

The Departure Lounge

Public attitudes to death and dying

Research Report – July 2019

Academy of Medical Sciences & Ipsos MORI

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Executive summary

In May 2019, the Academy of Medical Sciences (AMS) opened an immersive installation in Lewisham shopping centre called the Departure Lounge. The aim of the Departure Lounge was to provide information and encourage discussion among the public about death and dying.

Ipsos MORI conducted seven workshops in the space with pre-recruited members of the public to explore how different individuals and communities think and talk about death and dying. In total, 56 participants were involved in the workshops.

In addition to the workshops, Ipsos MORI created mini-discussion forms for 30 trained 'Guides' staffing the Departure Lounge during opening hours, to help them facilitate discussions with members of the public in the space. These mini-discussion forms broadly mirrored the workshop discussion topics. 64 forms were completed and thematically analysed alongside the findings from the workshops.

Alongside the qualitative research in the Departure Lounge, Ipsos MORI curated information from a range of sources on social changes which relate to how death might be conceived of and experienced now and in the future. This analysis helps to contextualise the stories from the Departure Lounge and the participants in the research.

Key findings from public workshops:

Death is still not discussed and palliative care not well understood.

- Participants tend not to **think** about death until someone close to them is dying, or when they reach the point where they have children and consider their own mortality. Thinking and talking about death is hard to do, and easier with strangers than family members.
- The public think about the practical aspects of dying e.g. the planning done before a death and the processes after. However, very few people think about what **happens in the last days/minutes of life and do not tend to think about the processes involved.**
- There are **age related differences**; younger people (25-35) found the idea of death harder to engage with than older people (65+). This may be because older people are more likely to have had caring responsibilities for children and/or experienced the death of someone close to them.
- There are significant cultural differences, particularly in the Muslim community, who resist talking about death "too early" as recovery is always seen as an option for a person of faith plus, there are elements of personal and family support which are seen as not the remit of healthcare professionals. Rather, palliative care should facilitate the community to deliver services and care rather than replacing it.

- Not everyone has heard of **palliative care** and even those who have are unsure who is entitled to it, how to organise it, where it can be delivered and what the benefits of it might be. This research suggests that for the public, medical treatment and personal, ‘soft’ care are each seen as quite different things; hospitals delivering medical ‘cures’ and other bodies, charities or friends and family, providing comfort and easing emotional distress.
- All participants welcomed the opportunity to talk about death in the context of the Departure Lounge space and suggested that more spaces like these would be a good thing for wider discussion and greater understanding.

Good end of life care can provide agency, control, choice and flexibility, right up until the moment of death and afford patients the opportunity to express personal values and beliefs.

- While participants were clear about taking **control** and making practical plans and **choices** (financial) for their death, they typically had not considered how they would like care to be managed at the end of life. Further research and communication may be needed to identify the kinds of care which are available, and the types of choices which might come up.
- End of life care should **support** time spent with friends and family; e.g. hospitals providing **flexible** visiting times and allowing multiple members of the family to spend time with the person dying.
- It was considered crucial that any care provided be flexible to support the **expression of personal values and beliefs**. Muslim faith participants felt that this should include a reflection that this type of support actually does not fit within the remit of the NHS. In future, the NHS will need to consider how it allows other agencies or community workers to play a part in the end of life, rather than the hospital or medical community wholly “owning” the space of death.
- There should be **choice** offered as to **where** the patient can receive treatment and where they can be at the end of their life; there is scope for different research to identify the different kinds of support necessary in hospital, at home, or in a hospice. There may be a need to support families to make the right choices for them (e.g. around the care they will receive and medical decisions such as Do Not Resuscitate orders) and enable them to have as much choice as possible by offering choice at the right moment.
- Dying at home is of particular importance for some faiths and cultures.

Key findings from wider social trends around death:

- Growing demand for **flexibility, choice and autonomy** in life as in death; if assisted dying becomes legal in the next ten years, this might also affect people's expectations around death in general.¹
- Questions around a person's **digital legacy** and ownership will become more prominent - our digital selves could create new needs for patients and their families to start to manage people's affairs well before death, and to curate and clean their 'data presence' as well as thinking about the patient's wishes, money and possessions. Digital Legacy Associations and services are already beginning to emerge, and there may be a need for end of life care to support this process, through a platform of their own, or by connecting patients better with these types of services. Demand for digital access, in general, to resources around end of life planning will continue to grow.
- **Ecological concerns** are likely to grow, and more people will want a sustainable death – this might influence the kinds of practices and care they ask for before death. Different generations and ethnic or cultural groups might think about sustainability differently; and end of life care may be the space where these discussions play out.
- Increasing **personalisation** in society, the decline of religion overall, and a move towards comfort with public and personal expression of thought and feelings; all this could mean that people have an expectation of a very tailored and personal death experience. Spaces like the Departure Lounge might become more common; palliative care providers will be able to integrate more with wider discussion forums and support networks. However, in a world where lots of advice is available and voices are not necessarily those of traditional authorities, state healthcare providers will need to make sure people are getting the right information and are well supported in the choices they make.

Implications for policy, practice and future research:

1. There is scope for all end of life care settings to offer more **joined up care around the emotional and practical aspects of death**. Participants in our research would appreciate assistance for the person dying around setting their affairs in order. Participants prioritised the opportunity to '**make their wishes known**'. Therefore, it may be useful to put in place access to legal advice, financial advice, or other mediation and support, or for end of life care to link better with agencies which provide this. This might help both family and healthcare professionals navigate difficult decision processes, e.g. choosing whether or not to refuse further interventions. While these linkages are not necessarily perceived to be within the scope of traditional healthcare, they reflect the ways death might be changing in line with social trends for sustainability, flexibility, and personalised experiences.

¹ Assisted dying was not a topic covered in the Departure Lounge, to prevent attention being detracted from the other ways that medical science can support people to have a 'good' death.

2. It may also be important for end of life care settings to help patients and carers navigate the **different advice** they get from a range of wider sources and sift verified and accurate information from inaccurate or harmful advice.
3. There could be scope for research or communications to help identify and communicate how the **psychological and emotional** aspects of dying relate to the physical aspects. Further research could investigate how healthcare professionals can best balance the needs of the patient for certain types of care, and the needs of the family to be involved in decisions about how this care is delivered.
4. There is a need for greater **communication** with the public, so that people can learn about the realities of death, especially the likelihood of dying from dementia; that dying is a process; that palliative care is a way of helping the whole patient, and where the opportunities are for the medical world to support families and carers. Future research and policy development can build on the important work already done in this area, for example, information provision and public engagement activities from Dying Matters and other organisations.
5. It is considered crucial that any provision of pastoral or emotional support be provided in a way that reflects and enables cultural and religious practices and beliefs.

Introduction

The Departure Lounge: immersive installation to explore the end of life

In May and June 2019, the AMS opened an immersive installation in Lewisham shopping centre called the Departure Lounge. The aim of the Departure Lounge was to provide information and encourage discussion among the public about death and dying.

The AMS received funding from the Wellcome Trust and The Health Foundation and commissioned The Liminal Space to set up the Departure Lounge. The Academy's core grant from the Government Department for Business, Energy & Industrial Strategy was also used to support development of the project.

The focus of the Departure Lounge was to open discussions with visitors about the end of life, defined as the point at which science stops trying to preserve life and starts focusing on quality of remaining life, covering biomedical, health and policy issues. The content focused on situations in which death is expected, rather than on sudden or unexpected deaths, because this type of death is most common, but perhaps the least talked about.

The AMS aimed to use the immersive installation, and research which took place within the space, to inspire new thinking about how the medical and health communities should approach end of life care, and to come up with policy and research ideas, which could inform future strategic discussions among healthcare practitioners and the research community.

The Departure Lounge was situated in Lewisham shopping centre to enable a broad mix of people to engage with the installation, including demographics who might be less likely to seek, or have access to information from sources such as healthcare providers, museums, news articles and journals. The space was free and open for anyone to explore.

The space was designed to look like an airport departure lounge by focusing the content and messaging around the 'departure' metaphor. It was open to the public for four weeks during May and June 2019 and coincided with Dying Matters week, the aim of which is to raise awareness about the importance of talking about dying, death and bereavement.

Inside the space, there were five key installations:

Lives well lived – An installation of suitcases with luggage tags detailing facts and figure from end of life research and stories of end of live experiences. This installation also included a film and audio soundscape reflecting elements of the stories presented in the installation

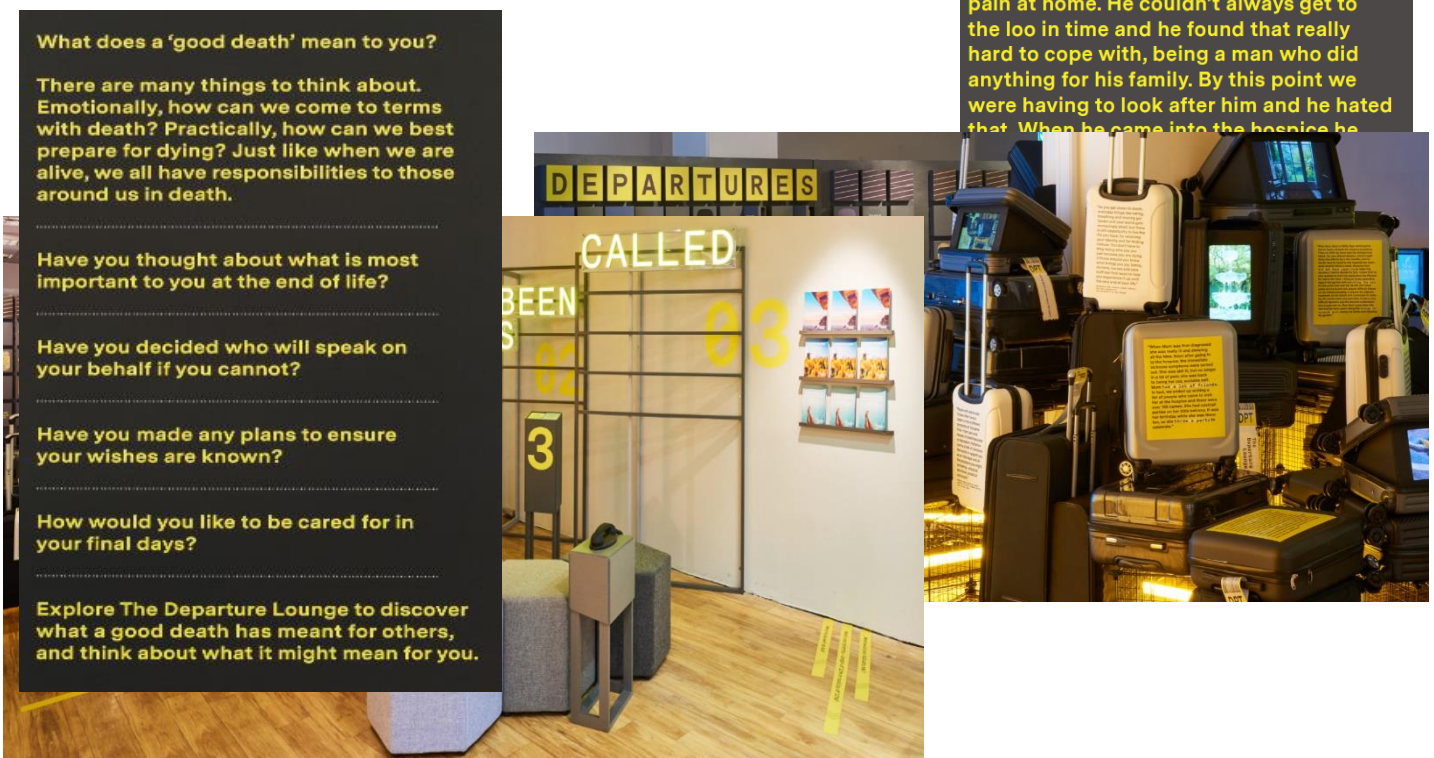
Windows on the world – an airport window light installation where stories and thoughts from visitors could be written on acetates to form part of the installation.

Departures board – A life size interactive departures board made of individual boxes opening to reveal information and stories about death and end of life care communicated through travel metaphors such as boarding passes, travel socks, and telephones where visitors could listen to stories from healthcare professionals.

Your gate has been called – Three departure gates and a seating area where trained Guides were available to have conversations and discussions with visitors. Postcards and leaflets with information on end of life care, legal terminology and questions to think about when planning for the end of life were also available to visitors. Guides also had access to a range of information and leaflets from a range of national and local support charities.

Window posters – travel themed posters in the window exploring different death euphemisms.

- Content for these installations were drawn from the following sources: Pre-recorded interviews with health and palliative care professionals from St Christopher’s Hospice, based in Lewisham.
- Stories collected from organisations such as Compassion in Dying, Marie Curie and Dying Matters.
- Quotes from Academy Fellows and Grant Awardees.
- Facts about palliative care, causes of death, and the future of healthcare collected from a wide collection of research papers and reports.





Up to four trained ‘Guides’ with relevant experience, including backgrounds in end of life research or end of life care were present in the Departure Lounge during opening hours to answer questions and facilitate conversations with the public. The Guides interviewed 64 visitors using a pre-prepared discussion guide with questions that broadly mirrored the workshop discussion topics, the findings from which are included in this report. Guides were paid for their time working in the Departure Lounge.

Research objectives

As part of the project, the AMS commissioned Ipsos MORI to conduct a series of workshops to take place within The Departure Lounge to understand the public’s needs, hopes and fears, and identify areas where policy and research could meet unmet needs. The outcomes of this research will help to develop insights which can be used to inform and catalyse policy activity and debate among stakeholders.

The specific research objectives were defined through a consultative meeting held by AMS², and the table below outlines how these objectives have been met through the research and analysis.

Research objective	How the objectives have been met
Identify needs generated by first-hand experiences of caring for loved ones near to death.	We did not ask participants directly about this due to the extremely sensitive nature. However, participants shared stories spontaneously and the moderators probed when appropriate. The stories shared by participants have been explored in detail through the analysis.
Understand the range and variation in participants’ experiences of healthcare and identify different needs.	
Understand awareness of palliative and end of life care, explore perceptions of the role of successful palliative care, and understand how	This topic was discussed as a group. We gained participants uninformed view by asking whether they had heard of the term and what it means to them. We then gained their informed view by providing a

² Academy of Medical Sciences (2019). *End of life and palliative care: the policy landscape*. <https://acmedsci.ac.uk/file-download/6898766>

<p>this differs among different communities.</p>	<p>definition of the term and asking whether it was surprising in any way or changed their understanding.</p> <p>We also draw conclusions from what participants said about general end of life care and what it means for palliative care.</p>
<p>Explore what a ‘good death’ means for individuals and communities.</p> <p>Understand what the public think they will want from healthcare in the last stages of someone’s life – what matters to them, what should happen when, what conversations, what information should be provided, and by who.</p>	<p>This topic was discussed as a group through the use of case studies. All the case studies described a scenario in which an individual and those around them are thinking about how to prepare for the end of the individual’s life. However, they were designed to be relevant to the participants in each workshop e.g. for the workshops with Muslims, the case study referenced the family’s local religious community.</p>
<p>Understand how culture, faith, gender, ethnicity and life circumstances might impact individual and community views of death and dying.</p>	<p>This was primarily explored through the analysis of the workshop notes and recordings. Findings were compared across the different workshop groups, and between individuals within the groups.</p>
<p>Uncover how the public view the importance of language in the context of death and dying: is it possible to dispel myths and misconceptions about death and dying in society, and if so, in what ways?</p>	<p>This was primarily explored through the analysis of the workshop notes and recordings. Findings were compared across the different workshop groups, and between individuals within the groups.</p>

Workshop methodology

The research involved conducting seven evening or afternoon workshops with the public in the Departure Lounge between the 16th May and 3rd June. The workshops lasted between 1.5 and 2.5 hours and participants received a thank you gift of £50 or £65 respectively. In total, 56 participants were involved in the workshops.

