare professionals was to help people put formal plans in place for their end of life care. However, none of the participants thought this was necessary until patients were either elderly or terminally ill. The healthcare professionals believed that they needed help to be able to do this, in terms of clarifying end of life care plans that could be put in place and how they would go about broaching the subject with patients.
Barriers and triggers for planning
Barriers and triggers for planning

In the preceding chapters we have discussed how people approach the subject of death, their willingness to discuss it and how aware they are of the plans that can be made around end of life care. Throughout the report so far we have touched on some of the barriers which prevent individuals from discussing these matters, as well as some of the enablers or trigger points which act to spur someone on to taking action.

In this section we summarise the key barriers before going on to outline how they might be addressed in the following chapter. Furthermore, we discuss the prompts, trigger points and motives for planning and how these might be utilised to encourage people to discuss these issues and make plans. We present the barriers and triggers here explicitly both for ease of reference, and because it is fundamental to understand them in order to enable behaviour change.

In this section we bring together the key findings from the quantitative postal survey, qualitative fieldwork and reference findings from the scoping study. If this section is being read in isolation, we strongly recommend referring back to the chapters in the respective reports explaining the methodology in order to fully understand the background, context and limitations of the research.

Summary of findings

- Generally, there is a lack of knowledge around what plans people can make, beyond the most simple, such as funeral preferences and making a will.
- There is also a lack of knowledge of why they might need to make any plans, particularly those relating to the care received at the end of someone’s life.
- Lack of information can also be an issue for healthcare professionals and consistency of information can differ from practice to practice.
- Perceived irrelevance is a key issue as people are unlikely to plan if they do not think there is a need.
- Plans relating to end of life are considered more difficult to make as they are often perceived to be made ‘out of context’ and are likely to change.
- There is a general view that death remains a taboo subject within society and is more hidden than in the past, particularly from the young.
- Cost can be a barrier preventing people carrying out financial aspects of end of life planning, like funeral wishes and wills.
• There is a **fatalistic view** held by some, that planning is futile as the NHS will not necessarily be able to deliver everyone’s preferences.

• **Relatives can be reluctant to discuss** plans with a close one as they do not want to consider a family member dying. Further to this, relatives sometimes prevent plans from being followed if they are not properly informed or do not support them.

• Having children, experience of the death of a close one, retirement, making a will, taking out life insurance and the discussion groups themselves, are all seen as triggers for initiating planning for end of life care. **Experience is particularly relevant**; those who have experienced the death of a loved one in the last five years are more likely to have discussed issues around end of life.
4.1 What are the key barriers?

4.1.1 Lack of awareness or information

Generally, there is a lack of knowledge of what plans people can make, beyond the most simple, such as funeral preferences and making a will. There is some limited knowledge of living wills, but this is predominantly based on previous experience with friends or family members who have considered them.

Generally, all the healthcare professionals felt it was important to raise awareness of the plans that could be made and why it was important to do so. They felt that if this was aimed at everyone, and not just those closer to the end of their lives, it may help build a baseline level of knowledge which could be called on later in life. This could, therefore, possibly lead to more patients making plans when death is felt to be more relevant, as they would already know what choices they could make.

“So you can at that point introduce it and say, look, when you’re old and infirm what would you like?  And it makes sense to, if you can, introduce that whilst they’re still compos mentis.”

GP, Peterborough

It is also important to note that ‘end of life care’ may be a more familiar term for some people than ‘palliative care’. Some healthcare professionals said they have come across people who did not understand the term ‘palliative’. This is worth taking into account when producing materials about these services, which might be read by people who are not familiar with the term.

4.1.2 Awareness of why one should make plans

Furthermore, as well as a lack of knowledge of the types of plans that one can make, participants are often unaware of why they might need to make any plans, particularly those relating to the care received at the end of someone’s life.

When it was explained that, currently, the majority of individuals would prefer to die at home but the majority actually die in hospital, this often strengthened participants’ appreciation of the need to plan. Once presented with these statistics, participants identified this lack of awareness as a key issue preventing people from planning.
“I don’t think people realise that you actually need to do it [plan]. Until I came here, I didn’t think about it but now you’ve said what about planning for how you want to die, I’m thinking, well why not? It seems silly that people don’t think about it.”

Female, 18-29, Watford

Participants in the discussion groups who went on to speak to their friends and family afterwards felt this was a key issue arising in the conversations. They found people were aware of plans such as wills but, while friends and family thought there might be a way to plan for end of life care, they were not at all sure how. Again, many drew on past experiences of relatives who had died and then reflected on what their wishes would be in comparison with that situation. It was felt that, in discussing these issues with people close to them, the conversations themselves helped to raise people’s awareness.

