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Public attitudes to death and dying in the UK

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Care and support
through terminal illness



Public attitudes to death and dying in the UK

Marie Curie Palliative Care Research Centre
Division of Population Medicine
Cardiff University School of Medicine



Canolfan PRIME Cymru
PRIME Centre Wales



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Executive Summary

We all hope for the best possible end of life experience for ourselves and our loved ones. However, that does not necessarily mean that we have given much thought to what that really means, had conversations about it with loved ones or professionals, or – as a society – that we provide the care and support that people need in their final years, months, weeks and days.

In 2021, during the Covid-19 pandemic, Marie Curie commissioned a survey company, Opinium, to coordinate a survey across the UK asking members of the public to give their views on a range of end of life issues including their fears, how they had planned for death and dying, their preferences around end of life care, their understanding of key terms, attitudes to survival versus quality of life, and more. The survey drew on questions already tested in earlier surveys of people in Wales and Northern Ireland during 2018 and 2019.ⁱ

The survey reached 8077 respondents from across all four UK nations. The responses were analysed by the Marie Curie Research Centre at Cardiff University with further support from the PRIME (Primary Care and Emergency Care) Research Centre at Cardiff University. The Northern Ireland data were transferred to Queens University Belfast for analysis.

The UK is at a critical moment for improving palliative and end of life care. Between 2015 and 2019, on average 604,000 people died each year in the UK. In 2020, when the Covid-19 pandemic began, the absolute number of people who died was just over 695,000 – an increase of 15% on the previous five-year average.^{ii iii iv} Our ageing population means that deaths from chronic illness in all four nations are projected to increase substantially in the next two decades, and this will increase demand for and pressure on palliative and end of life care services.

By better understanding public attitudes towards end of life experience – including the

care and support people hope to receive – it is hoped that this report can help the UK to face into the challenges ahead, and to provide a palliative and end of life care system which is fit for the future.

Key findings from the survey include:

The public believe that end of life care should be a priority for the NHS. Three-quarters of people think that end of life care should be given equal priority in the NHS as care for people in any other stage of life.

Being free of pain, with loved ones, and dying with dignity are most frequently reported as people's top priorities for their end of life experience. The top priority for people in their final days and last year of life is being free of pain and other symptoms. This is closely followed by being in the company of loved ones and being able to maintain personal dignity and self-respect. Notably, many people did not indicate a strong preference for dying at home – even though enabling this is often used as a performance indicator for services.

People's worst fears about dying are being helpless and dependent on others. Over 70% fear being helpless and dependent more than they fear death – reinforcing the importance of doing everything we can to ensure that people have their voice heard in the care they receive. Over two-thirds of people fear pain and other physical symptoms, and fear leaving their loved ones.

Access to a trained carer and privacy are top priority needs. Over half of people in the final years of their life name as their top two needs to be managed having a trained carer nearby and having privacy. Just under half prioritise having access to professionals for last minute concerns about family or legal affairs.

People prefer to make their own decisions about treatment and care. 71% of people think that their preferences around death and dying should take priority over the wishes of their next of kin or their doctor's advice.

Most people are comfortable to talk about death and dying – but the vast majority have not done so. Most people feel that as a society we do not talk enough about death and dying. 84% say that there is nothing to prevent them talking about this and at a personal level with family and friends, the majority feel comfortable having these discussions.

However, there is a huge gap between the proportion of people who say that they feel comfortable talking about death and dying, and the proportion who have actually done so. Most people think it is important to express future health and care preferences in advance of serious illness and dying, and their main reason for doing so is to lessen the burden on family and friends. However, just 14% of respondents have done this themselves. Only 20% of people have made financial arrangements for their funeral and only 40% have talked to someone about whether they want their body to be buried, cremated, or donated.

People do not know much about end of life care services and have mixed views on their quality. Over half of respondents do not agree or do not know whether there are adequate health and social care services available for people at the end of life, and the same proportion feel that way about whether cultural or religious/spiritual needs are adequately supported by these services. However, 71% think that people who are dying are treated with dignity and respect by health and social care professionals.

There is little public awareness of palliative care and advance care planning terminology. Most people are unaware of technical terms such as Advance Care Plan and Advance Directive.

Over half of people don't know where to find information on making advance care plans. Worryingly, 55% of people who are in their last years of life say they don't know where to find information on how to plan their care in advance.

Quality of life matters a great deal to people at the end of life. More than three-quarters of people say that if they were severely ill, the quality of their life would be more important than the length of their life. Similarly, over three-quarters of carers of people with terminal illness and bereaved carers believe quality of life is more important than length of life.

People are willing to involve others in decisions about life-supporting technology. Most people feel confident as a patient to be involved in decision-making around using life-supporting technology and 62% feel confident about involving others in these decisions.

With increasing mortality in the UK, and shortages of end of life services, the evidence in this report offers a unique opportunity to support the public discourse on dying, death and bereavement and inform the ongoing development of services for people at the end of life.

The findings speak to three principal changes we need to see to improve end of life care for the future – firstly, a better public discourse around dying, death and bereavement; secondly, closer listening to people about their own preferences for their end of life care; and finally, policy to treat end of life care made just as much of a priority as care and support at any other phase of people's life.

In order to meet these three key goals, Marie Curie's policy recommendations are:

Adopt a public health approach to encourage more open conversations about death and dying. As well as tackling taboos, this approach should seek to improve public understanding of technical terms related to palliative and end of life care and increase public awareness of which health and care services are available, what they can offer, and how to access them at the end of life. It should also include action to encourage and support advance care planning in a willing population.

Offer everyone approaching the end of their life a conversation about their personal needs, wishes and preferences for the end of their life. This conversation should cover all aspects of a person's care and support, and it should be conducted in accordance with best practice as set out in the What Matters Most Charter and ReSPECT process. Each person's advance care plan should be recorded, reviewed, and updated when appropriate, and shared with and acted upon by all the professionals involved in their health and care.