Each workshop aimed to explore the views of a specific group of people, in order to meet one of the primary objectives to investigate how culture, faith, gender, ethnicity and other life

circumstances might impact individual and community views of death and dying. Details of the seven workshops are shown in the table on the following page.

Workshop recruitment

The participants for the workshops were recruited particularly carefully, given the extremely sensitive nature of the discussions. At the recruitment stage they received an information leaflet about the research and were told in detail about the themes in the Departure Lounge as well as the content of the workshop discussions. Informed consent to participate was obtained at the recruitment stage and again prior to the start of the workshops.

In each workshop there were some participants who had experienced bereavement and some who had not. We used a specific definition in order to meet the research objectives and to avoid causing undue stress to participants. Those who met the 'experience of bereavement' criteria, had:

- Lost a close family member or friend due to old age or a long-term illness, but not in the last 6 months (or 11/12 months to avoid anniversary dates) and excluding the death of children; and
- Played a crucial decision-making role in the last weeks and days of the life of the person who died, for example about their care and funeral plans.

Workshop quotas

The table below summarises the number of participants engaged at each workshop, specific quotas and workshop durations.

Workshop	Number of participants	Quotas	Duration
1a: Muslims, mixed demographics, mini-group	5	Gender: male Age: 25-70 (mixed) Ethnicity: mixed Social grade: mixed Religion: Islam Experience of bereavement: min 2x experienced bereavement and 2x not experienced bereavement	1.5 hours
1b: Muslims, mixed demographics, mini-group	4	Gender: female Age: 25-70 (mixed) Ethnicity: mixed Social grade: mixed Religion: Islam	1.5 hours

		Experience of bereavement: min 2x experienced bereavement and 2x not experienced bereavement	
2: Older people with and without multiple health conditions, full-size group	9	Gender: mixed Age: 60-85 (mixed) Ethnicity: mixed Social grade: mixed Multiple health conditions: split group Experience of bereavement: min 3x experienced bereavement and 3x not experienced bereavement	2.5 hours
3: Younger people, pre-family and young family, full-size group	10	Gender: mixed Age: 25-35 (mixed) Ethnicity: mixed Social grade: mixed Children in household: split group Experience of bereavement: min 3x experienced bereavement and 3x not experienced bereavement	2.5 hours
4: The squeezed generation, ABC1, full-size group	9	Gender: mixed Age: 35-65 (mixed) Ethnicity: mixed Social grade: ABC1 Caring responsibilities: caring for both children and elderly Experience of bereavement: min 3x experienced bereavement and 3x not experienced bereavement	2.5 hours
5: The squeezed generation, C2DE, full-size group	10	Gender: mixed Age: 35-65 (mixed) Ethnicity: mixed Social grade: C2DE Caring responsibilities: caring for both children and elderly Experience of bereavement: min 3x experienced bereavement and 3x not experienced bereavement	2.5 hours
6: Faith specific, mixed Christians, full-size group	9	Gender: mixed Age: 25-75 (mixed) Ethnicity: mixed Social grade: mixed Religion: Christianity	2.5 hours

	Experience of bereavement: min 3x experienced bereavement and 3x not experienced bereavement	
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Workshop overview

The table below outlines the workshops structure and the discussion topics covered. The full discussion guide is included in the Appendix.

Section/ theme	Content
Introduction & setting the scene	<ul style="list-style-type: none"> • Introducing Ipsos MORI and the moderators • Aims of the research • Who the research is for (quick intro from AMS) • How the research will be used • Parameters and ground rules • Comfort setting: no need to answer questions you don't want to • MRS code of conduct and permission to record • Consent form • Overview of the workshop • Value of talking as a group • Feelings about attending the workshop • Thoughts on whether death is a taboo subject • Participant introductions (in pairs and then as a group)
Visiting the Departure Lounge	<ul style="list-style-type: none"> • Participants to look around the space • Discussion in pairs around what they learnt from looking at the space and what they found surprising • Feelings about exploring the space
Break	
Palliative care	<ul style="list-style-type: none"> • Discussion to gauge knowledge and understanding of palliative care • Provide definition of palliative care and explore whether this changes people's views • Relevance of palliative care to individual communities • Acceptability of palliative care
What is important at the end of life?	<ul style="list-style-type: none"> • Views on what is important to people at the end of someone's life and how this might differ among individuals and communities. • Case studies in break-out groups then feedback to group • What would the individuals in the case studies do: who would they consult, what services might they want access to, what role does religion play, what would their family members want? • Discussion around lifestyle and deathstyle • Discussion around survey finding that many people seek information about death and dying from family and friends.
Break	

Wind-down and close	<ul style="list-style-type: none"> • Views on the space • Thoughts on replicating the Departure Lounge elsewhere • Thank participants and hand out advice leaflets and incentives
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Moderating the workshops

Given the sensitive nature of the content in the Departure Lounge and the topics being discussed in the workshops, the moderating team consisted of experienced qualitative researchers with expertise in conducting research with the public and vulnerable people on sensitive issues.

Moderators did not directly question participants on first-hand experiences of death and made it clear that they did not have to talk about anything that made them feel uncomfortable or that they might find upsetting. However, many participants spontaneously spoke about personal experiences.

Other assurances were made to participants at the start of the workshops. For example, it was made clear that:

- Everything said would be kept confidential;
- Any words used in the final report would not be attributable to an individual;
- All data would be securely destroyed at the end of the project;
- Participants could take a break at any point or leave the space;
- Everyone needs to be respectful of other views and not speak over one another

Analysis of the workshop findings

The recording and notes from the workshops were thematically analysed. Differences between the workshops were examined, as were differences between individuals. Throughout the report we have highlighted where there is a diversity of views driven by different cultural experiences and expectations. Through the analysis, it became clear that there were key differences between the discussions at the workshop with Muslims and the other workshops. Therefore, these differences are reflected in the report.

Mini-interviews with the public

In addition to the workshops, we created mini-discussion forms for the Guides present in the Departure Lounge, to help them facilitate discussions with members of the public in the space. These mini-discussion forms broadly mirrored the workshop discussion topics, with the aim of meeting similar objectives.

The discussion forms included two open questions, one about quality of life at the end of life, and the other about death as a taboo subject. There was also space to record any other notes from the discussions and demographic details about the person, if consent was explicitly obtained. Given the sensitive nature of the conversations, it was left to the Guides discretion to decide if or when conversations were appropriate to move towards completing the formal discussion forms.

In total, 64 people consented to having their conversations in the Departure Lounge recorded in this way over the four weeks of opening. Demographic information about these people is included in the table below.

Demographic	Subgroup	Number
Ethnic group	White	48
	Asian or Asian British	3
	Black or Black British	6
	Mixed/Multiple	4
	Other	2
	Not scanned	1
Religion	No religion	27
	Christian	25
	Buddhist	2
	Jewish	1
	Muslim	1
	Quaker	1
	Other	4
	Prefer not to say	3
Age	18-20	2
	21-30	11
	31-40	10
	41-50	11
	51-60	11
	61-70	7
	71-80	7
	90+	0
	Declined	1
	Not scanned	1
Gender	Male	10
	Female	53
	Not scanned	1
Long-standing disability	Yes	11
	No	51
	Prefer not to say	2

Living in Lewisham	Yes	38
	No	26
Total		64

These forms were thematically analysed, and the findings are included throughout the main sections of this report in purple boxes. The mini-discussion form is included in the Appendix.

Trends analysis

Alongside the qualitative research in the space, we have curated information from a range of sources on social changes which relate to how death might be conceived of and experienced now and in the future. Our trends chapter sets out the framework of change we have used, and how we have collected expressions of the trends we think are relevant and important. These add context to the stories from the Departure Lounge and the participants in our research.

At the end of the trends chapter, we identify potential unmet needs that trends suggest patients and families may have in the future.

The trends are presented as examples of changes which are underway, which we can identify in the culture at the moment. They suggest areas where further investigation would be useful; for example, to quantify the prevalence of different themes, or to identify how they may shape views among different age groups, regional groups, or ethnic groups.

Conversations about death and dying

This chapter explores how participants talked about death and dying, and their experiences of the Departure Lounge. It identifies the myths that the Departure Lounge dispelled for participants and how participants felt about the concept of a ‘good death’.

Participant’s initial thoughts

Across all the workshops, participants acknowledged that talking about death is often difficult, and that it is uncommon.

“We don’t speak about death... how do you put it into words?” – Workshop with the squeezed generation (C2DE)

“It’s a depressing topic... you turn over the TV when you see adverts about funerals.” – Workshop with younger people

“It’s not your first choice of conversation.” – Workshop with the squeezed generation (C2DE)

“I won’t talk about this to my parents. I don’t feel comfortable and it hurts to even think about talking to them about their death.” – Workshop with people of Muslim faith (male)

Largely, participants felt that death is not openly discussed in society for two main reasons: it is a ‘depressing’ or ‘morbid’ subject and, because people are worried that talking about death will upset those listening, especially family members. Participants tended to use negative language and talk about the effect on others, often using “You” rather than “I” to distance themselves from the challenging feelings the topic might bring up and to find a way to broach the topic in a group situation.

“[You] don’t discuss it. It’s morbid.” – Workshop with older people

“What’s the point in having an upsetting discussion.” – Workshop with the squeezed generation (ABC1)

“I think the main reason why people don’t talk about it is because they don’t want to take a risk and upset the person they are talking to.” – Workshops with the squeezed generation (C2DE)

“I’m telling [my daughter] I don’t mind being cremated... and she’s like ‘oh mummy don’t talk to me about that, I don’t want to hear it.’” – Workshop with the squeezed generation (C2DE)

Mini-discussions with the public

The public acknowledged that whilst talking more openly about death and dying can help people to prepare for death, the topic is a taboo and largely avoided because of the potential for it to be upsetting. It was suggested that talking about death and dying can bring difficult memories ‘to the surface’ and this can be emotionally challenging.

“[Talking about] it might stir up bad memories of experiences.” – White male, Christian, aged 67

However, on reflection, some participants were pleased to have the opportunity to discuss the subject at the Departure Lounge and as part of the workshops.

“Glad to be breaking the taboo.” – Workshop with people of Christian faith

“Being here is a relief because I can talk freely without offending my family members.” – Workshop with the squeezed generation (C2DE)

Some felt that it would be easier to talk about this subject among strangers compared to their own family or friends. This was because participants felt they could be more open with strangers, or simply because they did not want to bring up an upsetting topic with friends and family.

“For me to say what my fears and anxieties are... it’s easier on that wall [exhibiting public stories in Departure Lounge] than with my family as they will tell me to shut up.” – Workshop with older people

“[This is like] release therapy because I don’t talk about it with my friends and family.” – Workshop with younger people

“It’s easier to speak to a stranger.” – Workshop with older people

In comparison, it was clear across the Muslim faith workshops that ways in which death and dying were spoken and thought about were very different to the traditional Western view. Participants cited cultural and religious beliefs and traditions including a fatalistic outlook, a focus on religious texts, and the need for appropriate cultural conduct. Participants made a distinction between religion and culture and how these may impact people’s views differently. As a faith tradition, Islam emphasises remembrance of death and completion of death rites in a timely fashion. In contrast, cultures can influence how readily or comfortably death and dying is discussed.

“We don’t like to talk about it culturally. But religion tells us that we [are] meant to be prepared for it. It is going to happen. So, there are two opposing sides. Culturally it is a taboo.” – Workshop with people of Muslim faith (male)

“Culturally we don’t talk about death. We believe it is bad luck. Cultural belief is that if you talk about it and it will happen.” – Workshop with people of Muslim faith (male)

Talking about the different stages of death and dying

It was clear across the sessions that some of the stages of death and dying were easier to talk about than others.

Generally, participants could understand the value in discussing death and dying, but mainly from the perspective of organising practicalities. For example, preparing a will, communicating wishes about preferred location of death, organising and financing a funeral and the distribution of assets were all key considerations for participants. Practical considerations were seen as being important to address primarily to minimise any burden on family members ‘left behind’.

“[I have] discussed wills and power of attorney with children. Really important issues which we should face... I am speaking to my lawyer to make things easier for my son and family.” – Workshop with older people

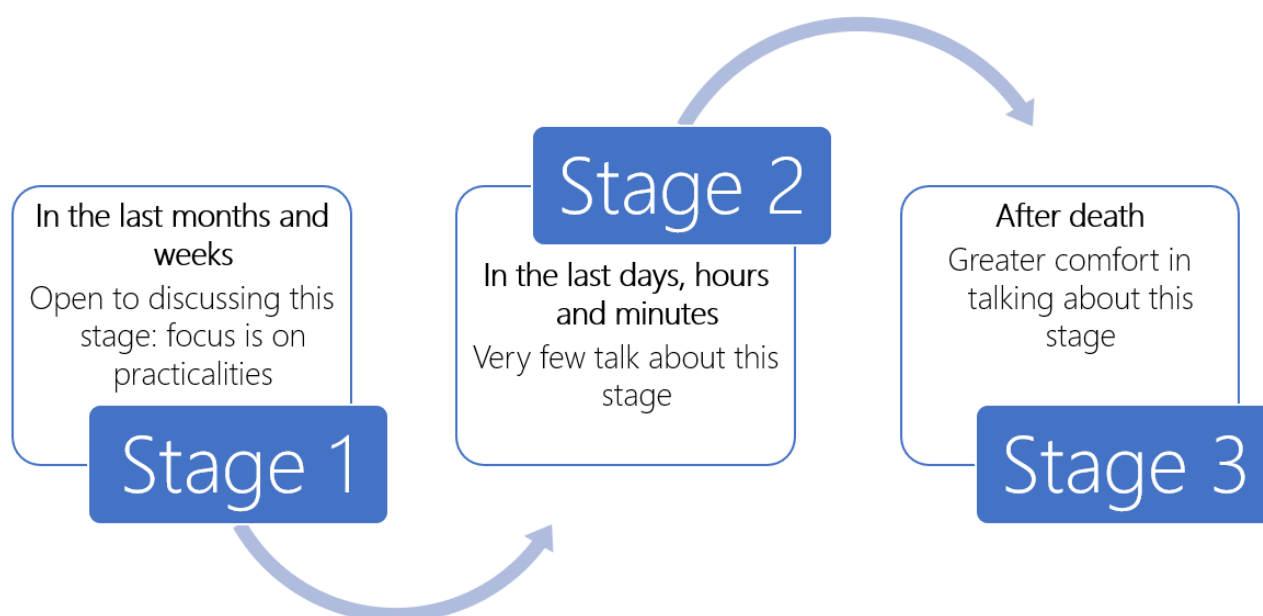
“I think for me it would be about not putting a burden on my children.” – Workshop with the squeezed generation (C2DE)

There was a sense among some participants, especially older people, that having affairs in order and practicalities dealt with meant that there was less of a need to discuss death with others.