“It isn’t the kind of thing you talk about until you find yourself ill really and then I think the pathway that you follow is determined by your illness. People are not aware they’ve got choices”

Female, 45-59, Peterborough

4.1.3 Awareness of who to initiate these conversations with

There are a minority of people who are unaware of how they could instigate the process of making plans to ensure their wishes are upheld. In some cases this is due to not knowing who they can have the initial conversation with. This is particularly true for those who have not considered these matters before and who do not have close family with whom to discuss it. From both the qualitative discussion groups and the postal survey, it was clear that the majority of people would prefer to discuss issues of end of life care with their friends and family in the first instance. Just over half (54%) said they would prefer to get information on end of life care from a friend or family member.

While the postal survey found that just under half of people (47%) would want information on planning for end of life care from their GP, this was challenged in the qualitative discussion groups. Once considered in detail, many thought their GP would not necessarily have the people skills, time, or inclination to do this. Both healthcare professionals and patients also thought that, unless prompted by the patient or a terminal diagnosis, a visit to a GP surgery would be an inappropriate moment to provide this information. Who people should go to for information, and to initiate these discussions, is not always clear.
The lack of information on how to initiate plans, and with whom, is reflected in the findings of the quantitative survey and is not restricted to the healthcare aspects; around one in three people are not confident that they could plan for their end of life either financially (31% are not very or not at all confident) or for the care and support they may need (36%). Those who are the only adult living in the house are less likely to have discussed end of life wishes. Of single-adult households who have not discussed any end of life wishes, 12% say this is because there is no one for them to discuss it with (compared to 5% overall).

This lack of information was also reflected by participants in the discussion groups.

*I'm single. I have no children…I have no family here. So, strictly, this is something that I ought to be dealing with because if I just pop my clogs next week…*  
*Having sort of been here tonight, it's made me aware that I need to do… I mean I have recently thought about having to make a will, which I should have done, but tonight's made me realise that I know very, very little.*

Female, 45-59, Peterborough

Furthermore, the postal survey found that, while the majority (81%) of people aged 75 and over had written a will, less than half (48%) had planned their funeral and only 14% had planned how they would support themselves financially while they are dying. This raises the question of why so few have thought about financing the period towards the end of their lives. This may be due to a lack of information on how to start the process or there may be an expectation that their care will be provided by the NHS.

### 4.1.4 Information on the process of dying

Healthcare professionals highlighted that it is important to raise awareness around what happens when people die in order to ensure that patients and relatives are better prepared. Practice / district nurses and GPs were clear that, while an individual could put plans into place, it is vital their families are aware and confident enough to see them through. It was also considered crucial that healthcare professionals provide support to ensure a patient’s wishes are fulfilled.

*"If that family felt that they could call on somebody and they felt supported, that was fine. What happens if he does this during the night? What happens if this happens? It's fine, do this, do this. Don't worry."*  
Practice Nurse, Peterborough
Furthermore, it is thought that, if relatives are empowered with greater knowledge about the
dying process, it would help avoid situations where the family actually prevent end of life
plans from being followed. One example given was of relatives calling an ambulance
unnecessarily if they have insufficient information about the process of dying or did not have
someone to contact. In this scenario a patient who has indicated a preference to die at home
would be taken to hospital if the ambulance was called.

“Even if you do put that on [preference to die at home] and someone calls an ambulance
that’s a big hassle... And then that’s really upsetting because the healthcare professionals
feel that they haven’t fulfilled that.”

Practice Nurse, Watford

4.1.5 Lack of information for healthcare professionals

It is also important to note that a lack of awareness was also an issue for healthcare
professionals; one GP admitted that, if they were asked for information on producing a living
will, they would not know where to direct someone and would advise they search for this
information on the internet. In this particular case, the GP was part of a large practice with
over 16,000 patients and she reflected during the depth interview that she needed to meet
with the palliative care lead to find out what information they provide on the subject.

This raises the question of whether the information provided to patients – both from practice
to practice and also within a practice - is consistent. One GP described an end of life pack
that they provide to palliative patients which gives information on palliative services and
where to go for more information. It was also designed to be used to inform out of hours
services of the patient’s preferences. The ultimate aim of the booklet was to ensure that
information provision is consistent for all patients – both from primary care provider to patient
and vice versa.

The qualitative research found that practice / district nurses are widely seen as a better
conduit of information than GPs, due to their role as a care-giver. It is also felt they would
have more time to discuss these issues. It may, therefore, be important to ensure district and
practice nurses are well informed of the choices people can make and how to go about
instigating them.
4.2 Irrelevance

4.2.1 Too far off

The vast majority of participants in the discussion groups agreed there is a need to make plans for end of life care. However, many (and not just the young) do not believe there is an urgent need to do so. Many participants felt death was a long way off and, therefore, discussions about their wishes were not (yet) perceived to be relevant to them.

“I'd think about my grand-parents and maybe my parents but for me? I think it's too far away to start thinking about it in a really serious way.”

Male, 18-29, Watford

While more prevalent among the young, this view was nevertheless true across all the groups, regardless of age or gender. Participants of a more advanced age also gave this as a reason for not discussing their wishes or making plans.