Palliative and end of life care should be a priority for NHS funding. Specialist and generalist palliative and end of life care is under-funded both inside and outside the NHS. Charitable hospices are the main providers of specialist palliative care across the UK, yet only around 30% of their income currently comes from the NHS and statutory sources. The remainder is raised through community fundraising, charity shops and their own investments. A much more resilient and sustainable funding model is urgently needed to ensure rising future demand for these services can be met.

Commissioning palliative and end of life care services should be compulsory in every part of the UK. Estimates suggest that while as many as 90% of people who die may have palliative care needs, only around 50% of people who die receive palliative care. Integrated care systems in England should be legally required to commission palliative care services for local populations, and these services should be available to dying people and their carers 24 hours a day, seven days a week.

End of life services should meet the cultural and spiritual needs of the whole UK population. This requires concerted action to tackle inequities in access to and quality of care for groups such as people living in deprived areas, religious and ethnic minorities, LGBTQ+ people, homeless people, and people in prison. We need to listen to and learn from the voices of individuals and communities with direct experiences of inequality.

Outcome measures for end of life care services should reflect the success of services in meeting people's own preferences, and not make assumptions about what outcomes they want. For example, our findings found that many people did not view dying at home as being an important priority for them, but many quality indicators for services are based on place of death with the preferred option of home. A more holistic approach is needed to measuring performance in end of life care that focuses on full range of a person's wishes, needs and preferences for the end of their life – and responds flexibly as these needs change over time.

Further research is needed into several areas related to our survey findings. There is increasing evidence that home is not the preferred place of death for many and further evidence synthesis is required to explore this. Further work is also needed to understand how social determinants affect the preferences and outcomes of patients.

Introduction

Even before the pandemic the number of people dying each year in the UK was increasing, in 2019, the UK mortality was 604,707, deaths, compared to 570,341 in 2014.^v This increased substantially during the COVID-19 pandemic. Between March 2020 and March 2021, there were 798,643 deaths in the UK, of which 147,282 were COVID-19 deaths and 17,672 were additional non-COVID-19 deaths.^{vi} This represented an increase of 119,241 (18%) compared to expected deaths.^{vii} In this period overall, compared to expected deaths, the number of people who died at home increased by 41%, in care homes increased by 23% and in hospital increased by 11%.^{viii} This significantly heightened demand for and pressure on palliative and end of life care services.

‘Hospice and palliative care services in all parts of the country reported being busier than normal during the pandemic – especially those working in the community. But many also experienced shortages of PPE, other equipment, medication, and staff. These shortages were made worse by hospices not being recognised as frontline NHS’.^{ix}

– Better End of life Report 2021. Marie Curie.

However, trends towards higher mortality rates is a longer term trend resulting from an ageing population. In 2017, a projection of deaths from chronic illness in England and Wales predicted an increase of 25.4% deaths in those countries over the next 40 years, with increasing pressure on palliative care services.^{ix} In Scotland, it is predicted that by 2040, the number of people needing palliative care will increase by at least 14%, and by 20% if multimorbidity is also considered.^{xi}

In this context it is particularly important to think about the support people receive at the end of life – and how we ensure that

everyone receives the care they need, and have their preferences heard and responded to. However, too often, we don’t even talk about issues of dying and death – making it all the harder to prepare for it.

In 2021, during the Covid-19 pandemic, Marie Curie commissioned a commercial survey company, Opinium, to coordinate a survey across all four nations based on the questions used in our previous 2018 and 2019 surveys in Wales and Northern Ireland.

Members of the public were asked to give their views on a range of end of life issues including their fears, how they had planned for death and dying, their preferences around end of life care, their understanding of key terms, attitudes to survival versus quality of life, and more.

The responses were analysed by the Marie Curie Research Centre at Cardiff University with further support from the PRIME (Primary Care and Emergency Care) Research Centre at Cardiff University. The Northern Ireland data were transferred to Queens University Belfast under a formal data transfer contract.



Philip Hardman/Marie Curie

Survey Methodology

Survey and Data Collection

The questionnaire closely mirrored the 2018 survey in Wales^{xiii} with few alterations, except to demographic question and answer fields to reflect the extended geographic scope and refinement of gender identity language.

Opinium administered all aspects of the survey from invitation to data collection and anonymisation. They invited adults (aged 18 years or over) and living in the UK from their research panels to participate in the survey. A total of 8077 UK adults participated to the survey: England 5076, Wales 2005, Scotland 485, Northern Ireland 506.

Respondents were asked about their personal circumstances, including if they would consider themselves to be in the last few years of their lives, if they were a carer for someone with a terminal illness or if they were a bereaved carer, who had lost a loved one in the last five years.

The number of respondents from the Wales and Northern Ireland was boosted for the purposes of comparison with previous versions of the survey in their corresponding devolved nations. The Wales subgroup is overrepresented when comparing this with the UK overall. A random subsample of 25% of the Wales data has shown the results to be comparable with the Wales results overall.

The anonymised data was shared with researchers at Marie Curie Research Centre, Cardiff University and Queens University Belfast for secondary analysis.

Quantitative Analysis

'Yes/No' answers and 5-point Likert-type scales ranging from 'strongly disagree' to 'strongly agree' / 'very uncomfortable' to 'very comfortable' were used to answer the questions. Some questions asked respondents to rank importance of a set of items. Descriptive analyses of the data were carried out across all variables; frequencies are presented in the main body of the results and in tables/bar charts. Cross tabulations

were used to look at the associations between the personal circumstances of the respondents and categorical data of the variables. IBM SPSS Statistics was used to analyse the data.

Free Text Extracts

Extracts of text taken from the open-ended responses in the questionnaire are used to illustrate and support the survey results. These responses were categorised into themes in NVivo 12 to allow for easier extraction of key quotes to illustrate quantitative findings.

Public Involvement

Seven public contributors were engaged throughout the development and piloting of the original survey for Wales. Their extensive input shaped the final 2018 Welsh questionnaire which was used as a template for the UK-wide 2021 survey.

Three public contributors were involved in the 2021 study, two had previously contributed as described above. Involvement was facilitated via email for comments on the protocol and report, and two public contributors actively participated in online meetings as members of the Study Management Group.