“The most important thing is everyone should make a will. I’ve [had] everything arranged for donkey’s years... I’ve got it all arranged so we don’t discuss it.” – Workshop with older people

Because practical matters were the top of mind considerations for the participants, when they thought about end of life, they most frequently spoke about preparing for the last years and months of someone’s life, or for what happens after they die. Very few participants spoke about their hopes or fears, for themselves or a relative, in the last few days, hours or minutes of life.

The diagram below describes the different stages of death, how commonly each were spoken about and the types of considerations that were discussed during the workshops.



Stage 1: In the last months and weeks

- When thinking about ‘the end of life’, many participants thought about the **last months and weeks** of a person’s life.
- Considerations for this stage focused on preparing a will and communicating wishes, such as preferred place to die.

Stage 2: In the last days, hours and minutes

- When thinking about ‘the end of a life’, very few participants thought about the **last days, hours and minutes** of a person’s life.
- Very few participants spoke about what their hopes or fears would be, for themselves or a relative, in the last days and minutes of life.
- This reflects key findings from the polling carried out on this topic³:
 - A third of people (35%) preferred not to answer questions about what happens to a person in the final hours and minutes of their life.
 - A third of people (33%) people said that they knew hardly anything or nothing at all about what happens to a person in the final hours or minutes of their life.
- Whilst acknowledging the benefits of talking about death and dying, the Muslim faith participants felt that it would not be culturally appropriate to talk to their family about the

³ Ipsos MORI polling for AMS: 966 British adults aged 18+, interviewed face-to-face 5 – 14 April 2019

subject even in the last days and hours of someone's life. Participants noted that it is important for those of faith to express that God could, and might, still save an individual, even if they are very ill. So, acknowledging someone is nearing the end of their life may not be acceptable, as it might be seen as giving up on the expression of faith. It is important to note that there are differing views about acceptance, awareness and discussions of death, for example intergenerational differences.

Stage 3: After death

- When thinking about 'the end of life', participants most commonly thought about the time **after a person dies**.
- Considerations for this stage focused on preparing a will and communicating wishes, such as specific funeral plans.
- Participants spoke about wanting to 'have things in order' to minimise the burden on their friends and family.
- Support for the friends and family of someone who has died was also a key concern for participants with many thinking about bereavement, grief and loss.
- By the end of the workshops, and having visited the Departure Lounge, the majority of participants felt compelled to talk more about death and dying in the future.

"I think I will have a conversation with my kids about death now." – Workshop with younger people

- However, many still felt reserved about talking about death and dying for the same reasons mentioned at the beginning of the workshops: it is a depressing topic and it is likely to be upsetting for those listening, particularly family members.

The Departure Lounge experience

Participants spoke very positively about The Departure Lounge. Many felt that the space was informative, interesting and constructive in that it provided people with the opportunity to learn and talk about a difficult and seldom discussed topic.

"It's like going to a museum – learning so much, been really refreshing." – Workshops with the squeezed generation (C2DE)

Overall, participants were very positive about the Departure Lounge and mentioned wanting to see something similar being installed elsewhere – in London and across the country.

“I think you should have them in all the town centres because people need to be more aware of what death is about so there is not such a taboo.” – Workshop with the squeezed generation (C2DE)

Participants across the workshops mentioned wanting access to more information and support on a range of end of life issues. Suggestions for how this information could be provided included:

- A ‘one-stop-shop’ style service

“Experts that are knowledgeable but also have empathy and are trained to be a go-to for all the issues you might face.” – Workshop with people of Christian faith

- DVDs or podcasts
- Documentaries
- Free phone number

In almost every workshop, participants suggested that the Departure Lounge should be made accessible to children and young people by exhibiting it at school and university fairs. It was felt that learning and talking about death and dying at an early age could be beneficial in preventing the subject becoming difficult to engage with later on in life. There was also a feeling that the Departure Lounge could help children and young people understand the value of life and therefore reduce conflict and violence.

“I also think the schools and institutions where there is gun and knife crime, bring them to these kinds of places so that they think before they have a fight.” – Workshop with the squeezed generation (C2DE)

Mini-discussions with the public

The public felt that children and young people should be encouraged to think and talk about death and dying so that the topic can be normalised and help them to deal with first-hand experiences later in life.

It was suggested that encouraging children and young people to talk about death and dying could help to drive larger societal change around how we perceive the topic.

“Speaking openly about [death and dying] with young people [would help society to feel more comfortable with the subject].” – Black female, other religion, aged 50

Muslim faith participants noted that it was interesting to consider preparing for death from a non-religious perspective, noting that when they thought about this topic they typically thought about their own religion. Similar reflections were shared by people from other faiths.

For some, particularly the older participants, the Departure Lounge was seen as a positive place and that the content had been sensitively curated.

“This is quite a sad place but also hopeful – some of the quotes are quite positive given the circumstances.” – Workshop with the squeezed generation (ABC1)

“[They] got the tone right.” – Workshop with older people

“A lot of it [is] about celebrating.” – Workshop with the squeezed generation (ABC1)

“This isn’t too depressing, it’s realistic. It’s very sad but it’s the right tone.” – Workshop with older people

“It’s about learning to value life.” – Workshop with the squeezed generation (C2DE)

However, for some it raised difficult memories.

“You learn to live with it, but you never get over it.” – Workshop with people of Muslim faith (female)

“These things in the lounge are emotional for me... I think this might work for some young people but not others, it depends on how raw their experience is...” – Workshops with the squeezed generation (ABC1)

Some participants, particularly the younger people, found the space emotive and hard-hitting. In particular, the personal stories and audio recordings were felt to be the most emotive elements of the installation.

“Quite heavy.” – Workshop with younger people

“I found the facts easier than the personal stories.” – Workshop with younger people

“Talking about it is fine [but] listening to it on the phone [installation with pre-recorded messages] is too much for me.” – Workshop with younger people

“[The] personal statements were a bit too personal... quite deep.” – Workshop with younger people

In some cases, the younger participants found the installations hard to engage with because of a lack of experience with death. Conversely, the older participants were most at ease exploring the Departure Lounge and talking about death. This may be related to the suggestion from participants that having personal experiences of death, and/or having children are two life

events that lead people to consider one's own mortality and feel more comfortable talking about dying.

“A place like this, you have to be ready for it... I couldn't really connect.” – Workshop with the squeezed generation (C2DE)

“When you're younger, death is more abstract – other people were going to die – when you get older when you've got kids, it becomes more relevant [because] you start thinking 'what's going to happen when I die, who is going to look after the kids, who is going to pay the bills. But death doesn't become [less of] a taboo, just more relevant.” – Workshop with the squeezed generation (ABC1)

“[You] don't tend to talk about [death] when you are younger unless you have a direct experience.” – Workshop with the squeezed generation (ABC1)

“Death doesn't frighten me like it does most people. My husband died when he was very young and [as] my children grew up I had to teach them about death.” – Workshop with older people

“When I was younger I might not have talked about [death] but as you get older you do because of personal experiences.” – Workshop with the squeezed generation (ABC1)

However, by the end of the workshops, and having visited the Departure Lounge, the majority of participants felt compelled to talk more about death and dying in the future.

“I think I will have a conversation with my kids about death now.” – Workshop with younger people

Some participants likened the taboo of talking about death and dying to how society has traditionally viewed mental health. It was noted that campaigns and media coverage has positively encouraged openness and debate on this topic and that the same could be done to expand existing conversations around death and dying.

However, many still felt reserved about talking to about death and dying for the same reasons mentioned at the beginning of the workshops: it is a depressing topic and it is likely to be upsetting for those listening, particularly family members.

“Once I leave here I will go back to my life and I don't want to think about this at all. Mainly because when you are busy, young and getting on with your life you don't want to talk about death and dying.” - Muslim faith (male) workshop

Whilst acknowledging the benefits of talking about death and dying, some participants felt that it would not be culturally appropriate to talk to their family about the subject. Discomfort in talking to family members for Muslim participants ties in with the belief expressed by some of these

participants that there is a conflict between acknowledging someone is nearing the end of their life, and the power/ will of a god to save an individual.

Dispelling myths and misconceptions

There were some elements of the Departure Lounge that participants found particularly surprising and led to myths being dispelled:

1. Death is not always painful and therefore doesn't always need to be feared.

The stories and pre-recorded messages from healthcare professionals re-framing death as an event that is not necessarily painful or scary, were particularly thought-provoking for participants. As we know from previous research, the biggest concern for people in the final few hours of their lives are that they would be in pain. In a recent poll⁴, people were asked what would worry them about being with a person in the final hours and minutes of their life and six in ten (62%) said that they would be worried that the person was in pain. Chiming with this finding, the workshop participants were very reassured to hear that pain can be minimised through palliative care.

“One of the telephones [installation with pre-recorded messages] is quite interesting. [It was] a palliative care doctor saying that our approach to death doesn't always have to be negative.” – Workshop with the squeezed generation (ABC1)

“There is no need to be afraid...the natural death where people lie in their bed...their organs shut down one at a time, so the body actually prepares you for death and you feel less pain because you have less organs working. You hallucinate, and you are out...that death I don't fear.” – Workshops with the squeezed generation (C2DE)

“We always think of death as a painful experience that is not going to be quiet... [but] a lot of it is quite peaceful... the recordings from the nurses talked about that.” – Workshop with the squeezed generation (C2DE)

Mini-discussions with the public

The public mentioned the disconnect between the way death is presented in the media and the actual experiences of individuals in real life, suggesting that death is always presented as traumatic and scary in films and TV, compared to in reality, where death can be undramatic and painless.

This led to a feeling that death should be normalised and spoken about as any other subject.

⁴ Ipsos MORI polling for AMS: 966 British adults aged 18+, interviewed face-to-face 5 – 14 April 2019

“Talking about it more would break the unhelpful media narrative.” – White female, Christian, aged 33

2. Hospices are caring environments, which can enable patients to retain agency, personality and dignity.

Some participants described hospices as uncaring and joyless places where decisions are made by staff on behalf of the patient, and family have little involvement. One story in particular challenged this view, as it described an elderly man asking, and being allowed to drink whiskey at the end of his life in a hospice.

“I was surprised that you can get anything you want, someone asked for a whisky and soda and got it, if you ask for it in a hospice, they give you what you want, keep you happier, shows you there is an element of care, because you haven’t got long left.” – Workshop with the squeezed generation (ABC1)

Muslim faith participants also commented on the percentage of people dying in care homes. They were surprised by this because it challenged their cultural and religious beliefs that elderly and unwell people should be cared for at home by the family.

“It suggests that there is a growing trend to fob off your parents to care homes. It contradicts our Islamic beliefs.” – Workshop with people of Muslim faith (male)

3. Dementia is the leading cause of death in the UK.

Participants were surprised to read that dementia is the number one cause of death and not, as many thought, that cancer is the most common cause. This could be attributable to the volume of cancer related adverts and charity events that the public see in the media.

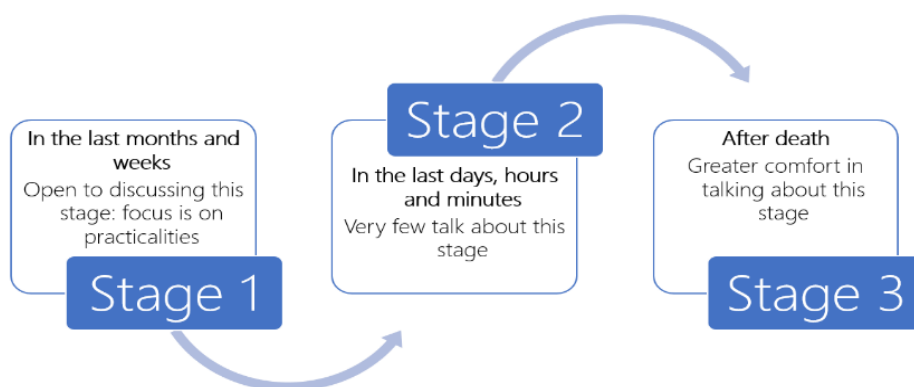
“So many people are going to be in hospices from dementia... it’s surprising.” – Workshop with older people

The concept of a good death

There was some debate across the workshops regarding the idea of a ‘good death’. Generally, there was initial push-back on the idea that death could in some way be ‘good’.

“No one is ready to die, are they? I would say most people don’t want people to die or their family to so how can it ever be a ‘good’ death?” – Workshop with the squeezed generation (C2DE)

This perhaps reflects the finding that participants felt least comfortable talking about the **last days, hours and minutes** of life (see diagram, right) and were therefore less likely to be thinking about what a good death during these final moments of life might look like.



Some reflected that the concept of a ‘good death’ sounded good in principle but queried whether the realities of death (e.g. pain and the emotional state of the individual and family members) made this feasible.

“There’s no such thing as a good death – [it might be] fine for the person who goes but not for the people who are around them.” – Workshop with older people

This was further reinforced by many participants questioning whether there could be a ‘good death’ for the family/ friends of those dying. Fears for family and friends tended to echo concerns raised around what happens **after death**, when family/ friends may be grieving or dealing with financial matters (e.g. paying for a funeral).

“No such thing as a good death - fine for the person who goes but not for the people who are around them.” – Workshop with older people

As participants engaged with the Departure Lounge and the workshop discussion, they were encouraged to further think about the idea of a ‘good death’ and what is important at the end of life.

Muslim faith participants tended to talk about death and dying from a cultural and religious perspective. This focused on preparing for death and a good afterlife.

Implications for policy and practice

- Scope to engage the public more on the stages of dying and death and focus on the last days and minutes; but this requires awareness that those with strong faith may not wish to engage with the discussion at the same moments or in the same way as others and that there may be variation in perspectives within and between different faith communities.
- Opportunities to fill gaps in knowledge; that dementia is a leading cause of death, and therefore encourage the public to think about what this death might involve and what patients’ and families’ needs might be.