As in the discussion groups, when participants spoke to other family members, age continued to be an important factor. Participants who spoke to relatives across different generations found that it was more relevant for people of an older age. Participants also reflected on their own situations through the conversations and identified times when it would feel more relevant and they would be more likely to plan.

“Maybe then [when I’m 70] I’ll reflect that my life is now limited and I’ll have grandchildren by then, that’s when I think I’ll be more open”

Male, 30-44, Cambridge

4.2.2 Out of context

As well as being the most well known plans that one can make, those which are related to the time after death - wills and funerals - are considered easier to make than plans leading up to one’s death. The latter involve areas which are thought to be likely to change, difficult to predict until the situation arises, and very much related to the particular condition or illness that someone has. Similarly, some considered there to be too many ‘what ifs’ for them to make a living will (a view echoed by some healthcare professionals). People therefore take a fatalistic view and do not plan because they do not think it will make a difference.

Moreover, some believe they will be taken care of by the NHS and so do not need to plan.
4.2.3 Timing of interventions

The qualitative research identified that, for some, when death feels a lot closer, for example if someone has been given a terminal prognosis, they may feel less comfortable discussing death. This can be due to their own discomfort in acknowledging their mortality, but can also be because those around them feel uncomfortable discussing plans with them. This means it may be vital to capitalise on the period in which death seems irrelevant, as it could mean people are more comfortable discussing plans for end of life care while death still feels a long way off. This would help to prime people for the time when these more difficult conversations do take place.

This places a great emphasis on the timing of any intervention; it must encourage people at a time when they feel comfortable discussing their plans but must also be timed so that death does not feel so far off that irrelevance becomes an impenetrable barrier. This highlights the difficulty of timing any intervention in this area.

Both GPs and practice / district nurses also identified a perceived irrelevance as the most common barrier. Moreover, they also felt this was a key barrier preventing them from bringing up the issue of end of life care or encouraging people to plan. GPs and nurses did not think they had a role to play - in providing this information or encouraging people to plan - until either prompted by a patient or until death became more relevant to them. Understandably, healthcare professionals need to use a consistent definition of what is meant by end of life and, to avoid uncertainty, use a terminal diagnosis as this indicator.

“I think it’s quite hard, but I think when, the ideal time is when they do have a terminal illness, when they are diagnosed.”

Practice Nurse, Watford

In this sense, most healthcare professionals felt that bringing up end of life care if the patient did not have a terminal diagnosis would be considered out of context. It is also often seen as conflicting with their role as someone there to cure illness and improve health.

Furthermore, if there is a lack of clarity in the trajectory of the patient’s condition (i.e. it is not clear how long they have left to live) it is more difficult to facilitate end of life care conversations. Unless it is known that the patient has less than six months to live, they cannot be placed on the Gold Standards Framework. In these circumstances, GPs expressed a fear of mentioning end of life services too early.
4.3 Influence of family members/societal taboo

4.3.1 Reluctance of other family members

Across all the of the discussion groups, participants identified that it can sometimes be hard to discuss issues related to end of life care because the friends or family members who they want to talk to are reluctant to do so. People mentioned family members complaining of them being overly morbid for bringing up these issues. In particular, those in the older group found that when they tried to initiate discussions with their children, they were dismissed.

“No I just haven’t spoken about it, they think I am going to live forever I think at the moment. But children don’t actually like talking, they say they don’t want to talk about it.”
Female, 60+, Norfolk

This indicates why it is important that not just those closer to the end of their lives should be made aware of the plans that one can make and why it is important to plan. People who find talking about death uncomfortable and who do not feel it is relevant to them can sometimes hinder the ability of those around them to plan.

Healthcare professionals reiterate this view, explaining that relatives can hinder discussions, particularly if it involves explaining what is happening to young children.

Those who were able to follow up the group discussion by broaching it with their family did, however, feel that humour helped them to open the conversations. In this way it was mentioned as a way to, over time, lead on to more serious aspects of end of life care.

“My parents made jokes about what they’d like so it was hard to get them to actually think about it because they thought I was being really morbid. But even though they were joking I still got an idea of what they want and I reckon if it was more real then they’d be more serious.”
Female, 18-29, Watford

4.3.2 Societal taboo

A common view through the qualitative research, with both the general public and healthcare professionals, was that death is far more ‘hidden’ today than it used to be. The movement away from living in close proximity with three generations of the family is seen as preventing young people from experiencing death.
The results of the quantitative survey suggest, to an extent, that this is true and that, although children might experience death, they are not necessarily exposed to some aspects of it, such as contact with the body. While the likelihood of experiencing the death of someone close in the previous five years does not differ significantly by age, people of an older generation are far more likely to have seen a dead body. Less than half (46%) of those aged between 25 and 34 say they have seen a dead person, compared to 90% of people aged 55 or over.