Confidentiality and Governance

Consent to participate

Survey participants gave written informed consent to participate prior to starting the questionnaire. The pre-survey information clearly stated that participation was voluntary. Panel members were neither able to skip questions, nor complete the survey more than once. It outlined the risks and benefits of taking part, including those associated with the sensitive survey topic area, with signposting to support services. Confidentiality, data protection and usage in line with Opinium's terms and conditions and privacy policy were outlined. Specific mention of the sharing of anonymised data for research purposes was made along with information on how to withdraw.

Ethical approval and Data Transfer agreements

The Study of Public Attitudes to death and dying in the UK was given approval by Cardiff University's School of Medicine Research Ethics Committee (SMREC21/48). Data transfer agreements were established between Opinium, Cardiff University and Queens University, Belfast (DSA38862/DSA38864).

Limitations

As a commercial survey, the respondents were invited to respond for a small fee, which may have impacted the quality of the data. The 'don't know' answers have been checked to confirm that there is a random pattern.

The quantity of free text data is notably reduced from our two previous surveys.

The representativeness of the population is limited to age and gender.

The boosted number of respondents for Wales and Northern Ireland (to match previous surveys) have been included in the sample for the UK analyses.

What Matters Most?

Being pain and symptom free and company of loved ones are most common top priorities.

Respondents were asked to select the three most important personal priorities they would like to be managed during their final days, and last year of life. The survey revealed that people's top priority was being free of pain and other symptoms. This was closely followed by being in the company of loved ones and being able to maintain personal dignity and self-respect.

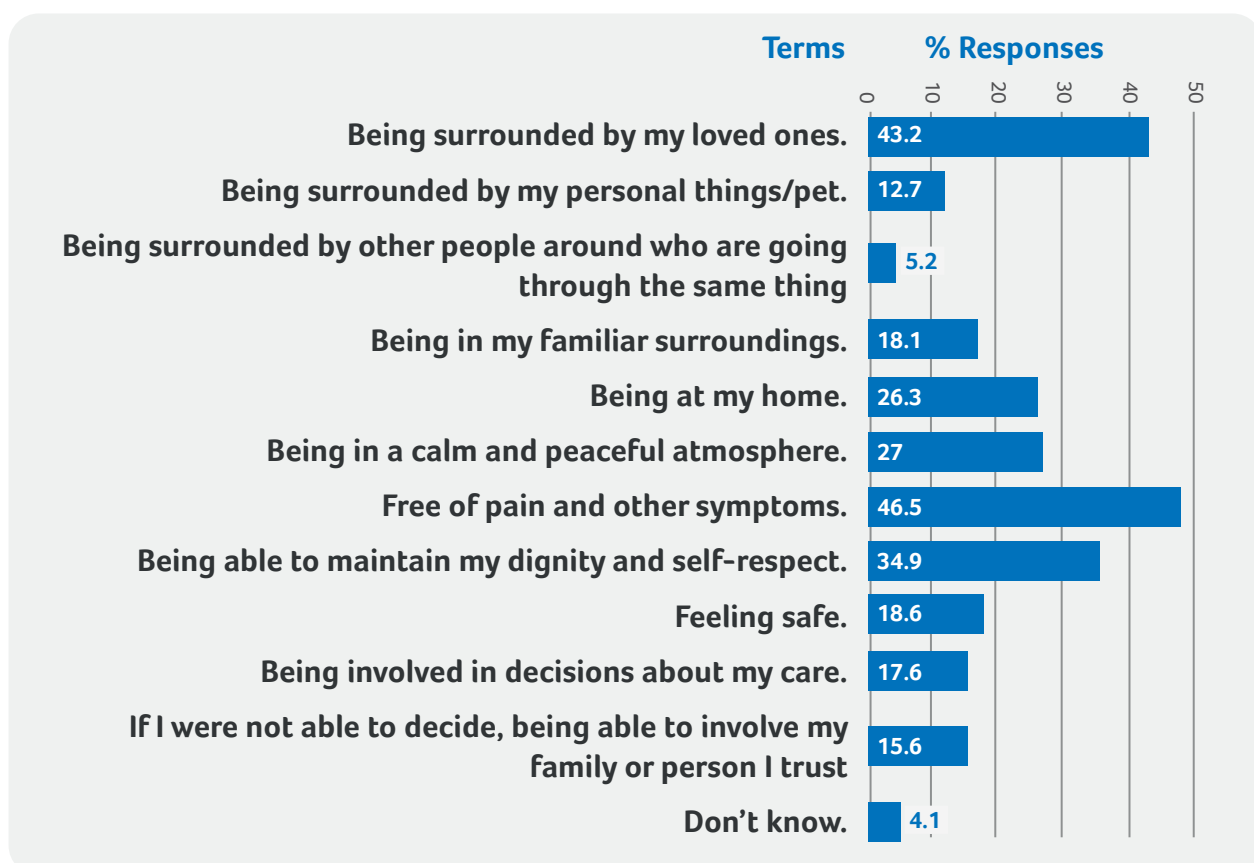
"I would prefer a quick and painless death."

For people's final days of life, the three top ranked overall priorities for individuals in the UK were:

1. Being free of pain & other symptoms **47%**
2. The company of loved ones **43%**
3. Being able to maintain personal dignity & self-respect **35%**

Notably, only a quarter of respondents (26%) indicated 'being in my home' as being important, which was in fourth place out of eleven named priorities.

Please select the 3 most important personal priorities you think you might want to apply during your final days of life



For people's final days of life, the three top ranked overall priorities for individuals in the UK were:

- 1. Being free of pain & other symptoms** **45%**
- 2. The company of loved ones** **41%**
- 3. Being able to maintain personal dignity & self-respect** **34%**

When asked about the final year of life, the top three priorities remain constant, but some of the lower-ranked priorities shift with slightly more respondents wishing to be at home, although this number remains below one third of respondents (30%).

"I would prefer to be at home but whatever is best for my family is what matters most."

"I just want to feel safe and comfortable. I would like to be with loved ones. I would like those involved to treat me with dignity and respect. I think everyone if at all possible should be afforded a 'good' death."