- A need to communicate differently with different age groups; but opportunities for all to benefit.
- Support from the public to engage with children and young people on the subject of death and dying, possibly through use of the Departure Lounge installation.

Healthcare and palliative care

This chapter explores participants' knowledge of palliative care including their understanding of what palliative care is, where it is delivered, who is entitled to it, and who delivers it; and the implications for developing future palliative care.

Awareness of term 'palliative care' was generally low across the workshops. Younger people typically had not heard of it.

"I've never seen that word before, but the first syllable is 'pal' like as in your friend? That's why I suspected it was to do with being supportive and being a friend." – Workshop with the squeezed generation (C2DE)

Those who had heard of it had typically heard via friends or family or through their own experience of a family member dying. Recognition of the phrase was highest amongst older participants.

What palliative care is

There was a lot of confusion amongst participants regarding what palliative care is, where it is provided, who was entitled to it, and who delivers it. Participant's views were often confused with reports and experiences of other healthcare services.

Spontaneously, participants struggled to articulate what palliative care was. Older participants were most likely to give their views on this.

"Make it an easy and nice death." – Workshop with older people

"Minister or Rabbi told medical staff what they could or couldn't do." – Workshop with older people

There was some confusion amongst participants about the aim of palliative care. Again, older participants felt most confident in understanding this, whilst others were unsure.

"They don't aim to prolong your life just make your life comfortable." – Workshop with older people

"Personally, I don't agree with it fully - I would allow the illness to progress naturally and not interfere with what's supposed to happen." – Workshop with people of Christian faith

Participants were provided with a definition of palliative care:

“End of life care includes palliative care. If you have an illness that can't be cured, palliative care makes you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you and your family or carers.”

Participants were often surprised and interested that this kind of palliative care would be holistic in approach, reflecting both physical and emotional needs. For some there was particular comfort to think that this support would extend to family.

Others were more informed and said they did expect palliative care to be holistic in nature, and that this was a particular benefit.

“I'd expect in this day and age there is support for the person and the family as part of the health service. It's also about emotional wellbeing - it's a supported journey.” – Workshop with people of Christian faith

For those who had already had experience of palliative care, the idea that it is holistic reinforced the positive experiences that they had had.

“I've seen someone in palliative care and they were looked after so much.” – Workshop with people of Christian faith

However, among those with less experience, further questions were raised about where it would be delivered, who would provide it, who was entitled to it, and whether it would reflect cultural/religious beliefs and practices. Muslim faith participants felt that there would be a social stigma associated with palliative care. This focused on the emotional and spiritual elements of palliative care (rather than the medical aspects e.g. pain management) and the idea of the NHS providing this type of support. Participants noted that they would feel ashamed to access this because it could be seen by family and/ or the wider community as a sign that they, or their families, were not sufficiently religious or dutiful. Participants noted that the older generation in their community would turn to faith for support and strength and would expect the younger generation to do the same.

“In my religion we pray for the person. And we believe that until the person has gone there is a chance for the person to live, so we can't talk about death and dying in such circumstances.” – Workshop with people of Muslim faith (female)

“My mother would not understand why I would want to talk to someone if I was depressed. She would tell me to pray, read the Quran or tell me off for not praying five times a day. The elders in our community won't talk to someone else about their feelings. I also feel that when I read the Quran it does ease my mind and I feel much better.” – Workshop with people of Muslim faith (female)

“When someone has passed away we are supposed to be praying, thinking and praying to god for the person and not talking to a therapist about it.” – Workshop with people of Muslim faith (female)

Muslim faith participants felt that palliative care would need to be communicated to their community in a sensitive way and at the right time, clarifying how it would be delivered in a way that reflected their cultural context.

Where palliative care is provided

There was some confusion over where palliative care is provided. Overall, there were mentions of hospital, hospice or home.

There were varied experiences and perceptions of what a hospice is. Some negative perceptions conflated hospices with care homes, which participants associated with poor experiences of care.

“I think it [palliative care] is provided mostly in hospices, with a bit in care homes, and hospitals do not have the bed space.” – Workshop with people of Christian faith

“Respect and dignity are important because you get bad reviews of care homes.” – Workshop with the squeezed generation (ABC1)

Across the workshops some participants shared positive experiences of hospices, which others found interesting and surprising. This was supported by information in the Departure Lounge about hospices.

“[I] found it a bit weird when [I] went in...all the rooms were really nice - in the canteen everywhere people chatting like they have just met over coffee! You wouldn't think there were people upstairs dying, couldn't get my head around it, because everyone was so happy.” – Workshop with the squeezed generation (ABC1)

“My Auntie was in a hospice...I was astounded by how people looked after her, it was like a 5-star spa place, room, her room was almost personalised, my cousins could stay overnight with her, there was nothing they wouldn't do, it almost seems like she wasn't going to die. If you're [going to] go I'd love to [go] somewhere like that where I'm treated with respect and dignity, people can come and go as they like. The whole thing was a completely different experience. It made me feel better when my Aunt was in there, there was nothing more I could have done for her, for people coming and going, it was amazing.” – Workshop with the squeezed generation (ABC1)

There were also mixed views about whether palliative care could be provided in hospitals.

“I think palliative care is provided in hospices but not in care homes and hospitals don’t have the bed space.” – Workshop with people of Christian faith

Some felt that hospitals would be an uncomfortable place to receive palliative care or that hospital staff would not be trained to deliver this type of care.

“In hospital you are in a very controlled environment...you are not in control, you are subject to a lot of processes and assessments. Palliative care means you can have the biggest and greatest level of control because you’re not bound by clinical.” – Workshop with the squeezed generation (ABC1)

Some Muslim faith participants noted that it would be very important for people in their community to be at home. They noted that the Quran states that it is a duty of the children to look after parents when they are old, and therefore the idea of parents living in settings such as a hospice or care home was felt to go against religious belief.

“For me looking after my parents would be to spend time with them and take care of them at home, rather than in a five-star care home.” – Workshop with people of Muslim faith (male)

Who is entitled to palliative care

Participants queried who was entitled to palliative care, and whether individuals needed to pay for the care. This view was often the result of participants conflating palliative care with care homes which they were aware were often privately funded. Views were also influenced by broader views about access to NHS services, with mentions of a ‘postcode lottery’ for healthcare.

“It’s such a grey term. It makes me question, they’re saying the UK is the best place to die - I get that, we have an NHS...but it’s a postcode lottery.” – Workshop with younger people

This view extended to some querying whether you needed to specifically ask for this type of care or would be automatically offered it if required.

“You have to ask for it.” – Workshop with older people

“You’ve got to fight for your service, if you don’t know, people won’t pass on the knowledge.” – Workshop with older people

There were also queries around whether you would still be able to access palliative care if you had previously refused treatment.

Across the workshops many participants expressed surprise that palliative care included ‘psychological, social and spiritual support for you and your family or carers’.

Those who were particularly engaged by this idea had previously expressed concern for family members, often thinking about what support they might need once bereaved.

Some were aware that this type of support for families was provided by charities.

“Macmillan don’t leave you when that happens, they continue until you get back to a normal way of life.” – Workshop with older people

Those less engaged by this idea of support for family noted that this type of support was provided within their community. This reflected cultural and religious practices.

“We [Jamaican culture] have a party for days afterwards and you are not alone...if you go upstairs and come down there is someone in the house.” – Workshop with the squeezed generation (ABC1)

However, there was some broad interest in the idea of this support but queries around how it could be offered in a culturally sensitive way. Amongst Muslim participants there was a suggestion that this type of support could be more useful after bereavement rather than before.

Who delivers palliative care

Overall there was confusion over who delivers palliative care. Some participants associated palliative care with charities (particularly younger participants) and assumed that they provided this type of care. Others felt that it was offered by the NHS or through private healthcare but there was an assumption that it would be provided by specialists, and a focus on emotionally supporting the family as much as the patient.

“Groups who do palliative care are very good at dealing with it - they know it’s heart-breaking for the family and they do care which is very comforting - it takes the pressure off.” – Workshop with older people

“It is not usual that they support family members. I know that the focus is on the patients. But I know these days charities like Macmillan do a lot to support families and the patients.” – Workshop with people of Muslim faith

Some participants noted that this type of care for relatives who were at the end of life, and family around them was carried out by family, community and faith leaders. This reflected cultural and religious practices.

“In my culture [Islamic] your parents look after you so then you look after them in return...when my Mum was dying they offered a hospice and I said no, but now I understand it a bit more can see the role and purpose of it.” – Workshop with the squeezed generation (ABC1)

There was push-back amongst Muslim faith participants, in particular about emotional and spiritual support being provided by the NHS with queries around how this would be culturally sensitive and whether the NHS had the resources to provide in a culturally sensitive way.

“The elders are involved in such conversations [about ensuring spiritual support]. It is normally the community that gets involved.” – Workshop with people of Muslim faith (male)

Overall, there were some comments - from those with experience - that there could be a disconnect between family/ community and healthcare professionals. These participants felt that decisions were made without fully discussing these with the family and highlighted the importance of keeping family involved in care decisions.

Mini-discussions with the public

It was mentioned that a better understanding of palliative care among the public might help to de-stigmatise the subject and therefore encourage people to talk more about it.

“[People need more] education about the role of palliative care and how it can help people get through a difficult time.” – Chinese female, Buddhist, aged 27

Implications for policy and practice

- This research suggests that for the public, medical treatment and personal, ‘soft’ care are each seen as quite different things; hospitals delivering medical ‘cures’ and other bodies, charities or friends and family, providing comfort and easing emotional distress. There could be scope for research or communications to help identify and communicate how the psychological and emotional aspects of dying relate to the physical aspects. Further research could investigate how healthcare professionals can best balance the needs of the patient for certain types of care, and the needs of the family to be involved in decisions about how this care is delivered.
- There is a need for communication with the public, so that people can understand that palliative care is a way of helping the whole patient, and where the opportunities are for medical and caring professionals to support families and carers.
- It is considered crucial that any provision of pastoral or emotional support be provided in a way that reflects and enables cultural and religious practices and beliefs.
- For some, especially people of Muslim faith, there are parts of care which are seen as not part of the remit of medical practice; in fact, palliative care could be rejected or seen

as intrusive at an already stressful time as it may be considered to be something the family, faith community or a community organisation should provide. Further research could identify how families could be best supported and how the NHS and other bodies can help wider communities e.g. faith communities and carer groups.

What is important at the end of life?

This chapter explores what participants felt was important at the end of life, and the implications for future research and communications.

Throughout the workshops there was strong agreement that end of life and any care received or provided during that time should embody **dignity and respect**.

“This is the most vulnerable time [in life].” – Workshop with the squeezed generation (C2DE)

“[Palliative care] can make you comfortable and give you the dignity you need.” – Workshop with the squeezed generation (ABC1)

“Keeping your dignity...no one feeding you or cleaning you.” – Workshop with older people

Three key factors were seen as crucial to **enabling** dignity and respect; agency and control; choice and flexibility and support. These factors are shown in the diagram below.



Across the workshops, participants felt that dignity and respect at end of life should be reflected in the following ways:



Where you spend the end of your life

Participants agreed that there should be **choice** over where you spend the end of your life, and that this was a personal decision. A range of places were mentioned including home, hospice and hospital. Some acknowledged the potential for logistical and financial difficulties in enabling loved ones to die ‘back home’ in their country of birth.

“Most of my friends are first generation immigrants [who] want to be buried at home [but] can they afford it?” – Workshop with younger people

As mentioned earlier, there was some confusion over what a hospice was, how you get there, and mixed perceptions of what the experience would be like if in hospital or hospice.

“Can you choose your own hospice - I don’t know how it works.” – Workshop with older people

Some participants specifically noted that it would be important to have privacy, citing negative experiences of relatives dying on a ward.

“If they’re in their last stage give them a private room.” – Workshop with younger people

Participants in the young people workshop who had not been born in the UK, or whose parents had not been born in the UK, noted that some people may choose to return to their native country and wondered how this would be facilitated from a financial perspective.

Some felt less comfortable with the idea of dying at home noting that it could make it emotionally difficult for the family to continue living in the home after the person had died there.

Across the workshops, in line with cultural or religious practices and expectations, participants with strong faith practice would choose to spend the end of their life at home, as this would enable them to stay among family members, have better access to religious, spiritual or other community leaders, and the freedom to practice any rituals and traditions.

Spending time with loved ones

Spending time with loved ones at end of life frequently emerged as a central factor when thinking about what was important at end of life for a range of reasons:

- For the person dying to share their time with the people in their life that were important to them.

“I want to make my peace with everyone...I don’t want any drama when I’m going, I just want to go peacefully like in the film Ghost and follow the light...your hearing is the last thing that goes, so you can still hear people around you.” – Workshop with the squeezed generation (ABC1)

- For family members to share their time with the dying person.

“With my great grandmother they were expecting it, so we organised a family reunion with people all over the world to tell her how much she was loved.” – Workshop with the squeezed generation (C2DE)

- To share family histories, creating memories and ensuring the legacy of the person dying.

“I had questions for my grandfather about things in the past - what happened, how did you end up in England...so I could pass this information on.” – Workshop with the squeezed generation (C2DE)

“My gran is really good at making cakes and she’s got a really unique recipe and it was really important to learn that recipe.” – Workshop with the squeezed generation (C2DE)

Participants felt that **flexibility** and **support** would be required to enable people to spend time together.

Participants felt that hospitals are currently set up for visiting from small nuclear families, and this was seen as not wholly meeting the needs of different family groups.

“[As a Muslim] we would need to have the whole family around which can be hard in hospital when there are too many people.” – Workshop with the squeezed generation (ABC1)

It was agreed that workplaces and educational institutions had a role to play in ensuring that people had compassionate leave and enough time away from work/education to spend time with the dying person. There were both positive and negative stories about this amongst participants including examples of being able to defer a University place for a year, to family members struggling to secure time off work to spend time with a dying parent.

“I don’t think there is enough support in the workplace. When my grandfather was ill there was a problem with my mum trying to get time off work.” – Workshop with the squeezed generation (C2DE)

Making your wishes known

Across the workshops there was much discussion about putting plans and wishes in place. These typically focused on plans for what would happen after you died, again reinforcing that participants felt least comfortable talking about what happened in the last days, hours and minutes of life and tended to focus on what happens before or after this time.

It was clear that participants felt a desire to exert **control** over practicalities for what would happen after they died.

“You want to know you’re not leaving a mess behind.” – Workshop with older people

This often focused on financial planning and making plans for a funeral.

“You may not feel you’re rich, but you want to make sure the right people get the things you’ve worked so hard for over the years.” – Workshop with the squeezed generation (ABC1)

“What I witnessed with my grandmother was what was important to her was paying for her own funeral and allocating certain amounts of money to certain people and she had organised her own funeral down to the music so for her it was all about passing without being a burden and letting everyone know her wishes.” – Workshop with the squeezed generation (C2DE)

Impact on surviving family was often the key consideration when thinking about plans and wishes. This included putting plans in place so that support would be available to family members, finances or decisions regarding funeral plans would not need to be made or reducing the pressure for family members to make these types of decisions especially where they were unlikely to have been discussed.