The quantitative survey also indicates that a sizeable proportion choose to protect children from some aspects of death; just under a quarter (23%) do not agree it is suitable for children under the age of 12 to attend funerals. Furthermore, people who are more uncomfortable with discussing death are less likely to agree that children should attend funerals. It is possible that this perpetuates the taboo around death and reinforces the view that it is something to be kept from children.

### 4.3.3 Fear

As has already been mentioned, it is likely that there will have been a certain level of self-selection bias in the sample involved in this research. Whilst the majority of participants in the group discussions were relatively comfortable discussing death and end of life care, they acknowledged that many people they know are not. Fear of dying was felt to be an important reason why some people do not want to talk about it and therefore would not make plans.

“I think people are just frightened to talk about the inevitable.”

Female, 45-59, Peterborough

However, it was felt that a lot of fear is around the unknown aspects of the dying process, for example whether it will be painful. Clearly this is a difficult barrier to address, but participants thought that raising awareness of what happens when someone dies would help. This is potentially quite a divisive subject, as many will just not want to know, and this would need to be treated sensitively.

Interestingly, most of the participants who took part in the post task and spoke to other people after the group said the people they spoke to were happy to talk about these topics. In most cases, they found the participants’ experiences of the groups interesting. This could suggest that having a prompt to discuss the issues related to death and dying, without it
being related to a personal agenda, can help to overcome this barrier. The setting that these conversations took place in might also be relevant; broaching these subjects among friends in a relaxed atmosphere may help encourage people to open up more than if they were with healthcare professionals or family members.

However, it was still felt by some that relatives or friends would be fearful of the loss of a loved one and so may still be reluctant to discuss the issues in relation to personal wishes, unless there was a strong need to do so.

“Talking about it with family is different because nobody wants anybody in the family to die so while you’re well it doesn’t seem right that you’re talking about it”

Female, 45-59, Peterborough

4.3.4 Hope

Both the discussion groups with the general public and healthcare professionals found that, when someone is either old or very ill, hope often prevents them from thinking about end of life care. GPs and practice / district nurses gave examples of family members instructing them not to use the words ‘dying’ or ‘death’, or to discuss that prospect with their loved one as they did not want them to give up hope. In these cases, healthcare professionals can find it difficult to reconcile the duty to be honest with a patient with their role as a care-giver.

4.3.5 Cost

Discussions with some practice / district nurses and GPs highlighted the financial costs of preparing end of life care preferences as a barrier. It is felt that, for some, the cost of preparing a will or planning their funeral prevents them from taking action. This is particularly pertinent for those on low incomes and who already find it uncomfortable to think about end of life care. In this way, the financial cost to them is the ‘competition’ they face to making plans — there are many other, perhaps more enjoyable, things the money could be spent on.

This may also be a factor for more elderly people on a low income. The postal survey found that 81% of people aged 75 and over had written a will, less than half (48%) had planned their funeral and only 14% had planned how they would support themselves financially while they are dying. It may be that is because they do not know how to go about making these plans but it could also be because they cannot afford to.
4.4 Triggers

Findings from general public

Throughout earlier chapters of this report, certain ‘triggers’ have been identified as potential motivational factors that can help encourage or prompt people to plan for their end of life care. This section will now examine if they could be utilised in interventions.

4.4.1 Having children

Many of the participants stated that having children was a key reason for planning, both for what will happen after death, and for what will happen in the time leading up to death. Participants who had made a will said they had done so to ensure that their estate will be passed onto their children.

“I said well my kids are going to get it or my wife is going to get it. That kind of...moved me and I want to write my will now.”

Male, 30-49, Cambridge

This view was also echoed by the healthcare professionals.

“When you have children that usually prompts you to make a will because you want to make allowances for them, and you might think of guardianship and those sorts of things as well for children, in case you die while they’re still under the age of consent or whatever.”

GP, Peterborough

Having children could be a key point in people’s lives when an intervention to encourage people to plan would be effective, as they are already thinking about their future. However, the quantitative survey showed that people living with children under the age of 17 were less likely than average to have written a will (31% compared to 43% overall) or made plans about their funeral (17% compared to 27% overall). This might be because it seems irrelevant to them to plan for their end of life care as they are likely to be fairly young. Despite this, it could still provide an opportunity for raising awareness of the issues and help to generate increased comfort around end of life care issues. Moreover, it could help encourage people to more openly discuss it within their family, if the emphasis is on helping other members of one’s family.
4.4.2 Experience of the death of a close one

Across all the groups, participants identified the experience of the death of a family member or close friend as a key prompt for discussions about death and dying. Further to this, participants in the older groups also used the experience of the death of relatives or friends as a reference point for their own preferences. This experience, it seems, is a key driver prompting people to start to think about their own mortality and end of life preferences.

“My experience of it was when my mum had senile dementia and then you sort of have to face it and it makes you realise that you may need the care as well.”