Please select the 3 most important personal priorities you think you might want to apply during your last year of life



For respondents who self-reported that they were in the last years of life, their top three ranked priorities for their final year of life were:

- 1. Being free of pain & other symptoms**
- 2. Being at home**
- 3. Being able to maintain personal dignity & self-respect**

Over a third of people who self-identified as being in their last years of life did not specify a preference to be at their home during their last year of life and in their final days of life.

^{xiii} However, it's noteworthy that being at home in the final year and days of life was more important to those who are currently in their last years of life than for the general population. This implies that peoples' priorities may change as they get closer to the end of their lives.

Research suggests that people's preferences for the end of their life often depend on prior experience and knowledge of palliative care, their own fears around death, and their personal experiences of health and care services.^{xiv} However, there are gaps in research evidence related to many aspects of death and dying, and the complexity of public attitudes suggest a need to continuously revisit current assumptions, and current policies and practices.^{xv}

Access to a trained carer is a top priority need

Respondents were asked to select the top three priority needs that would need to be managed during their final years of life. The options offered focused on practical needs, as opposed to the holistic priorities that were covered by the questions above.

In the UK overall, the top priority needs to be managed in the final years of life were:

- | | |
|--|------------|
| 1. Having a trained carer nearby | 57% |
| 2. Having privacy | 55% |
| 3. Having access to professionals for last minute concerns about my family or legal affairs | 47% |

Notably, the same top three priority needs mattered most to people who identify as being in their last years of life, with over half listing having a trained carer nearby as their number one priority. The other top priorities selected by this group included privacy (53%), and access to professionals for last minute concerns about family or legal affairs to (42%).

“[We] need to have personable, caring carers who still respect and maintain someone's dignity who is dying even if they are unconscious”



Layton Thompson/Marie Curie

Quality of life matters a great deal to people at the end of life

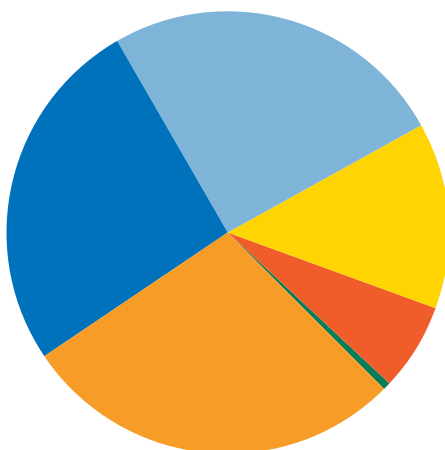
The survey questions asked respondents to indicate the extent to which they agreed with statements around treatment and care preferences.

In the UK overall, more than three-quarters of respondents either strongly agreed or agreed (77%) that if they were severely ill, the quality of their life would be more important than the length of their life.

Similarly, over three-quarters of people who identified as being in their last years of life (79%), carers for people with terminal illness (76%) and bereaved carers (81%) believe quality of life is more important than length of life.

Please show to what extent you agree or disagree with the following statements on your preferences about death and dying

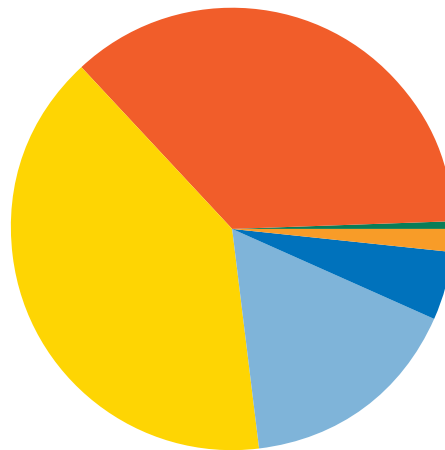
If I was severely ill with no hope of recovery, I would want to be kept alive at all costs



28.1% - Strongly disagree
 26.2% - Disagree
 25.4% - Don't know
 13.5% - Agree
 6.4% - Strongly agree
 0.4% - Other

Aligned to this, more than half of respondents (54%) said that they would not want to be kept alive at all costs. An even greater number of people, two-thirds (60%), who are currently in their last years of life said that they would not want to be kept alive at all costs if seriously ill.

If I was severely ill with no hope of recovery, my quality of life would be more important than the length of my life.



1.9% - Strongly disagree
 4.8% - Disagree
 16.5% - Don't know
 40% - Agree
 36.5% - Strongly agree
 0.3% - Other

"I would not want to be kept alive if my quality of life was poor."

Many peoples' views about quality of life versus survival will change over time, particularly with diminishing health. Given full information about the extent of disease, many express a preference for quality of life over survival^{xvi xvii} but individual definitions of quality of life may vary according to life stage or personal characteristics.

People prefer to make their own decisions about treatment and care

Respondents either strongly agreed or agreed (71%) that their preferences around death and dying should take priority over the wishes of their next of kin or their doctor's advice.

"It should be personal to the person, and their wishes should be respected however much other people may not agree with it."

End of life care is recognised as a priority for the NHS

The survey found that people recognised the importance of end-of-life care, with over three-quarters of respondents strongly agreeing or agreeing (77%) that end of life care should be given equal priority in the NHS as care for people in any other stage of life.

A similar proportion of people who are in their last years of life (77%), carers (81%) and bereaved carers (83%) believe end-of-life care for dying people should be as much of a priority by the NHS as care for people in any other stage of life.

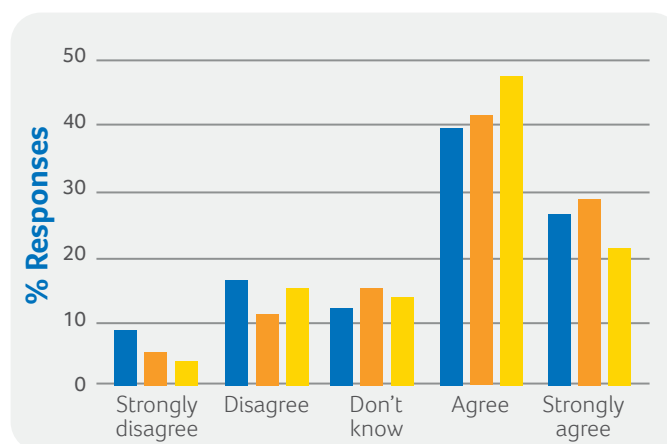
Over three-quarters of respondents indicated that they either strongly agreed or agreed (78%) that end of life care for older people should be given equal priority for the NHS as care of people in other age groups.