“It was comforting to know his [father’s] wishes and what he wanted because...[we] don’t always talk about it.” – Workshop with the squeezed generation (ABC1)

Impact on surviving family members was mentioned by participants across the workshops. In particular, some Muslim participants noted that a key priority for married men in their community would be ensuring they had discussions with the extended family to discuss what the status of their surviving wife would be in the family. This reflected traditional structures in Asian families regarding the role of women/wives in family decision making.

Across the workshops there was also a strong sense of putting financial plans in place to avoid being a burden on family members.

“I think for me it would be about not being a burden on my children.” – Workshop with the squeezed generation (C2DE)

Participants noted that these types of plans were often done without any discussion with family members. Some felt that this was the way they would prefer to do this, to minimise upsetting family members. However, there was a reflection that this would be a lonely process and perhaps benefit in making this process more supported and conversational.

Making your wishes known was for most associated with putting a will or funeral plans in place, with very few participants thinking more broadly about the other types of wishes that might be relevant to express towards the end of life. A few did mention wishes and **choices** around refusal of medical intervention and treatment. These participants anticipated that these types of wishes could be difficult to accept for family members.

“The hardest thing will be to give the dying person what they want even if you don’t think it’s good, respecting their decisions without resentment.” – Workshop with the squeezed generation (ABC1)

Whilst visiting the Departure Lounge, participants noted information about making these types of end of life decisions and reflected that it was something they had not previously considered.

Expressing your personality and beliefs

Participants felt that it would be important that people had the **choice**, and **agency** to express their personality, cultural and religious beliefs at end of life.

“Dignity is a key word, I wouldn’t like people to pity me, in fact the opposite, I would want people to let me be myself, respect my little routines for what it’s worth.” – Workshop with the squeezed generation (ABC1)

“Being able to make decisions about how your day plans out, what’s in your room, who you get to see.” – Workshop with the squeezed generation (ABC1)

Participants felt that **flexibility** and **support** would be required to enable people to express themselves in these ways. This included support and flexibility from hospital or hospice to facilitate this.

The idea of expressing personality at end of life was often something that participants had not previously thought about, although expressing personality after death through your funeral was much more commonly cited (e.g. music choices). With this in mind, participants were often surprised but inspired to think about ways in which personality could be expressed and reflected at the end of life.

“I would want it to mirror what it would be like as if I was at home so the only difference is location - flowers, nice room, people say ‘hi, how are you?’, help me get dressed and make me feel nice and put my lip-gloss on, so I don’t have time to think about, and until it happens I will [be] fighting to the end, treat me with respect.” – Workshop with the squeezed generation (ABC1)

Muslim faith participants talked about the importance of prayer and preparing for the final journey and a good after life when preparing for end of life. This included making financial plans (will, clearing any debt); ensuring provision for family (wife, children); a trip to Mecca; doing good deeds such as charitable donations.

“As a Muslim faith is very important...we as a family want to pray more and recite Quran when people are in agony, we feel peaceful and we believe in afterlife so the more you recite the more we are preparing for that.” – Workshop with the squeezed generation (ABC1)

Christian faith participants mentioned the importance of Last Rites and the role of the church in helping individuals and families feeling prepared for death.

“The church is very supportive – the priests will agree to visit the patients wherever they are.” – Workshop with people of Christian faith

It was felt strongly that family, community and faith leaders would provide this type of support and it should not be within the remit of the NHS.

Being comfortable

Participants talked about being emotionally and physically comfortable at the end of life. Physical comfort tended to focus on making sure that the person dying was not in pain and was often aligned with receiving pain management **support** from the NHS.

“It’s about knowing you have no choice and accepting it...if you are in so much pain then people just want it over and done with.” – Workshop with the squeezed generation (C2DE)

Muslim faith and Caribbean participants strongly felt that this type of support (aside from medical needs) would be provided by family, community and faith leaders.

However, it should be noted that very few participants spoke openly about the physicality of dying, again reflecting the lack of comfort in thinking or talking about the last days, hours and minutes of life.

Emotional comfort included feeling at peace, without regrets, and not feeling alone or scared.

“[Important to] make people feel special, they are still worthy and important...we are fighting this with you...must be scary for them but they might think they can’t show it, so you talk about something and nothing because they don’t want to make it scary for people around them.” – Workshop with the squeezed generation (ABC1)

Some talked about the importance of interactions from healthcare professionals during this time, noting that they hoped that they would be sincere, “offer care from the heart”, and get to know the person dying to support both physical and emotional needs.

Female Muslim faith participants noted that any discussions around care would typically take place between healthcare professionals and the older generation in a family. This has practical implications for issues such as advanced care planning decisions, establishing roles for the rest of the family, and identifying key decision makers.

“It is usually the older people in the family take charge. Even though it should be a matter between the husband and the wife [in the scenario where one of them is nearing end of life], it would be both sets of parents involved in the conversations.” – Workshop with people of Muslim faith (female)

Mini-discussions with the public

Having choice at the end of life was felt to be very important to visitors to the Departure Lounge. In this context, having choice means being able to choose: where to die, who will be there, who is involved in the discussions and decision-making, and the type of care and

support received. The importance of having these wishes respected was made clear by the visitors.

When thinking about what is important at the end of life, the public mentioned dying at home or in a comfortable place, being surrounded by friends and family and not being alone, having the support you need from medical staff (physical and psychological needs met), maintaining dignity (being clean and eating well and attended regularly if unable to look after oneself), and not being in pain (by way of access to medication and pain relief).

“Being alone and fearful, not knowing what to expect and not having choice [would affect quality of life at the end of life].” – White female, no religion, aged 29

Implications for policy and practice

This research has drawn out the priorities of patients and families for palliative and end of life care. Dignity, choice and agency are all important, and can be achieved in different ways:

- Whilst participants were clear about taking **control** and making practical plans and **choices** (financial) for their death they typically had not considered how they would like care to be managed at the end of life. Further research and communication may be needed to identify the kinds of care available, and the choices which might come up whilst deciding.
- End of life care should **support** time spent with friends and family; e.g. hospitals providing **flexible** visiting times and allowing multiple members of the family to spend time with the person dying.
- It was considered crucial that any care provided be flexible to support the **expression of personal values and beliefs**. For example, Muslim faith participants felt that this should include a reflection that this type of support actually does not fit within the remit of the NHS. In future, the NHS will need to consider how it allows other agencies or community workers to play a part in the end of life, rather than the hospital or medical community wholly “owning” the space of death.
- There should be **choice** offered as to **where** the patient should be; there is scope for different research to identify the different kinds of support necessary in hospital, at home, or in a hospice. There may be a need to support families to make the right choices for them and enable them to have as much choice as possible by offering choice at the right moment.

- There is scope for all end of life care settings to offer more joined up social care. Participants in our research would appreciate assistance for the person dying around setting their affairs in order. Participants prioritised the opportunity to '**make their wishes known**'. Therefore, it may be useful to put in place access to legal advice, financial advice, or other mediation and support, or for end of life care to link better with agencies which provide this. This might help both family and healthcare professionals navigate difficult decisions processes, e.g. choosing whether or not to refuse further interventions. While these linkages are not necessarily within the scope of traditional healthcare, they may be what the public want in the future. (See trends chapter for more details).
- Dying at home is takes on greater importance for some faiths and cultures.

Broader social trends around death

This chapter describes some of the changing social attitudes around death that we observe. Here, we identify both strong and weak signals of how attitudes to death may be evolving and changing.

Selecting the right trends

To create these trends we have selected five themes from Ipsos MORI's Global Drivers of Change, which are drivers Ipsos MORI has identified as being relevant in 2019 across a wide range of consumer, social, business and government contexts. Ipsos MORI has identified these drivers from the cumulative findings of the full range of their survey, qualitative and advisory work with clients across many sectors.

We identified five drivers of change we thought have particular relevance to the challenges of end of life care in the UK. In summary, these are below, along with how they might impact the world of death and palliative care.

1. Changing Authorities

The democratisation of authority that stems from our increasingly connected, disrupted and diversified world. Governments and brands have had to find new and less formal ways to speak to their citizens and consumers to be heard amongst the noise.

Journalism is a good example of this; newspapers compete for our attention alongside online publications, forums, and social media; different voices speak differently, and the idea of "truth" or "advice" is changing.

In death and palliative care, this means we may see discussion of the issues via non-traditional authorities; online support systems, popular literature (autobiographies, non-fiction and fiction), smartphone apps.

2. The Experience Economy

Technology and disruptive brands have increased the expectation that products and services should be seamless, immersive – even gamified. Fast, smooth and transparent connections have become the norm in many industries: others are expected to keep up. Amazon is a strong player in this space; the Director of Amazon music has spoken at length about the importance of removing friction points in order to 'carve out the path of least resistance for your customer.'⁵ Same-day delivery, dash buttons and predictive algorithms means that simple processes like buying a toilet roll are now part of wider service integrated effortlessly with everyday life. McKinsey say that 'personal-

⁵ <https://firstround.com/review/amazons-friction-killing-tactics-to-make-products-more-seamless/>

consumption expenditures (PCE) on experience-related services... have grown more than 1.5 times faster than overall' levels.⁶

In this world, different people feel newly validated to talk about taboo subjects like death. The possibilities of personalised products and services, sometimes even including augmented and virtual reality, might change our expectations of death and bereavement.

- 3. Micro-knowledge.** More and more data is collected about us, including the data we give freely and consciously and the data which is collected as we go about our lives, through our smart phones, credit cards and so on. In the future we will have vast amounts of data available on individuals, including information on genomics, nutrition, behaviour, as well as the evidence we all leave behind us of thousands of interactions on the internet. When we die, we will potentially need to integrate the data we leave into the process of dying; our friends and relatives may be able to memorialise us differently, and there may be changes in law around who is able to access and use the data we leave. This may change social expectations of identity, privacy, and how we prepare for our deaths; such as 'death cleaning'.

4. Flexible Expectations

Flexible working, living and being has become the norm. Renting is on the up – ownership is down, whether it is flats, transport systems or luxury goods. Concepts too are becoming more flexible; gender role are seen as less binary, the gig economy has disrupted the idea of a 9 to 5 job and work increasingly takes account of caring responsibilities or life outside work. Governments and brands have had to respond to a society that is flexible, modular and less certain; people expect to be able to exert choice and control over all aspects of their lives. The biggest implication for the way we die is the growing call for assisted dying to be legalised; with significant implications for how end of life care is considered in future. However, it is acknowledged that assisted dying did not feature in the content of the Departure Lounge.

5. Repair the World

A growing awareness of environmental concerns has led to an increase in demand for sustainable and ecologically friendly products and services. Governments and brands are expected to be proactive and aware. This driver of change might promote ecologically friendly burials, cremation, water cremation and other sustainable practices.

⁶ <https://www.mckinsey.com/industries/private-equity-and-principal-investors/our-insights/cashing-in-on-the-us-experience-economy>

Exploring sources

To complete this analysis, we researched a wide range of sources. These included:

- Google Trends and our social media intelligence suite, Synthesio⁷. This gave us a point of view of how people were thinking and talking about death and dying in the UK.
- Brief literature review of various books recently released on this topic. These included: *Being Mortal* by Atul Gawande, *When Breath Becomes Air* by Paul Kalanithi, *The Iceberg* by Marion Coutts and *Until Further Notice, I am Alive* by Tom Lubbock.
- Intensive research into online sources published by newspapers, academics, charities and organisations. The work of The Global Wellness Institute and The Global Wellness Summit was particularly rich. We also read work by The University of Southern California, Columbia University, and The Wharton School of the University of Pennsylvania. Publications by the BBC, The Guardian, The Atlantic, The Independent, The Spectator and Forbes were also analysed.
- Review of promotional literature from crematoriums and funeral parlours.
- Review of online forums and social support groups.

A full bibliography is included in the Appendix.

Changing Authorities: change in traditional channels of information and voices of authority

We see this trend is already affecting end-of-life care and is likely to continue to do so; the cult of wellness, decline of religion, and dissemination of scientific information are reshaping people's experience and expectations of death.

Decline of Religion

Active participation in religion has declined in the West, which has destabilized traditionally religious ceremonies like marriages, christenings and funerals; the emotional ritual remains compelling while the scaffolding does not. On the physical side, it has subverted traditional expectations of churches and graveyards or undertakers and priests, and from a psychological perspective, risks a vacuum in end-of-life ritual. Christianity was the most prevalent religion in the UK, but this is decreasing, which has consequences for the funeral industry.⁸ Cremation was traditionally unpopular in Christian religions due to historically pagan connotations and the Biblical idea of resurrection; however, cremation is increasing exponentially and is now the most popular type of funeral in Britain and other Western countries⁹. 'Dead and buried' is no longer a given. Churches may not feel appropriate for secular funerals, and the expense – and often

⁷ <https://www.synthesio.com/>

⁸ https://en.wikipedia.org/wiki/Religion_in_the_United_Kingdom#Attendance

⁹ <https://news.usc.edu/143438/what-we-think-about-death-and-funerals-is-changing/>

impersonality – of funeral parlours is leading to a growing interest in home funerals, both the wake and some cases, a more protracted grieving process.

The authority of the funeral director is diminishing in many cases, as families and friends want and expect a more personal and involved role. Life has become individualised, and transparent: people are coming to expect this from the end-of-life too. The semiotics of grief are shifting away from black, bowed heads, and flower arrangements to a more flexible and uncertain process of letting go. “We’ve begun rejecting the institutionalized version of aging and death, but we’ve not yet established our new norm. We’re caught in a transitional phase... With this new way, in which we together try to figure out how to face mortality and preserve the fibre of a meaningful life, with its loyalties and individuality, we are plodding novices. We are going through a societal learning curve, one person at a time.”¹⁰

This may, in part, be due to the increasing multiculturalism in Britain, which generates new ideas and brings old ones into question. Muslim families frequently personally wash their deceased relatives; open caskets are common at Hindu funerals and cremation is the status quo.¹¹ Many funeral companies offer Humanist burials, or more natural funerals; Dignity offers a non-religious Humanist burial which can take part at a ‘cemetery, crematorium or woodland burial site.’¹²

Diverse cultural exposure offers alternatives to religious tradition, which can be seen in the trend of ‘FUN-erals’ with their focus on celebrating life as much as mourning death.¹³ The decline of religion is likely to continue, as it is more pronounced in younger generations, who are therefore less likely to raise religious children.¹⁴ Even if this were not true, the less religious young currently alive are less likely to have religious funerals, driving the growth of secular alternatives.