Female, 45-59, Peterborough

“I think probably over 50 most people then have had experiences of their contemporaries dying and having illnesses and they actually would think about it, and they’ll also have parents who have been elderly and had something to do with it. So I think that’s quite a good time, but I don’t think when you’re in your 30s or whatever it’s going to, you don’t want to think about that”

Practice Nurse, Watford

This is borne out in the quantitative survey; those who have experienced the death of a loved one in the last five years are more likely to have discussed issues around end of life care (dignity, preferred location of death, privacy/peace, and medical and nursing care) and also to have written a will and recorded their end of life preferences.

While experience has a very direct impact in this way, it could be extremely difficult to utilise in terms of developing any intervention; identifying these individuals would be very difficult and there is a clear ethical dilemma if approaching or targeting them. It may, however, raise the question of whether the NHS can work with the funeral sector to ensure that people who have been recently bereaved have the necessary information and support to discuss their own end of life preferences if they wish to do so.

4.4.3 Retirement

Across the discussion groups, participants felt there would be ‘an age’ when planning for end of life care might have greater relevance for them. This was often felt to be around retirement age, i.e. the sixties. Indeed, participants felt retirement could be a key opportunity for the NHS to target members of the public and raise awareness of the plans they could make.
“Retirement could be a good point. In your final wage packet, some health information.”

Female, 45-59, Peterborough

However, it is worth noting that there are still people in their 60s and 70s who say they feel that death is a long way off. There are also questions of how all people reaching retirement age would be approached.

When brought up in the discussion groups, the suggestion of automatic letters to everyone of retirement age, prompting them to consider end of life care, produced very polarised responses. On the one hand it was thought to be a very good idea as it could be presented as a general initiative aimed at everyone, rather than singling out individuals. This was considered a positive factor as it would help normalise the process and minimise the risk that people think they had been approached for a reason related to their health.

Conversely, there were also concerns that such a letter would cause too much confusion and worry, as well as concerns that it sends the wrong message to people.

4.4.4 Making a will or taking out life insurance

Some participants mentioned that making a will or taking out life insurance could be a prompt for people to consider other plans relating to end of life. In making a will they felt people have already acknowledged their mortality and expressed a willingness to plan.

“I think the only pathway for me would be say if I was writing my will and somebody offered me that plan that might seem reasonable.”

Female, 30-44, Cambridge

This could be explored as a potential avenue of joint working with the financial and insurance industries to encourage people to put additional plans into place beyond a will.

While many participants said they only made a will once they had children, this was not always the case. This trigger could therefore be relevant to a wider audience than just those who have children. However, this may not be relevant to many who are unlikely to have made a will, potentially because they do not have children, they are younger or feel they have few possessions to pass on. Further triggers would need to be explored to ensure a wider audience could be reached.
4.4.5 The discussion groups

Many participants mentioned that the groups themselves had prompted them to think about the issues related to planning for end of life care. They felt that the group had highlighted to them the need for planning and had raised their levels of awareness of the plans they could make.

This form of open discussion could be utilised to encourage people to discuss and then plan. The informal nature allowed participants to discuss the topics in a less serious way but also allowed them to think about the options that were available to them. Hosting opportunities for discussions within communities could be a way of encouraging people to think about the issues related to end of life care.

“I think it was almost like a counselling session. She [another participant] was saying she found it quite helpful because she can’t really talk to her family. It made me think about whether I would want to write down something that I hope would happen at the end”

Female, 45-59, Peterborough

“People give you examples of their own life experiences and it affects you somehow. Remember, I told you I don’t have a will… well you tend to think about that now.”

Male, 30-44, Cambridge

Further to this, upon reflection after the group and talking to friends or family afterwards, some participants felt they were now more likely to make plans. The group raised their awareness and highlighted why it was important.

“I hadn’t thought about my funeral at all, it seems such a long way off, so I really ought to think about it a bit… It’s never cropped up because I don’t feel old enough but obviously, at my age, I suppose I ought to think about it”

Female, 60+, Norfolk

GPs and practice / district nurses generally agreed that, by starting discussions about death and dying, people could be encouraged to talk about the issues. Simply by starting a dialogue, such as in the discussion groups, people would start to contemplate the topics. This would raise awareness and could, in turn, lead to a greater willingness to plan. Indeed, the nurses in particular felt more open discussions were vital for both healthcare professionals and the general public to ensure that more people planned for their end of life care.
“It's just that sowing the seed isn't it? After this I shall probably just go and talk to my husband. It is just getting people to talk about it.”

Practice Nurse, Norfolk

Information provided at locations such as libraries was suggested by some participants and healthcare professionals. This would allow people to find out about some of the issues surrounding end of life care, and also to engage in discussions about planning.
Recommendations for interventions
Recommendations for interventions

The remit of this research was to provide insight to feed into the development of social marketing interventions. The following chapter therefore presents our recommendations, both for interventions and also key considerations to be borne in mind when developing interventions. It explores some ways in which the barriers, discussed in the previous chapter, may begin to be addressed. This is based on the insight from the scoping study, the quantitative survey and qualitative fieldwork.