"It is important because when it gets to that time you might not get treated right."

The top fears of dying are being helpless and dependent, and in pain

These are also the most expressed fears for people who identify as being in the last years of their life. Three quarters of people in their last years of life feared being helpless and dependent (75%), with 68% fearing pain and/or other physical symptoms and 56% fearing leaving their loved ones.

To what extent do you agree with the following statements?



I fear dying because I have to leave my loved ones

I fear being helpless and dependent more than I fear death

I fear pain and/or other physical symptoms

"I love my family and partner and don't want to leave them. I'm afraid of losing my dignity and being helpless before I die."

"I do not want to be dependent on anyone, family or stranger."

Less frequently expressed fears around dying concerned the loss of role in the family or community. Only a fifth of respondents either strongly agreed or agreed to fearing the loss of their role in the community more than they fear death.

Over one third of participants either strongly agreed or agreed (43%) that they are not afraid to die.



3/4

Three quarters of people in their last years of life feared being helpless and dependent

How Do People Plan for Dying

Most people are happy to talk about death and dying

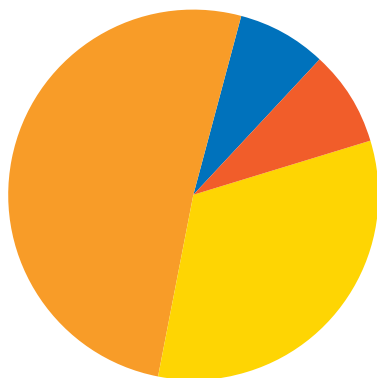
The survey questions asked respondents to indicate the extent to which they felt comfortable discussing death and dying.

In the UK overall, around half of the respondents (51%) thought that as a society we do not talk enough about death and dying.

“As death is a certainty, we, as a society, should be more open with each other about our wishes leading up to and including funeral arrangements.”

“People need to be more open and honest about death. It should not be a taboo subject and should be considered a natural consequence of life. It should be discussed as any other part of life”

As a society, how much do we talk about death and dying?



8.4% - Too much

32.8% - About the right amount

51.1% - Not enough

7.7% - Don't know

Similarly, 46% of people who are in their last years of life, 55% of carers and 60% of bereaved carers think that as a society we do not talk enough about death and dying.

Previous research has found that people often feel that as a whole, society is disinterested in or disapproving of talking about dying and death, as this is a sensitive topic.^{xviii}

Around one third of UK respondents thought that we talked about death and dying the right amount. Whilst most people felt that as a society we do not talk enough about death and dying, the vast majority (84%) of respondents indicated that there is nothing to prevent them talking about this. Likewise, 87% of people in their last years of life, 81% of carers and 82% of bereaved carers indicated that there is nothing to prevent them from talking about death and dying.

At a personal level with family and friends, most respondents reported feeling either very comfortable or comfortable discussing death and dying in general (65%). In terms of specific conversation topics, an even greater number (over 70%) of respondents reported feeling very comfortable or comfortable discussing: their end of life wishes around treatment and care (72%), their end of life wishes around death (74%), their funeral arrangements (74%), and their financial affairs (75%).

Among people in their last years of life, carers and bereaved carers, more than 80% said that they feel comfortable discussing the range of end of life topics with family and friends.

“I had a Heart Attack a few months ago and have a blood disorder. I talk about it all the time with Health professionals and friends as that is the best way to deal with it. For my friends particularly.”

Most respondents also indicated feeling very comfortable or comfortable (74%) selecting someone to decide on treatment decisions when they are unable to do so themselves.

An exception was where only 45% of respondents felt very comfortable or comfortable discussing the arrangement of their virtual possessions, such as social media accounts, with family and friends, with 17% of respondents indicating they ‘don’t know’ and 18% feeling uncomfortable. Similarly, one fifth of people in their last years of life,^{xix} 17% of carers^{xx} and 17% of bereaved carers^{xxi} felt uncomfortable discussing the arrangement of virtual possessions. A relatively recent focus, this highlights that care of virtual possessions may require particular attention within end of life care planning.

The fact that most people reported being comfortable talking about issues of dying and death, makes it all the more notable that (as we shall see) most people have not in fact done so, or made plans for their end of life care.

There is low awareness of services for the end of life, and people have mixed views on their quality.

The survey questions asked respondents to indicate the extent to which they agreed with statements around the adequacy of end of life services.

In the UK overall, over half (58%) of respondents either did not agree, or did not know, whether there are adequate health and social care services available for people approaching the end of life. Notably, a similar proportion of people in their last years of life (60%), carers (58%) and bereaved carers (60%) did not agree, or did not know, whether there are adequate services available for people approaching end of life.

“At this time I think NHS resources are not so available to assist with good quality end of term care.”

Almost half (45%) of respondents either did not agree, or did not know, if people who are thought to be approaching end of life are able to access end-of-life care facilities. This was echoed by people in the last years of life, with 45% saying they did not agree or did not know if people who are thought to be approaching end of life are able to access end of life facilities. More positively, between 55% and 76% of people who have made advance plans perceive that people who are thought to be approaching end of life are able to access end-of-life Care facilities.

In terms of the perceived adequacy of services to meet specific needs, over half of respondents (59%) either did not agree, or did not know, whether cultural or religious/spiritual needs are adequately supported by end of life care services. Notably, the vast majority of respondents indicated ‘don’t know’, suggesting a lack of awareness of available services.

“I think it’s a service people know very little of.”

On the positive side, most respondents (71%) either strongly agreed or agreed that people who are dying are treated with dignity and respect by health and social care professionals. More than half of respondents (60%) either strongly agreed or agreed that people approaching end of life are able to take part in the decision-making process in regard to their health care.

There is low awareness of palliative care and advance care planning terminology.