Private becomes Public

Professor David Sloane argues that from the 1830s to the mid-20th Century “grief was something that was supposed to be very private,”¹⁵ but that subsequent decades have seen private emotion enter the public sphere. Traditional media figures, like journalists or television/radio presenters, are able, even encouraged, to talk openly about personal experiences, death and bereavement included, that transcend their area of expertise. This can be seen in the publication of quasi-medical books surrounding illness and death, that are often written by people with no experience in grief-counselling, psychology or medicine. The internet,

¹⁰ Atul Gawande (2014). *Being Mortal*, page 217. Published in partnership with the Wellcome Collection.

¹¹ <https://www.spectator.co.uk/2014/11/death-wears-bling-the-glory-of-londons-caribbean-funerals/>

¹² <https://www.dignityfunerals.co.uk/arranging-a-funeral/types-of-funeral/alternative-funerals/humanist-funerals/>

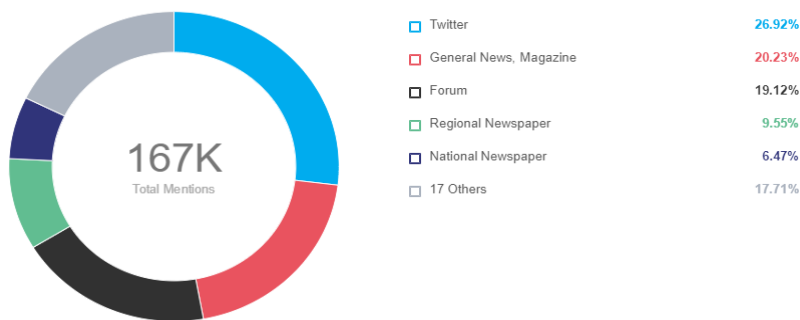
¹³ <https://www.independent.co.uk/life-style/health-and-families/features/what-a-lovely-send-off-fresh-thinking-for-funerals-8212369.html>

¹⁴ <https://www.pewforum.org/2018/06/13/young-adults-around-the-world-are-less-religious-by-several-measures/>

¹⁵ <https://news.usc.edu/143438/what-we-think-about-death-and-funerals-is-changing/>

however, allows authority to pass even to relatively anonymous figures: twitter, forums, YouTube, Quora, and more, are platforms that allow anyone to share their experience and to be ascribed authority.¹⁶ Podcasts are another medium for sharing; there are numerous podcasts – both serious and humorous – focussing on the personal, historical, scientific and mysterious elements of death. Due to the human propensity for personal experience, anecdote and stories, their activity can change the balance of power between medical professionals and patients¹⁷ – particularly when combined with other cognitive biases like anchoring, optimism bias, confirmation bias, or the continued influence effect.¹⁸ The balance of conversation has shifted from traditional media to twitter even in the past year, despite twitter use overall plateauing.¹⁹

Media Type Share of Voice

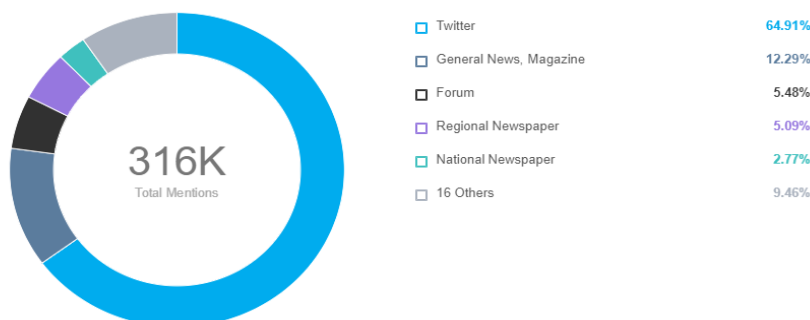


SOCIAL MEDIA MENTIONS OF DEATH 2018 VS. 2019

In 2018 Twitter was responsible for only 27% of the mentions of death, with general news taking 20%. By 2019, 65% of the conversation took place on Twitter, while general news only accounted for 12%.

The number of Twitter users has not grown in this period.

Media Type Share of Voice



¹⁶ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

¹⁷ <https://www.theatlantic.com/health/archive/2013/08/how-social-media-is-changing-the-way-we-approach-death/278836/>

¹⁸ Anchoring is the tendency to over-value the first piece of information encountered; optimism bias is the tendency for people to believe they are at less risk of experiencing negative events than others; confirmation bias is the tendency to notice, remember or seek out information that confirms current beliefs/opinions; the continued influence effect is the tendency to retain beliefs that have been discredited/proved false.

¹⁹ <https://www.theverge.com/2019/2/7/18213567/twitter-to-stop-sharing-mau-as-users-decline-q4-2018-earnings>

Cult of Wellness

Wellness has become a movement and an industry – but in a world where wellness is synonymous with health then we are living in a society which does not have a place for death.

The Global Wellness Institute points to increasing costs of healthcare as a catalyst for the movement: ‘by 2014, more than half of global employers were using health promotion strategies... and self-help experts who promote wellness (such as Drs. Mehmet Oz, Deepak Chopra and Andrew Weil) became household names.’²⁰ However, at the Global Wellness Summit, it was argued that we are living in “an increasingly death-denying society” due to “a Silicon Valley biotech industry that now aims to “cure death” and radically extend life” and “The wellness world itself, with its insistent stay young, do-this-and-don’t-age messages.”²¹ Billionaires like Mark Zuckerberg are investing heavily in disease eradication and Google’s Calico states that its “mission is to harness advanced technologies to increase our understanding of the biology that controls lifespan.”²²

While dying well is desirable, the dying process is now likely to be longer than ever; dying is becoming a life stage, not a moment. As such, it is likely that wellness and death will come closer together. At the Global Wellness Summit, it was argued that “we now must tackle dying well...or how can we lay claim to ‘wellness’ at all.”²³

Reclaiming the Taboo of Death

As new voices and informal styles break the taboos of what we can talk about, there is a new interest in discussing death. The Atlantic argues that “the growing “death movement” is a reaction against the sanitization of death that has persisted in American culture since the 1800s.”²⁴ Death dinner clubs are becoming popular, with one – Death Over Dinner, having “organised more than 200,000 dinners, translated to nearly a million people served.”²⁵ Death Cafés are a further manifestation of this trend. Jon Underwood founded Death Cafe in 2011.²⁶ These events demonstrate the human desire to engage with death: “nearly a million people have downloaded the starter kit for the Conversation Project, a guide to discussing plans for the end of life... believing that the silence impoverishes the lives leading up to it.”²⁷

²⁰ <https://globalwellnessinstitute.org/industry-research/history-of-wellness/>

²¹ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

²² <https://www.independent.co.uk/news/people/mark-zuckerberg-is-giving-3-billion-to-cure-all-disease-a7322071.html>; <https://www.calicolabs.com/>

²³ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

²⁴ <https://www.theatlantic.com/health/archive/2013/10/death-is-having-a-moment/280777/>

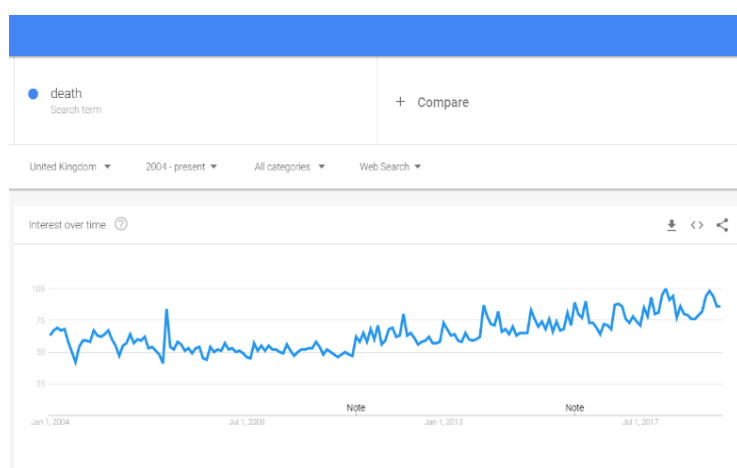
²⁵ <https://screenshot-magazine.com/the-future/how-to-prepare-for-death/>

²⁶ <https://deathcafe.com/profile/2/>

²⁷ <https://www.nytimes.com/2018/06/22/nyregion/the-positive-death-movement-comes-to-life.html>

Are we getting good advice?

In the next decade, we may see a wider range of new authority figures emerge in the form of global medical providers (e.g. GP apps) or AI entering this sphere to diagnose, treat, prescribe, or even console. We must ensure the official channels of information match pace with the unofficial ones. Research for Compassion in Dying discovered that “a third of dying people... had not been given enough information about the options available to them.”²⁸ Given the proliferation of information online, it will be increasingly important to ensure misinformation is not spread – and that structured and consistent support through official channels remains available. With tens of thousands of people using Facebook support groups like GriefShare or GriefAnonymous or posting on forums like mumsnet or Reddit (which has multiple subreddits centred around death with over 10,000 members) it is likely that these unofficial channels are a primary means of support for some.



GOOGLE TRENDS

The amount of people searching for 'death' on Google has risen in the UK since 2004. We can conclude this using Google Trends, which evaluate the number of searches for a given term relative to the total number on Google in the same period.

The Experience Economy: demanding seamless, interactive, gamified experiences

The Experience Economy is the increased demand for seamless, immersive, interactive and gamified experiences, partially driven by the omnipresence of technology, which is all of these things. Disruptive brands, like Amazon, Uber, Netflix, or Deliveroo, which focus strongly on service, also sit behind this driver. In the Experience Economy, everything is connected, and algorithms replace human effort. Smartwatches and apps are a link between the Experience Economy and the healthcare/end-of-life industry. The Experience Economy also drives change through shifting expectations: people begin to expect the same level of seamless interactivity from booking a doctor's appointment as they receive when using an online banking app.

As death becomes more of a phase of life, it is likely that expectations of palliative care will also shift. Multimorbidity (living with more than one long-term health condition) is increasing; many patients will spend the last years of their lives managing different chronic disorders. This

²⁸ <https://www.politicshome.com/news/uk/social-affairs/assisted-suicide/opinion/compassion-dying/100227/culture-change-needed-way-we>

requires flexibility, particularly on the part of medical services, as needs become more dynamic and particular due to the unique interactions of the diseases: “dying has become a phase of our life, instead of being just an instantaneous sort of flash event.”^[1] One response to this could be to expand and nuance the palliative care offering, to meet the demand for a ‘one-stop-shop’ for the myriad needs related to death and dying. Easy access to a singular online platform that prepares people for the different aspects of death will be important if death and disease continue to become a more integral part of old age. A deeper exploration of this can be found in The Academy of Medical Science’s report, *Multimorbidity: a priority for global health research*, which explores the trends, prevention, treatments and management of multimorbidity.²⁹

Augmented Reality

The Experience Economy is strongly linked, and perhaps most at home, in entertainment and leisure. Much has been written about the rise of experience-based holidays, and the same has occurred on a micro-scale in entertainment, with escape rooms and immersive theatre becoming common activities.³⁰ The growing feasibility of virtual and augmented reality – and the subsequent rising excitement surrounding it – is driven by the Experience Economy. While virtual and augmented reality are often synonymous with video games, they also have a practical element: augmented reality can be used to test make-up, trial home décor and even improve healthcare.³¹ It has also been used to create a more interactive graveyard.

In the Future Cemetery project, academics and media professionals worked together using Augmented Reality to create an engaging experience. Using this technology, they were able to tell stories about the individuals buried in that graveyard that went beyond the headstone, to add “depth to the site without altering its historic nature.”³²

Personalisation

The Experience Economy is centred around user experience, and often personalisation is necessary to achieve the seamless immersion it promises. In the private sector, Amazon again is an example of this: the algorithms that it uses make every experience an individual one. The technology that makes the Experience Economy possible sits behind this personalisation; it allows even traditional brands, like Coke, to launch their viral personalised can campaign ‘Share a Coke.’³³

In the end-of-life space, the growing demand for an individual experience is also at play. In part due to the decreasing likelihood that death will be sudden, living funerals – or pre-funerals –

^[1] <https://knowledge.wharton.upenn.edu/article/modern-death/>

²⁹ <https://acmedsci.ac.uk/policy/policy-projects/multimorbidity>

³⁰ <http://www.travelweekly.co.uk/articles/54421/adventure-travel-on-the-rise-claims-research>

³¹ <https://www.forbes.com/sites/bernardmarr/2018/07/30/9-powerful-real-world-applications-of-augmented-reality-ar-today/#62d1d7e62fe9>

³² [https://www.nationalgeographic.co.uk/photography/2019/05/it-time-we-changed-way-we-think-about-death?image=11-10-18%20AV%20AR%20\(65\)](https://www.nationalgeographic.co.uk/photography/2019/05/it-time-we-changed-way-we-think-about-death?image=11-10-18%20AV%20AR%20(65))

³³ <https://www.smartcompany.com.au/marketing/branding/rise-of-personalisation-brand-you/>

have risen in popularity.³⁴ Living funerals make grief a more interactive experience and shift the focus more to celebration. This unconventional approach to death is also seen in FUN-erals, mentioned in the *Decline of Religion* chapter, which have been described as “personalised ceremonies... that reflect their loved one’s true character” by including quirky and individual elements.³⁵ “The new funeral is about orchestrating something that really captures that person—whether at home, an event space, a mountaintop or the beach.”³⁶ Both living funerals and FUN-erals demonstrate the modern tendency to value experiences, and subsequently to personalise them. Technology may soon allow for new ways to personalise the funeral experience; WPNC suggests the “holographic appearance of a dead person at their funeral” might be a viable option by 2040.³⁷

The desire for personalisation can also be seen in Death Doulas, a relatively new phenomenon based on the more established Doula profession. The International End of Life Doula Association (INELDA) offers training for these Death Doulas to enable them to offer a similar level of emotional support to dying individuals as a traditional Doula offers during birth. This care can be both emotional and practical, entailing “everything from where they would like to rest, to what kind of music should be playing at their funeral.”³⁸

Micro-Knowledge: managing huge amounts of data about ourselves

In modern society, there is the ability to know almost anything about almost everything. People know their lives in data: from genomics to credit ratings. The intersection between this and the healthcare industry has the potential to be particularly charged, due to the emotive nature of health, illness and death. While many want to know more about the scientific and medical facet of healthcare, this can lead to increased anxiety: “Not only do they fear death, they also fear what it takes to die. Because it involves so many different procedures, surgeries, etc., that they are very, very fearful of.”³⁹ This intersection between data and death, however, has ramifications beyond personal anxiety.