We discuss the strengths and weaknesses of each as well as the challenges of implementing them. In addition, we outline how some of the key themes and findings from this research should be considered in the context of any future information or communications around end of life services.

It is likely that some people reading this report may not be familiar with the idea of social marketing. Therefore, before discussing the implications for social marketing interventions, we give a brief summary of what social marketing is. We also set out why research is vital to influencing and directing any social marketing interventions.

5.1 What is social marketing?

Health-related social marketing is “the systematic application of marketing, alongside other concepts and techniques, to achieve specific behavioural goals, to improve health and to reduce inequalities.” In the case of this research, the overall aim is to make it easier for people to discuss end of life matters, with the behavioural goal being to make plans for their end of life.

The National Social Marketing Centre’s ‘customer triangle’, illustrated in the following diagram, represents the approach we take to social marketing.

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Essentially, this places the research subjects at the centre of the process and aims to understand their behaviour and what influences it. Social marketing insight research is based on the assumption that the research target groups are the experts, and our recommendations are based on their insight, views and perspectives. The key principles of social marketing insight research are:

- **Customer or consumer orientation**: the research is based on understanding (a) where residents of the East of England (and GPs and practice/district nurses) are starting from in terms of their knowledge, attitudes and beliefs relating to death and dying, as well as (b) the social context in which they live and work.

- **Behaviour and behavioural goals**: we aim to understand existing behaviour in relation to end of life planning, and key influences upon it, so we can identify what defined goals are achievable.

- **Audience segmentation**: We aim to understand how people can be divided up in relation to these issues, in order to inform the design and implementation of interventions and to better target them.

- **‘Exchange’**: We explore the process of exchange i.e. what is being expected of people and the real cost to them, to uncover what is likely to encourage the desired behaviour.
‘Competition’: We undertake competition analysis, i.e. understanding the factors that impact on people and that compete for their attention and time. These may act as barriers which prevent someone from, for example, making plans for their end of life.

5.2 The role of research in social marketing

The customer triangle therefore illustrates why it is essential that the research subject – residents of the East of England and the GPs and District/Practice nurses they interact with – are the starting and focal point of any intervention. It ensures that resulting recommendations are appropriate for their audience, more likely to be effective and are not enforced on a population.

Indeed, a range of interventions may be required, each tailored to a specific audience. As we will discuss, the way issues around end of life are viewed are highly individual and what may work for one audience may not work for another. We would therefore highly recommend that any intervention is piloted before it is fully implemented (as will be discussed further below).

It is important to note that social marketing interventions can be from a wide range of activities. They can range from wholesale changes in service design, right through to the way a message is delivered and communicated. Furthermore, they do not necessarily have to be significant in their scale or scope; small changes can have a valuable impact.
5.3 Using the research findings to develop interventions

There were many barriers identified in the groups as issues that would prevent or discourage people from planning for their end of life care. Some of these are quite fundamental issues, as a result of ingrained attitudinal, value-driven and, in some cases, cultural factors. However we now discuss some of the ways these could be broken down or lessened, where possible. While some of these barriers may be too powerful to overcome, we discuss some ways in which any messages can be presented to increase the likelihood that they are effective.

*Piloting interventions*

It is crucial that any intervention is piloted for suitability. The interventions we discuss should not be treated as ‘one-size-fits all’ – the way that people approach end of life issues differs markedly and it should be noted that there will have been, inevitably, some degree of self-selection bias in our samples; those who find the discussion of death inappropriate, or too difficult to contemplate, are less likely to be willing to take part in the research. There will remain a significant proportion of the population for whom the idea of discussing death, the process involved and how they would be cared for, a subject too difficult for them to contemplate. Some will, therefore, actively avoid and prevent these discussions from taking place.

As an indication of this, some of the incomplete questionnaires returned to us from the quantitative survey give illuminating reasons behind non-response. Comments written on them included that having a questionnaire covering this subject matter was distasteful; insensitive; too morbid; only something that almighty God could answer; a subject that they would prefer not to talk about or answer questions on; and too distressing to respond to due to a recent bereavement.

Furthermore, a small number of responses and phone calls questioned whether it was sent as a result of the recipient’s condition. This was also mentioned in the discussion groups as a danger of sending out any blanket mailings; inevitably some individuals will find the subject more difficult to consider due to their particular circumstances.

All of this means that any interventions should be tested for appropriateness with each target group. No intervention in this field would be without risk, given the sensitive nature of the subject, and these will be described alongside the benefits of our suggestions below. Many interventions in this area could potentially be quite divisive and, therefore, we highly
recommend that any intervention implemented is done so after consultation with the communities involved, and piloted before it is rolled out more widely.

5.3.1 Information provision

What knowledge gaps exist?