The survey asked respondents to indicate which end of life terms they were familiar with from a list. This list of 15 terms included, for example, Advance Care Plan (a way for you to think, discuss, decide, document and share with your healthcare team what matters most to you at the end of your life) and Advanced Directive (which consists of a Living Will and a medical power of attorney). In the UK overall, 78% of respondents reported being unaware of the term Advance Care Plan and 88% were unaware of the term Advance Directive.

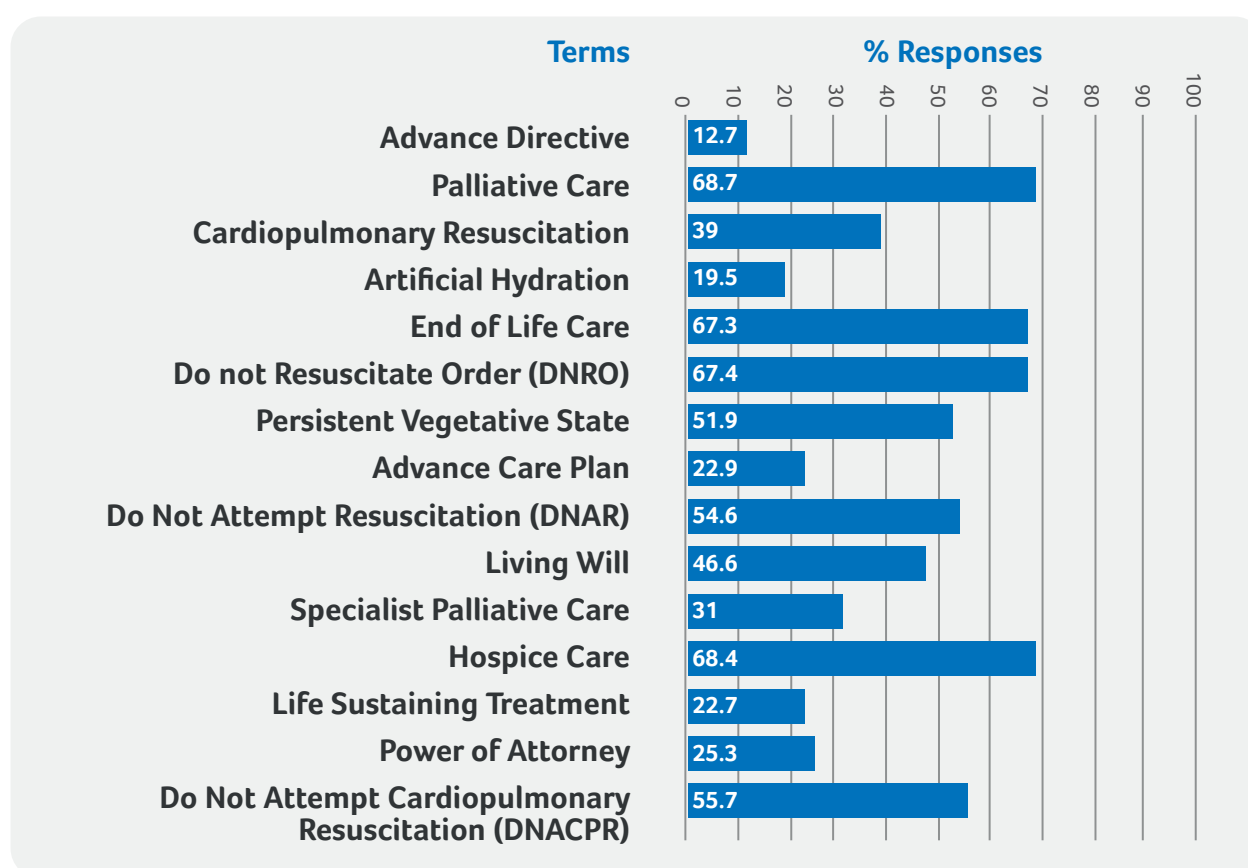
The terms which were most familiar to respondents were Palliative Care and Hospice Care, although around a third of respondents were unfamiliar with their meaning.

“I have heard of some, however I am not familiar with any.”

Definitions of advance care planning, palliative care, supportive care, hospice care, and other elements of end of life care and treatments vary.^{xxii} Sentences, phrases and terms can mean different things to different people and this can influence their decision making, which becomes especially important in advanced disease and towards end of life when shared engagement in key discussions is needed.^{xxiii xxiv}

Adopting a public health approach to palliative care could encourage more open conversations about death and dying and should seek to improve public understanding of technical terms related to palliative and end of life care.

Please select from the list below the terms that you are familiar with



Not everyone is confident that they have access to information on planning in advance for end of life care

The survey questions asked respondents to indicate the extent to which they agreed with statements around availability of information and end of life services.

Despite a lack of familiarity with advance care planning terms, almost half of UK respondents reported that they know where to find information on how to plan in advance for care at the end of life. Worryingly, more than half of people who are in their last years of life said they didn't know where to find this information (55%).

Over 70% of respondents either agreed or strongly agreed that if they were to make plans for the end of their life, they know who among friends or family they could discuss it with.

"My feelings are known to my wife and there are documents in place to assist my son in dealing with funerals, the wills and probate when it falls to him."

Over half of those surveyed either agreed or strongly agreed (54%) that if someone close to them were to die, they know where to find support. In contrast, only around two-fifths of bereaved carers did not know where to get support if someone close to them dies (41%).