Death in the Digital Era

Death is on the rise and it will need to adapt to the digital era: “The World Health Organization forecasts that global deaths will jump from 56 million in 2015 to 70 million by 2030—a staggering 25 percent growth”⁴⁰ By 2030 a significantly higher percentage of those dying will

³⁴ <https://www.yourfuneralchoice.com/living-funerals/>

³⁵ <https://www.news.com.au/lifestyle/sunday-style/culture/the-new-trend-is-funerals-with-a-rise-in-personalised-ceremonies/news-story/b6641240f37dcb2454c134a9bf5fb8d2>

³⁶ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

³⁷ <https://wpnc.agency/news/the-year-is-2040-how-have-death-remembrance-changed>

³⁸ <https://screenshot-magazine.com/the-future/how-to-prepare-for-death/>

³⁹ <https://knowledge.wharton.upenn.edu/article/modern-death/>

⁴⁰ <https://screenshot-magazine.com/the-future/how-to-prepare-for-death/>

have an online presence, which raises difficult questions about the future of social media profiles once someone is dead. The issue of the Facebook accounts of the dead has seen heavy news coverage, with the BBC suggesting 5 different ways to manage social media after death - including adding instructions to your will.⁴¹ However, the future of personal data post-death extends beyond online profiles. In 2018 Hossein Rahnama began working on an application called Augmented Eternity which, through capturing this data, hopes to mimic the personality of the deceased.⁴² Elon Musk has taken this yet further, with his company Neuralink which “wants to create a new era of transhumanism.”⁴³ This hopes to achieve a true artificial intelligence based on the deceased:

“The dead live in tech already. There’s dead people’s data everywhere: their Amazon reviews, their Trip Advisor recommendations. You may encounter something that influences you and have no idea whether it is authored by a dead or a live person. The dead remain socially active in a way that is unprecedented. They are undifferentiated, ambiguously there.”⁴⁴

Dealing with our digital ghosts

For social media brands, managing the policy towards the accounts previously owned by deceased people will be a continued challenge; Facebook continues to develop their narrative of connecting people by developing new responses to the death of its users.⁴⁵ Moreover, like many countries, Britain has no legislation on digital inheritance.⁴⁶ This “dearth of legal commentary” is unlikely to continue given the discrepancy with other countries like the United States.⁴⁷

Wealth stored in the digital medium through things like films, games, music and books is likely to increase, making a clear legislative stance increasingly necessary.⁴⁸ This will likely have an impact on policy regarding other elements of a digital legacy, and on the conversations surrounding it. The ethics of data handling, and how companies protect, use and assign ownership of the data of a deceased loved one is likely to be a growing concern.

Death Cleaning

In Sweden, we see the trend of *döstädning* – or death-cleaning. “Death cleaning applies a simple formula to the process of dealing with our possessions before we die...’will anyone I

⁴¹ <https://www.bbc.co.uk/programmes/articles/5nWRmrwXCRxDQD9h1skfYYy/five-ways-to-manage-your-social-media-accounts-after-you-die>

⁴² <https://screenshot-magazine.com/the-future/what-should-happen-to-your-social-media-profiles-after-you-die/>

⁴³ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

⁴⁴ <https://www.theguardian.com/technology/2019/apr/27/elaine-kasket-what-happens-to-data-when-we-die-ghosts-in-the-machine>

⁴⁵ <https://www.wired.com/story/facebook-rolls-out-more-features-dead-people/>

⁴⁶ https://en.wikipedia.org/wiki/Digital_inheritance

⁴⁷ https://pure.qub.ac.uk/portal/files/137420014/Digital_Assets_Grattan_and_Conway_final_.pdf

⁴⁸ <http://www.kluwerlawonline.com/abstract.php?id=EuCML2017055>

know be happier if I save this?”⁴⁹ This demonstrates both an increased presence of death in everyday life and a more sustainable perspective on personal legacy.⁵⁰ As “we are living longer and dying slower” people will be more likely to have the capacity to death-clean – an experience often previously left to family and friends.⁵¹ Doing so would allow people to remove items with little value, sentimental or otherwise, and order their remaining belongings into a curated collection of possessions that they believe should be inherited. This could be a collaborative process, ensuring that stories and memories aren’t lost or forgotten.

Friends Expectations: modular and personalised experiences are the norm

Choice over life length and death positivity

In our society, time and rituals are becoming more flexible; we increasingly shop, eat, get married or divorced, have children, and work, on a more flexible timetable and on-demand. As the potential to extend our lives might increase, the question of whether we should be able to choose life or death becomes more prominent.

As it becomes increasingly possible to extend life despite degenerative diseases, the question of what constitutes life is likely to rise. “Is life just the fact that our organs are beating, or our cells are dividing? Or is death the loss of personhood that occurs in so many disease states?”⁵² The relevance of this question may be reflected in the continuation of the assisted dying debate. In June 2019, the British Medical Association voted to survey the opinions of its members on the question of assisted dying - shortly after a similar decision was reached by the Royal College of General Practitioners, who are now officially neutral towards the concept.⁵³ As a counterpoint to the Silicon Valley biotech industry, who are focussed on extending life, there may be an increase in the public acceptance of choosing death, particularly in the face of terminal illness. This, then, might affect the way we want to be cared for when we are dying ‘naturally’; and the kinds of palliative care we want to discuss. It is noted that this topic did not explicitly feature in the content of the Departure Lounge, although visitors were able to freely discuss ideas or thoughts inspired by the installation.

Repair the World: demand for sustainable options in all areas of life

Climate change, plastic, mass extinction and consumerism are an accepted and troubling facet of modern life, which people recognise the need to respond to in a holistic and increasingly uncompromising manner. Healthcare and death are a part of this growing movement towards

⁴⁹ <https://www.theguardian.com/news/2018/jan/12/how-death-got-cool-swedish-death-cleaning>

⁵⁰ <https://www.titlemax.com/discovery-center/lifestyle/trash-one-person-produces-year/>

⁵¹ <https://www.bbc.co.uk/news/health-43159823>

⁵² <https://knowledge.wharton.upenn.edu/article/modern-death/>

⁵³ <https://www.politicshome.com/news/uk/home-affairs/justice-system/press-release/dignity-dying/104834/british-medical-association>

choices that are better for the world that will survive us. Long life in itself is a concern: “will it become a choice between our long lives and reproduction (mandating zero population growth)? What is a world without new generations and ideas? Who takes care of all these old people? Where will they live?... The surgeon Atul Gawande, in his book *Being Mortal: Medicine and What Matters in the End*, which is about controlling the narrative of one’s own life until the very end, argues that more meaningfully “solving” the “problem” of death would mean funding improvements in palliative care and making people’s end of life more comfortable.”⁵⁴ Even in death, sustainability concerns live on.

Moving from burial to cremation

Cemeteries are not particularly ecologically friendly. Due to population growth, space is at a premium – and some cemeteries are full. “Ecologically conscious people may choose to be cremated or to be placed in natural burial grounds that eschew embalming and pesticides, in some cases with the promise that that land will remain a public conservation area.”⁵⁵ Perhaps in part due to this, cremation is on the rise; “by 2030, forecasters believe the cremation rate will be 70 percent.”⁵⁶ The environmental benefits of cremation over burial are clearly advertised as a benefit, and some companies have progressed to offering an even more sustainable cremation by using eco-friendly coffins and urns.⁵⁷ The resonance of this concern is perhaps demonstrated in the popular 2019 BBC drama *Years and Years* which features water cremation as a more sustainable option than either burial or cremation.⁵⁸

Environmentally friendly burials

An alternative to cremation, which releases carbon, is a more ecologically friendly burial. Cor Geijtenbeek, who co-owns the Dutch design firm Coffin in a Box Company, argues that a sustainable burial is better for the environment than cremation.⁵⁹ Their flat-packed coffin is designed to have a reduced environmental impact. Eternal Reefs offer an alternative, with their environmentally-safe concrete ‘reefs’ which lend the permanency of a graveyard to sea burials. Other such options are biodegradable shrouds, produced by the company Vale, which both reduce the space needed for a grave and do not require wood.⁶⁰ Recycling headstones is a further solution to the problem of burial. In the City of London old graves are being reused; “headstones that meet the requirements for reuse can be turned around and re-inscribed with the names of the newly buried.”⁶¹ This allows people to have a traditional burial and grave in a

⁵⁴ <https://www.globalwellnesssummit.com/2019-global-wellness-trends/dying-well/>

⁵⁵ <https://news.usc.edu/143438/what-we-think-about-death-and-funerals-is-changing/>

⁵⁶ <https://news.usc.edu/143438/what-we-think-about-death-and-funerals-is-changing/>

⁵⁷ <http://www.agreenerfuneral.org/greener-funerals/earth-friendly-cremations/>

⁵⁸ <http://resomation.com/news/water-cremation-in-bbc-drama-years-and-years/>

⁵⁹ https://www.theguardian.com/world/2018/apr/20/from-flat-pack-coffins-to-water-cremation-how-to-have-an-eco-friendly-death_
<https://coffinabox.com/eco-funeral-products/index.html>

⁶⁰ <https://www.theguardian.com/news/2018/jan/12/how-death-got-cool-swedish-death-cleaning>

⁶¹ [https://www.nationalgeographic.co.uk/photography/2019/05/it-time-we-changed-way-we-think-about-death?image=21-01-19%20CLCC%20\(31\)%204](https://www.nationalgeographic.co.uk/photography/2019/05/it-time-we-changed-way-we-think-about-death?image=21-01-19%20CLCC%20(31)%204)

city with severe space challenges. In the future, technology might offer more unusual options for those who want the physical and enduring nature of a gravestone without the environmental challenges. A design group at Columbia University have created the concept of “Constellation Park, a system of hundreds of burial pods suspended under the Manhattan Bridge that together create a twinkling public park.”⁶² While this might seem futuristic, and a little morbid to have death so visible, the issue of death and sustainability is likely to grow. The iconic idea of the gravestone may need to be challenged to reduce the cost of death, both to the family and to the environment.⁶³

Implications for policy and practice

These social trends might affect the way death is imagined and the way groups engage with it the way we manage death in a variety of ways, both significant and niche.

- **Flexible Expectations** has the greatest potential to disrupt the healthcare industry if the growing demand for flexibility, choice and autonomy leads to the legalisation of assisted dying; recent announcements by institutions like the British Medical Association indicate this might happen over the next decade. This could significantly affect public ideas around palliative care.
- **Micro-knowledge** and the increase in digitisation, data laws and artificial intelligence will also drive change. The problem of a digital legacy and ownership will become more prominent and nuanced as the internet continues to expand. Data privacy will be a further element of the conversation; we might see GDPR for the dead or a growing desire for the right to be forgotten. The modern propensity to know our lives in data will also challenge the entire healthcare industry to integrate with private sources of personal health data, which have increased in scope, variety and detail over the past 5 years. This could create new needs for patients and their families to start to manage people’s affairs well before death, and to curate and clean their ‘data presence’ as well as thinking about the patient’s wishes, money and possessions.
- The need to **Repair the World** suggests that ecological concerns are likely to grow. It is possible that the concept of a sustainable death and funeral will become a mainstream imperative; there might be contrasting needs felt between different ethnic, cultural and age groups in the way people think about a sustainable death, and end of life care may be the space where these discussions play out.
- **The Experience Economy** may drive change in the way the public think about death; through increasing personalisation and the growing desire to talk and engage with the idea of death.
- The **Changing Authorities** driver reflects the decline of religion overall, and a move towards comfort with the public and personal expression of thought and feelings. All this

⁶² <https://www.6sqft.com/columbia-universitys-deathlab-proposes-a-suspended-cemetery-of-twinkling-pods-under-the-manhattan-bridge/>

⁶³ <https://www.lhlic.com/consumer-resources/average-funeral-cost/>

could mean that spaces like the Departure Lounge become more common; palliative care providers will be able to integrate more with wider discussion forums but also will need to make sure people are getting the right information, and that different groups are catered for.

Conclusions and areas for further research

From the research project overall, and the trends review we have conducted, we identify ideas as to how policy and practice in end of life care could develop in future.

Further scope for conversations and communication about death and dying

From our public research we see an openness to talking about the topic of death and dying and a willingness to 'break the taboo'. This fits with the overall trends we see for openness in this area.

The Departure Lounge installation as well as the opportunity to speak to strangers about this topic are considered a positive way to begin this conversation. Extending the Departure Lounge to other groups and locations (reflecting the different demographic profiles across the country) will increase the opportunity for communities to engage in this topic, which was seen by participants to be inherently positive

There is clear need for further, culturally sensitive information and engagement on the following topics:

- What palliative care is, where it is delivered, who can access it and who delivers it.
- Death is not always painful and therefore doesn't always need to be feared.
- Inspiring and reassuring examples of ways in which people can retain agency, personality and dignity at end of life.
- Dementia is the leading cause of death.
- What hospices are, how they differ from care homes and how they can provide patients with a caring environment in which to spend the end of their life.

This could be provided via a one-stop shop for information and support such as a 'Citizens' Advice for death'. Our trends analysis indicates that seamless, friction-free interactions are not only desired but expected. Information is becoming both a boon and a barrier due to the high volume created every day. We are increasingly reliant on search engines to curate this data into knowledge but cannot take this for granted in the medical sphere. It is important that our public health services consolidate information in easily accessed, reputable formats. This will give citizens the agency to make informed decisions, extend equal opportunities and ensure support is available when needed.

More joined-up end of life care

Dignity and **respect** are seen to be at the centre of what is important at end of life, and how care is provided at end of life care. This care must be **culturally sensitive**, and reflect the following key enablers:

Support

What support is available, and who provides this.

- There is lack of knowledge regarding the inclusion of emotional and spiritual support in palliative care. This is seen as important especially when thinking about being comfortable and expressing your personality and beliefs at end of life.
- Support for families is viewed as being crucial at the end of someone's life. However, there is a lack of knowledge around what support is available. Information and provision of palliative care needs to be culturally sensitive.
 - In particular, for the Muslim community: emotional and spiritual support is seen as outside of the NHS remit and something that is provided by family, community and faith leaders.

Choice

Choice for where a person spends the end of their life.

- There is a need to increase awareness of where palliative care can be provided. It will be important to clarify what can be provided at home.
- There is a need to clarify what a hospice is, reflecting that there is confusion between different NHS services and often conflation of hospice and care home.

Flexibility

Flexibility during end of life care to ensure people can spend time with family and express their personality and cultural and religious beliefs.

- The place where the person is spending the end of their life needs to offer flexibility around spending time with family members.
- There is also a need for support in engaging employers/educational institutions in supporting compassionate leave to enable people to spend time with family members who are at the end of their life.

- There needs to be flexibility for how palliative care supports people in expressing their personality and cultural and religious beliefs. This includes:
 - Flexibility for your surroundings, having things around you that are important, maintain routines.
 - Sensitivity that this type of support is considered within the remit of family/community/faith leaders.

Control and Agency

Control over and agency in expressing personality and cultural and religious beliefs and in making your wishes known.