- **There is the need for a greater awareness of the plans that can be made for one’s end of life.** Participants in the research felt that more information is needed on the plans that people can make for their end of life care, particularly those leading up to someone’s death. This was also intimated by those who say ‘what’s the point, I won’t be here anyway’; they are viewing planning for end of life care solely in relation to wills and funerals, rather than the things that could help when they are dying. It is necessary to increase this level of awareness across all age groups, not just those approaching the end of their lives.

- **More emphasis is needed on the importance of planning.** The majority of people do not have an appreciation of all of the reasons why it might be important for them to plan. If we apply Prochaska and DiClemente’s Stages of Change Model (illustrated below), the majority of people are at the ‘pre-contemplation stage’ i.e. they are not aware of the need to change their behaviour. Stressing the importance of planning may help people to understand the benefits to them and encourage them to take action. Explaining the gap that exists between people’s preferred location in which to die and the reality helps people to understand the issue.
The stages of change

- **Pre-contemplation**: not aware of the need to change
- **Contemplation**: aware of need to change and considering it
- **Preparation**: decided to act and making a plan, setting goals
- **Action**: putting the plans into action
- **Maintenance**: keeping the plan going

The majority are here (unaware of the need to plan)

Generally those with long-term conditions and more elderly

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- **Information on the dying process is sometimes lacking for people and their families, which can lead to care plans not being followed.** Moreover, this makes it difficult for people to make plans if they are not aware of what might happen to themselves or their loved one when they are dying.

- **Information provided on the subject needs to make it relevant to people.** Presenting scenarios of situations where planning helped individuals may help to show the benefit of planning and show it as the social norm. Real life cases and the testimonies of families showing why they are glad they planned, may also help to make it more relevant to people.

**5.3.2 Tone of the message / key messages**

- **Offer people an ‘exchange’**. If a person or group is to be encouraged to adopt or maintain a particular behaviour, there must be a clear benefit to them. For those who see planning as irrelevant to them, it needs to be highlighted what is ‘in it for them’ (the concept of an ‘exchange’). For example, there may be those who see themselves as being too young to make end of life plans; rather than being presented as a way for individuals to help themselves in the future (as this will seem a long way off for many) it might be better to emphasise that planning is a way to ‘Help yourself to help your loved ones’. Although younger people may not be considering these issues themselves yet, they are likely to have older relatives who are. This provides a
more short-term goal and may encourage people to educate themselves as to what plans can be made so as to help take part in the care of their loved ones.

- There may also be individuals who are not interested in planning as they have no money or belongings to pass on – in these instances it is important to emphasise the non-financial aspects of planning.

- **Offer to help remove the burden on loved ones.** Likewise, for the more elderly, it may help to present it as a way to protect those close to them, such as their children or next of kin. Engaging in these discussions will mean that family members will not have to make tough decisions on their behalf, therefore lessening the burden on their family.

- **Emphasise that plans are reversible.** It is important that it is made clear that any decision regarding end of life care is reversible and people can change their mind if they wish. A common response to planning for end of life care (e.g. aspects such as refusal of particular treatments and preferred location of death) is that there is no point because it is likely that they will change their mind, depending on the circumstances later in life. Emphasising that decisions are not final may help people feel it is worthwhile exploring what the choices are.

- **Highlighting the ability to update choices may also help** to combat the fatalistic view that some hold; that there is no point planning as it might not happen or NHS services may not be able to deliver it. To help break this down, it is also important to provide examples of how individuals’ plans for end of life care have successfully been met.

- **Instigating discussions in a relaxed atmosphere, for example among friends, may be an appropriate way to start these conversations.** The qualitative discussion groups illustrated how people can soon open up in these situations.
• Consider the use of humour carefully. For some, humour can be a way to broach the subject informally and as a ‘staging post’ on to more serious conversations. Examples were given by families who began discussing their preferred choice of funeral music and then advanced to more difficult aspects from there. Views in the discussion groups towards the posters produced by St Nicholas Hospice Care in Bury St Edmunds (right) were also predominantly positive. Most thought they successfully highlighted the key issues. However, any use of humour in this subject matter is difficult (a minority felt it is inappropriate), and it would need to be used with caution.

• Stress that making plans is not giving up hope. Hope can be a powerful barrier to exploring the plans that can be made for one’s end of life. Those living with a condition (and indeed those close to them) can avoid making plans as it is considered a form of giving up. While healthcare professionals need to respect the wishes of patients and their families, it is important for them to highlight that thinking about and making these plans is not a sign that someone is giving up hope.

• Planning is about choice and empowerment. A strong theme from the qualitative research (with both the general public and healthcare professionals) was that the process of making plans should not be forced on people. A minority are apprehensive of a drive to encourage planning as being bureaucratic and about saving money for the NHS. Highlighting that making these plans can empower people to have the death they want may help combat this.