There is a large gap between intention and actions in advance care planning despite the perceived benefits

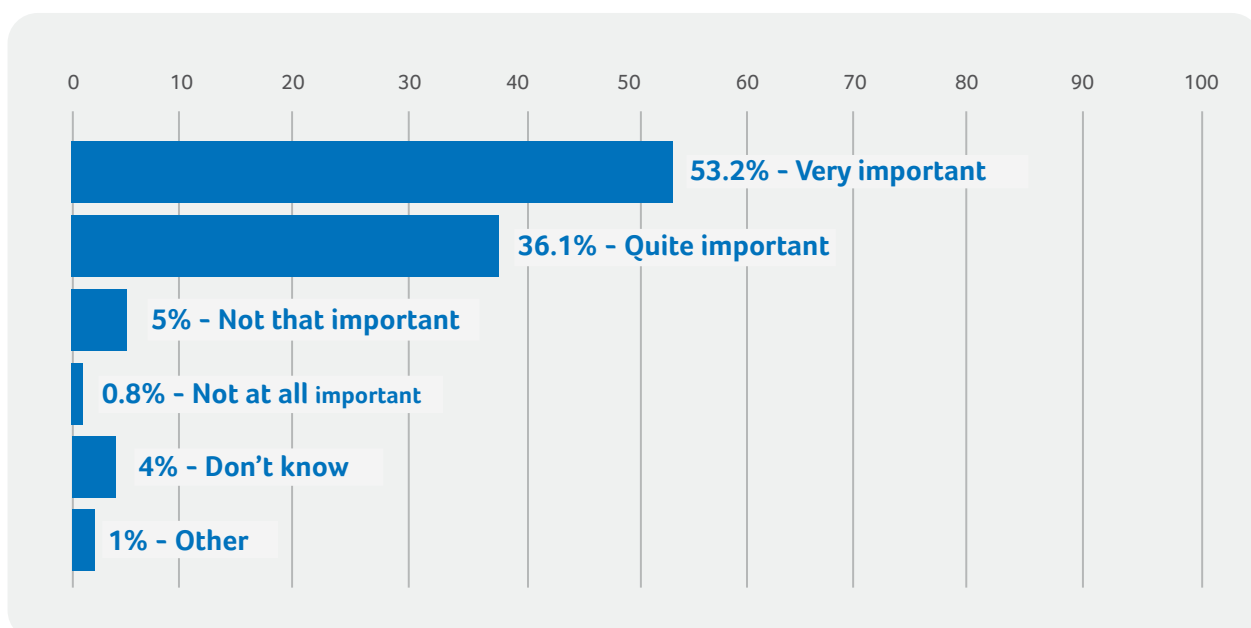
The survey questions asked respondents to indicate the most important benefits of advance care planning, as well as their intentions and behaviours towards engaging in advance care planning.

Nine out of ten respondents thought it was either quite important or very important to express future health care preferences in advance of serious illness and dying.

55%

Worryingly, more than half of people who are in their last years of life said they didn't know where to find information on how to plan in advance for care at the end of life

How important do you think it is to express your future health care preferences in advance of serious illness and dying?

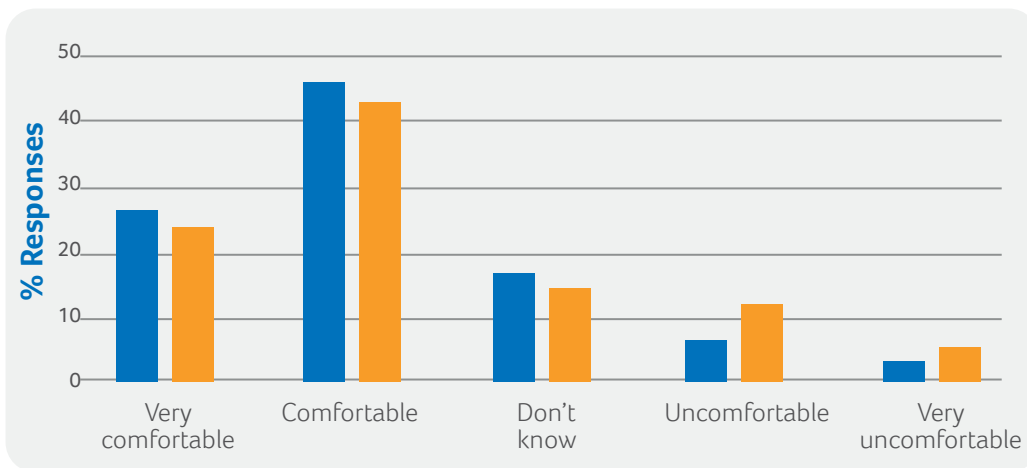


The most important benefit of advance care planning chosen with greatest frequency, by almost a third of respondents was to lessen the burden to family members/ friends. Interestingly, only 17% of respondents saw the most important benefit of advance care planning as preventing them from having treatment they don't want.

The majority of respondents (74%) report feeling very comfortable or comfortable discussing their end of life wishes with doctors and nurses, with the majority (70%) also feeling very comfortable or comfortable with their family member or loved one discussing their end of life wishes with them.

"I would not wish to burden my family with such decisions."

To what extent do you agree with the following statements?



Discussing my End of Life wishes with my doctors and nurses

A family member/loved one discussing their End of Life wishes with me

Despite most people reporting feeling comfortable discussing their end of life wishes, just 14% of respondents have formally expressed their future health care wishes and preferences. Similarly, only 15% have talked to someone about their end of life care wishes. Only one fifth of people have made financial arrangements for their funeral. This is despite around half indicating they intend to have these important conversations and plan for their end of life.

“So far I have NOT discussed with my sons but intend to do so fairly soon.”

There is a large gap between intention and actions in making end of life arrangements, despite people seeing the benefits of making plans. However, some areas of planning end of life arrangements were more accessible. Many people stated that they had already talked to someone about whether they want their body to be buried, cremated, or donated (40%) and made a decision about organ donation (40%). This may indicate that these are areas which could lead to a broader advance care planning conversation.

“I hope it’s a long way off for me personally & the only thing I’ve stated is wanting my body donated to medical science after any organ donation”


In terms of supporting family members/friends to plan their end of life arrangements, only 16% of UK respondents have asked a family member/friend whether they have made a living will and only 15% have asked what type of care support they would want at the end of their lives.

The numbers of people who are in their last years of life who have planned are worryingly low. Up to 13% of people who are in their last years of life and up to 15% of bereaved carers have made any advance plans, whilst fewer carers have done so. Only 6% of people in their last years of life said that they have made a living will, whilst 13% have made financial arrangements for their funeral.

More work is needed to increase public awareness of which health and care services are available, what they can offer, and how to access them at the end of life. By adopting a public health approach to palliative care, these points could be addressed, as well as including further action to encourage and support advance care planning.