- Control is typically exerted through making plans for what will happen after death.
- People have not previously thought about making plans/wishes known for what will happen during the last days/hours/minutes of life e.g. treatment refusal but are open to this. Information about this in the Departure Lounge was well received but would need to be treated with care for the Muslim community who think about end of life in a different way.
- Participants were inspired and moved by the idea of expressing personality at end of life but had not previously thought about this in detail. There may be ways of linking traditional medical care with other support available in the community (e.g. legal or financial support) to allow the end of life process to be more streamlined and support families better.
- It is important that family/community play a role in end of life care to allow for the expression of cultural and religious beliefs.
- Our trends work suggests that it may be important in future to help those dying, and their loved ones, to navigate modern choices around death, for example, how to deal with the data presence that someone leaves behind.

Suggestions for future research

This piece of research has indicated the need to further explore public perceptions of death and dying and amplify the conversations that are already taking place among the public and policymakers. Future research should build on the important work that has already been done in this field.

- This research has highlighted that there are different cultural and religious beliefs and practices around end of life care, and what this means for delivery and acceptance of palliative care. Future research could explore these differences further. Specifically:
 - The different experiences and views among first and second generation citizens within different cultural communities.
 - Different views among those practising non-Western religions.
- On the other hand, an increasingly secular Britain will be more likely to challenge established traditions in typically religious areas and expect end-of-life services to include help for those of no faith. This will require sensitivity towards a wide variety of ways of expressing grief, and in some cases, guidance and support for those who lack a traditional roadmap for this difficult period. Appropriate training will be required for healthcare practitioners to facilitate these conversations.
- Exploring the public response to trends would give a deeper understanding of the relative desirability of these changes. Research into the enduring elements of death and the end-of-life process (it would seem likely that a personal touch, a ceremony, and the presence of loved ones would be among these essential features) would help ensure these needs continued to be met in the future.
- The participants involved in this research were largely positive about having the opportunity to discuss death and dying and learnt more about it from the Departure Lounge. Future research could aim to evaluate the benefits and impacts of discussing the topic, e.g. how decision-making at the end of someone's life is impacted by the prevalence (or lack of) discussions about death and dying.
- Research into the impact of the data presence of a loved one after death could be beneficial; and learning on the impact of social media on palliative care may be helpful. Understanding the extent to which social media could be helpful, isolating or harmful to the dying person or their carers, would inform future advice and support. It would also facilitate understanding and subsequently learning from what works in these unofficial channels – the individual, personal, and human. Elements of this could be incorporated into the palliative care offer to ensure optimum support.
- As more people opt for sustainable funeral options, practitioners must be able to provide sensitive support and education. Therefore, further research is needed in this area. This trend may have the potential to feed into end-of-life care in a positive way; given the connection every human has with Earth, empowering patients to leave it in an ecologically friendly manner may be a welcome concept. An element of death-cleaning may be finding more sustainable and charitable ways to handle the possessions that won't be inherited.

Appendix

Workshop discussion guide

Introduction (30 mins/20 mins)

Moderator to welcome participants and introduce themselves.

Then introduce the research, the Departure Lounge and the workshop.

- Ipsos MORI, an independent research company, is doing research for the Academy of Medical Sciences (AMS) to explore how different people think about death and dying. This will help AMS understand how culture, faith or background might impact how we feel and what we think about death and dying.
- AMS has set up this space, 'The Departure Lounge', with a company called Liminal Space. The overall aim of the space, and the research as a whole, is to encourage the public to think and talk about death and dying. So, the space will be open to the public, to wander in and take a look at the exhibits and have conversations with researchers and other members of the public.
- Today, the space is closed so that we can have a group discussion. We will be asking about your experience of exploring the space. We will also talk about what a 'good' death means and what kind of support or care is expected when someone is dying.
- We won't specifically ask about any personal experiences and you do not need to share anything you feel uncomfortable doing so. There aren't any right or wrong answers – we are just interested in your opinions.
- This is a really interesting piece of research and it is very exciting that you can all be involved, so thank you. The research findings will help AMS to make decisions about policy and future research opportunities.
- Does everyone feel clear on what the research is about and roughly what we'll be doing today? Does anyone have any questions at this point?

Explain parameters and ground rules.

- Obviously, this is quite a sensitive topic so we want you to know that you really don't need to talk about any personal experiences (unless you want to), there are absolutely no right or wrong answers (we're just interested in your opinions) and you can stop or take a break at any time with no problems at all.
- Please respect everyone's opinions and try not to interrupt others or talk over them.

- It is totally fine to disagree with someone – we will all have different experiences and views - but please do so respectfully and remember that people might be talking about things that are quite personal or sensitive to them.
- You don't need to answer anything you don't want to, and you don't need to speak about anything you don't want to.
- Toilets and drinks are over there. Feel free to get up at any time if you need a break.

Mention MRS code of conduct.

- All our research adheres to the Market Research Society Code of Conduct and the General Data Protection Act.
- This means that all data collected is confidential, anonymised and kept securely.
- We won't tell anyone else anything you say today. The only exception to this is if we think that you or someone else is in serious danger.
- Please also respect this by not sharing anything that other people in the group say today.
- Although we might use your words in the final report we write for AMS on the research findings, we will never use any names so nothing could be attributed to you as individuals.
- After today, if you think you don't want your words or opinions being included in the report, that's also fine – you can let us know any time before 28th June and we won't include anything you have told us.
- If you are all happy, we would like to audio record the discussion, so we don't have to scribble down lots of notes as we are talking. Is that okay with everyone?
- We also want to get your written consent to participate, so if you are happy to continue, please could you sign your name on the sheet going around?

Introducing the discussion.

- How many of you have taken part in a workshop or focus group like this before?
- Obviously, it is quite unusual to talk in a group like this with strangers, and especially about a topic like death and dying!
- How did you feel about coming along today?
- Has anyone walked past/ seen this space whilst out and about in Lewisham? What did you think about it?

- Before we get into it any further, it would be good to do some introductions. In pairs, can you tell the person next to you, your name, where you live, and what you were doing today before coming here. Then I'll ask you to swap and introduce your partner to the group.
- Some people say that death is the last taboo, meaning that as a society it's still something that we really don't like talking or thinking about. Is it something you would naturally talk about?
- What assumptions do you think people make about what happens at end of life?
- How informed do you think people are about what happens at end of life?

Now we have a chance to look around the space, so we might find out a bit more!

Visiting the Departure Lounge

Individual exercise: spend 20/15 minutes looking around the space, interacting with the installations. We will be discussing your initial thoughts on the space afterwards.

Exercise in pairs: tell the person next to you one thing you learnt from looking around the space, and one thing you found surprising.

Exercise as a group: report back to the group on what you discussed in pairs.

Moderator to generate themes on a flipchart.

PROBES:

- Why do you find that surprising?
- Do others agree/disagree? Why/Why not?
- How did it make you feel looking around the space?
- What did it make you think about?
- Does it encourage you to speak about death and dying? Why/why not?

Healthcare and palliative care

One of the topics explored in this space, is something called palliative care...

Moderator to write 'palliative care' on a flipchart and start to generate themes.

Has anyone heard of 'palliative care'?

How much would you say you know about it?

What do you know about it?

What does it mean to you?

STIMULUS 1: Moderator to share definition of palliative care

Is this definition surprising to you?

PROBE:

- In what way?
- Why do you say that?

Does the definition change your view of palliative care in any way?

PROBE:

- In what way?
- Why do you say that?

How is palliative care viewed in your family or community?

- Positively? Negatively? Why is that?

What does good palliative care look like?

What is important at the end of life?

I'd now like to think about what things are important at the end of someone's life...

Moderator to generate ideas on the flipchart.

What sorts of things do you think are important at the end of someone's life?

What words come to mind?

STIMULUS 2: here are some aspects of end of life needs or concerns for us to consider...

PROBE:

- How the person spends their time at the end of their life
- Where the person spends their time at the end of their life

- Where would be a good place to be?
- Who is around the person at the end of their life (family/ friends/ religious or spiritual leaders)
- What is around the person at the end of their life (music, photographs, objects, other things?)
- How that person feels
- How the people around them feel

Moderator to split the group in two and provide a case study to each mini-group.

For case study 1 please explore:

- What types of things might Paul be thinking about?
- What types of things do you think will be important to Paul?
- What types of things do you think will be important to June?
- What information or support do you think Paul and June might want?
 - What questions might they have?
- Paul feels strongly that the end of his mum's life should reflect the way she has always lived her life and the things that are important to her. What types of things might Paul be thinking about?

Moderator: come back together as a group and share thoughts on your case studies

Now that we have talked more about end of life, what do you think about the fact that this topic is often a taboo topic in society?

Have any of your thoughts on this changed? Why?

Moderator to explain that we ran a short survey with around 1000 people in March and one of the findings is that: "42% of participants said that conversations with family and friends is where their understanding about what happens or may happen to someone in the final hours or minutes of their life comes from."

Does this surprise you?

Do you agree? Why/why not?

Are you more likely to discuss the topic of death and dying with your family after today?

Wind down

Moderator to explain the discussion is nearly finished but it would be good to get the participants final thoughts on the Departure Lounge and the discussion today.

How have you found it today talking about death and dying?

How has it been having a discussion in a group?

How has your experience been today exploring the Departure Lounge?

What are your overall thoughts on the space?

Moderator to explain that AMS would like to install similar spaces in other places across the country.

What do you think about that?

What do you think the public's reaction would be?

Do you think it will help to encourage people talk about death and dying?

Moderator to close the discussion by thanking everyone for their time and asking the group to give themselves a round of applause. Hand out incentives.

Participant demographics

The table below shows the key demographic quotas by the number of individuals who participated in the workshops.

Demographic quota	Breakdown	Number of participants
Gender	Female	33
	Male	27
Age	20-29	6
	30-39	20
	40-49	9
	50-59	15
	60-69	5
	70-79	5
Ethnicity	White British	19
	White European	6
	African	2
	Caribbean	2
	British Bangladeshi	6
	Black British	13
	British Bengali	2
	British Pakistani	5
	Argentinian	1
British Somalian	1	

	Mixed	3
Religion	Muslim	14
	Jewish	7
	Christian	29
	Atheist	1
	Baptist	1
	Rastafarian	1
	None	7
Social grade	B	10
	C1	29
	C2	12
	D	6
	E	3
Total		60

Mini-discussion form

Using this document:

Please use this handout to record the content of your discussions with the public where you have good rapport with them/ feel that they would be interested to answer these questions. There are two suggested questions to ask participants, as well as space to record anything else covered in your discussions. At the end, there is a section containing demographic questions. Please offer participants the option to self-complete this section.

At the end of the discussion:

Please sign post participants to information/ leaflets at the end of the discussion to make sure they are able to access information / support for anything that the installation or discussion may have raised.

Example introductions to be read out to participants:

1. *Thanks very much for discussing your thoughts so far. Would you be happy to discuss this a little bit more? Just to let you know this would be a slightly more structure conversation as I have a few specific questions I'd like to ask you. I'd also like to make a few notes as we speak, if that's okay?*
2. *Thank you for sharing your personal experiences with me. Today I am also collecting peoples' views and experiences for a piece of research. Would you be happy for me to make some notes about what we just spoke about? It would be helpful if we could do this together, so I can make sure what I write down reflects how you feel and what you have said.*

READ TO ALL: *We are having these conversations with people aged over 18 years old, as part of a project being run by Ipsos MORI on behalf of the Academy of Medical Sciences. The aim of the project is to understand how different people think about death and dying.*

The information you tell me will be anonymous. This means that no-one will know that you have taken part and I won't record your name. If you are happy for me to write some notes as we chat, they will be kept securely by Ipsos MORI and securely destroyed at the end of the project.

The discussion will only take 5-10 minutes. You do not need to answer any questions that you do not want to and can stop at any time.

Please can I check, are you happy to take part?

IF YES, CONTINUE. IF NO, STOP DISCUSSION.

If happy, continue to ask the questions below:

Q1. Some of the information here talks about ensuring quality of life in the last days/weeks/months of someone's life. What do you think about this?

PROBE ON:

- What do you think about when you think of quality of life in the last days/weeks/months? Why?
- Other than medical care, what else do you think might affect the quality of life for someone in the last days/weeks/months of their life?

Q2. Lots of people in our society find it difficult or uncomfortable to talk about death.

Why do you think this is?

PROBE ON:

- What, if anything, might make people feel more comfortable talking about death? Anything that you have seen in the installation today?
- To what extent do you think it would be good for society if more people felt more comfortable talking about death? Why?

Space to record anything else that was discussed. This could include: experiences of the Departure Lounge, what people have learnt, what they may have found surprising, who they might tell about their experience.

Finally, would you mind answering a couple of additional questions about yourself? This will help us understand more about the people we speak to as part of this project. You can read and fill these in yourself or I can read them out if you prefer. You do not have to answer these questions if you don't want to – it is entirely optional.

IF PARTICIPANT WANTS TO READ AND FILL IN DEMOGRAPHIC QUESTIONS THEMSELVES, PASS THE FORM TO THEM WITH THE FOLLOWING PAGE OPEN AND A PEN.

IF PARTICIPANT WANTS YOU TO READ AND FILL IN DEMOGRAPHIC QUESTIONS, THEN CONTINUE TO ASK THE QUESTIONS ON THE FOLLOWING PAGE.

IF PARTICIPANT DOESN'T WANT TO ANSWER THESE QUESTIONS, STOP AND THANK PARTICIPANT VERY MUCH FOR THEIR TIME AND SIGNPOST TO INFORMATION.

D1. What is your age? (Please write in the box).

D2. Which of the following best describes yourself? (Please tick the appropriate box).

Female	<input type="checkbox"/>
Male	<input type="checkbox"/>
In another way	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

D3. What is your ethnic group?

Choose one option that best describes your ethnic group or background and tick the appropriate box.

White:	
English / Welsh / Scottish / Northern Irish / British	<input type="checkbox"/>
Irish	<input type="checkbox"/>
Gypsy or Irish Traveller	<input type="checkbox"/>
Any other White background	<input type="checkbox"/>
Mixed/ Multiple Ethnic groups:	
White and Black Caribbean	<input type="checkbox"/>
White and Black African	<input type="checkbox"/>
White and Asian	<input type="checkbox"/>
Any other Mixed / multiple ethnic background	<input type="checkbox"/>
Asian or Asian British:	
Indian	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>
Chinese	<input type="checkbox"/>
Any other Asian background	<input type="checkbox"/>
Black or Black British:	
Caribbean	<input type="checkbox"/>
African	<input type="checkbox"/>
Any other Black / African / Asian background	<input type="checkbox"/>
Other ethnic group	

Arab	
Any other ethnic group	

D4. What is your religion? (Please tick the appropriate box).

No religion	
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	
Buddhist	
Hindu	
Jewish	
Muslim	
Sikh	
Any other religion	
Prefer not to say	

D5. Do you have a long-standing illness or disability that affects your day-to-day life?

Yes	
No	
Prefer not to say	

D6. Do you live, work or study in the borough of Lewisham? (Please tick the appropriate box).

Yes	
No	
Don't know	
Prefer not to say	

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