5.3.3 Who should this information be targeted at?

• Targeting interventions around end of life care is highly challenging. There are numerous reasons why targeting specific interventions in this field is difficult. Identifying people who are open to having these discussions is difficult and there is an ethical dilemma of approaching people who are of an older age, have a long-term
condition or who have experienced the death of a loved one (i.e. groups who are more likely to have thought about these issues). As we have outlined in this report, there are multiple factors which influence an individual's propensity to engage in end of life planning. There are also certain stages in one's life where one may be more open to discussing these issues. Further quantitative research to quantify these particular groups would help identify segments that are more appropriate to target.

- There is general consensus that there is a need to educate the population more widely about end of life care and the choices they can make. Trying to increase the awareness of the population overall is likely to help encourage discussions across generations (facilitating greater openness within families) and may also help reach those for whom death feels irrelevant.

- Capitalise on men's focus on the financial/practical? Anecdotally, men often look at end of life planning from a financial point of view and are less likely to consider it from an 'emotional' standpoint (a view raised by some in the discussion groups). The quantitative survey shows that men are more likely to plan and be confident around the financial aspects of end of life. There may be an opportunity to use this as a 'staging post' and move on to other areas, such as funeral wishes and end of life care and support.

5.3.4 How should information be provided and by whom?

- Providing information via leaflets in GP surgeries was generally thought to be an appropriate way to disseminate knowledge. While some questioned whether it would be acceptable to provide this in an environment where people go to be healed, the majority thought it would be suitable. However, this approach is unlikely to be effective for those who are less open to discussing these issues or who feel it is not relevant to them. It would be a passive way of disseminating information and is unlikely to be read by a significant proportion of patients. It may, however, be a good way to further educate those who might have started to consider these their end of life.

- Furthermore, providing information in GP surgeries will go someway to meeting the desire from people to receive information via their GP, without GPs having to proactively bring up end of life planning.

- It is important that practice and district nurses are well informed of the choices people can make; they are generally seen as a better conduit of information than
GPs, due to their role as a care giver and are thought to have more time to discuss these issues.

- **Education on end of life care in schools was generally thought to be a good way of lessening the taboo around death and dying and normalising it as a subject to discuss.** It is also seen as a possible way to fill the gap now that death is considered to be far more removed and ‘hidden’. The idea of ‘Life and death’ classes was suggested as a way to bring issues around death into PSHE (Personal, Social, Health and Economic education). This would enable conversations to take place within families if school children could go home and discuss it with their parents. However, it was also thought to be quite contentious and could provoke concern among parents. It was only thought appropriate for secondary school age and not for anyone younger than 16. Hospices and/or charities were seen as well-placed to provide this information.

- **Celebrity endorsement of a cross-society campaign to educate and inform people is considered one of the most effective ways to raise the profile of end of life planning.** By making it a campaign aimed at all age groups, it could help combat the problem of family members preventing discussion being had, and enable more people to plan their end of life care.

- **Exploring links and cross-working with the funeral and financial sectors may help to build on some of the plans that people have made.** This could uncover ways to reach individuals and families who have started to consider end of life care (through funeral planning and wills) but lack information on how to make plans for other aspects of end of life care.

### 5.3.5 Groups requiring further assistance

- **The majority of older generations have not planned financially for their death.** This may be due to a lack of information about who to speak to, concerns about their financial situation, or it may be because there is an expectation that the NHS will provide adequate care when it is needed. Further research with the more elderly may help to shed light on the reasons behind this lack of planning.

- **Emphasising that it is free to make plans for end of life care may help encourage some on low incomes to explore them.** Information on what support is available, or low cost options for funerals and will services, may also help.
People with no immediate family may need further information or support in discussing end of life care. Areas where they can share experiences or advice, such as online chat-rooms, may help.

### 5.3.6 Supporting healthcare professionals

- Both GPs and district/practice nurses do not feel it is appropriate (or their job) for them to proactively discuss end of life care, unless the patient is within the Gold Standards Framework or have been given a terminal prognosis. It is therefore unlikely that a campaign to raise awareness through GPs and nurses will be accepted without further incentive.

- Examples of good practice in information provision should be shared between GP surgeries. This may also help ensure that information provided to patients is consistent.

- Healthcare professionals feel there is a need for some training around end of life planning, predominantly on broaching these subjects with people approaching the end of their lives. However, they also question whether it will raise enough interest, given the large amount of information they receive on training courses. Nurses in particular showed an interest in this training and felt they were better placed to use it than GPs.

It appears that there is a need for more information on end of life matters – predominantly about the plans that can be made but also about why it is important to plan. By educating the population more widely, it may help stimulate conversations which, in turn, are likely to encourage people to explore the plans they can make. Allowing this to happen across society, rather than targeting only those with a long-term condition, will help prepare people for making these choices when they feel that it is appropriate to do so.
In order to identify whether interventions would be more appropriate for particular groups, we would advise that the next step would be to further quantify any key segments. The research findings suggest that some groups approach the subject of death differently; a quantitative segmentation would provide insight as to the size of these groups and how they could be influenced. Message testing would also be preferable in order to ensure that interventions are suitable for the groups they are targeted at, whether by age, cultural group, gender or other demographic characteristics.