People are willing to involve others in decisions around life-supporting technology

Most UK respondents either strongly agreed or agreed to being confident as a patient to be involved in decision-making around using life-supporting technology (72%) or involving others in the decision-making (62%). However, around two-fifths (42%) also strongly agreed or agreed that involving others in the decision-making of using life-supporting technology would limit their privacy.



14%
Around 14% people have formally expressed their future health care wishes and preferences



13%

Up to 13% of people who are in their last years of life and up to 15% of bereaved carers have made any advance plans, whilst fewer carers have done so.

Who Makes Advance Care Plans?

As shown in the previous section, the most common arrangements advance care plans (ACPs) made included:

1. **Talking to someone about whether they want their body to be buried or cremated or donated** **40%**
2. **Making a decision on organ donation (opt-in or opt-out)** **40%**
3. **Making financial arrangements for their funeral** **20%**

We have taken a closer look at the personal circumstances and social characteristics of those who reported having made advance care plans.

Around a quarter of those with ACPs were people currently in their last years of life, carers, or bereaved carers (13%). This implies that people who have had experience of terminal illness, whether personally, or through caring for someone with terminal illness are more likely to have planned. Over half of respondents with ACPs (54%) identified as members of the public who have an interest in the subject of the survey. This could demonstrate that people with an existing interest in making preparations for death and dying, and have greater knowledge of how to do so, are more likely to have planned.

There were some differences of note with regards to gender and age depending on specific advance care plans. We compared gender and age with the more common advance care plans made alongside the personal characteristics of those who had made plans.

Respondents who had talked to someone about whether they want their body to be buried or cremated or donated were more likely to be female (54%) and older. Over half of those who had done this were aged 55-74.

Respondents who had made a decision on organ donation were also more likely to be women (55%) and older (aged 55-74).

“I would like all my wishes to be taken into account, especially regarding organ donation (member of the public).”

More men had made financial arrangements for their funeral (55%) than women (44%). Those who had done so were also older, with one fifth of 55-64-year olds and a third of 65-74-year olds stating they had made financial arrangements.

Out of the range of advance care plans that respondents were asked about, overall, people were least likely to have spoken to their doctors/nurses about their end of life care wishes (7%). Of those who had spoken to their doctors or nurses, 60% were male and younger (one third of 25-34-year olds and one-fifth of 35-44 year olds).

Those who were more familiar with the terminology were also more likely to have made advance care plans.

Responses to Covid-19

While the survey did not ask specific questions relating to Covid-19, some themes around the impact of Covid-19 on attitudes to death and dying were evident in the free-text responses.

Some participants reported changes in the way we talk about death and dying as a society due to Covid-19. For example, participants expressed how Covid-19 has highlighted the importance of talking about death and dying because of the heightened likelihood of losing loved ones:

“Other people don’t want to talk about death. If I mention anything, they change subjects because they cannot handle the issues. However, it is important to discuss stuff like death especially during the pandemic and vaccine roll out because it can happen out of the blue.”

Some participants reported that the amount that we talk about death and dying as a society has improved due to Covid-19, and suggested that we can use this as an opportunity to continue increasing the amount that we talk about death and dying as a society:

“This situation can be increased by families using the unprecedented nature of this current pandemic to start a conversation about what kind of death we would like for each other should a family member becomes critically ill and life and death choices have to be made.”

“I think COVID has increased the conversations, but we need to keep it up.”

The main theme emerging from participants’ reports about Covid-19 related to suffering. This was mainly surrounding the circumstances of the death of loved ones. Many participants reflected on the difficulty and suffering they had experienced watching loved ones die during the pandemic, and how these difficulties had changed some of their own fears and preferences:

“I had to watch my mum die through a window in her nursing home because of the Covid restrictions in July 2020. It was the hardest thing I ever had to do and my heart is still breaking. I hope no one else has to go through a similar experience ever again.”

“I would want my family round me as due to my dad passing away during Covid in a hospice we were unable to be there at the end of his life and this is something that I can’t come to terms with, as I keep thinking he died thinking we didn’t love him, as we weren’t there for him as he passed away.”

While Covid-19 has clearly increased and normalised talking about death and dying, which participants viewed positively, it has also enhanced the suffering surrounding death and dying. Participants reported the difficulties and hardship of watching loved ones die from a distance due to Covid-19 restrictions, and the fears and worries about death and dying that these challenges have caused.

Conclusion

With increasing mortality in the UK, and shortages of end of life services, this evidence offers a unique opportunity to support the public discourse on dying, death and bereavement and inform the ongoing development of services for people at the end of life.

The findings speak to three principal changes we need to see to improve end of life care for the future – firstly, a better public discourse around dying, death and bereavement; secondly, closer listening to people about their own preferences for their end of life care; and finally, policy to treat end of life care as just as much of a priority as care and support at any other phase of people's life.

1. We need a better public discourse around dying, death and bereavement

The results highlight the longstanding issues around communication and the language surrounding death and dying. A general lack of awareness of key terminology obstructs individuals' ability to engage in effective planning around end of life. Only 14% of respondents reported having created a plan expressing their priorities and preferences for the end of their life, although nearly 90% of people consider it important.

Notably, we often assume that dying is a “taboo” topic which people are uncomfortable discussing. The results of this survey challenge this – finding that most people report being ‘comfortable’ discussing issues related to dying. However, the results also show a huge gap between the proportion of people who say they are (in principle) comfortable to discuss death and dying, and the *proportion of people who have actually done so*. This may indicate the need for more holistic consideration of why people haven't had conversations about dying, and rather

than assuming that this is simply because they are uncomfortable doing so.

The results of the survey also highlight a considerable (and likely related) problem around understanding of end of life care – with 31% of people unfamiliar with palliative and hospice care, and around 80% unfamiliar with Advance Care Plans and Advance Care Directives. Many of these terms are in common use within the professional environment but are not well understood by patients and families,^{xxv} thereby excluding the people to whom open conversations are most important.

Respondents noted that with Covid-19 and the impact it has had on the likelihood of people facing sudden and unexpected deaths, it is important to discuss end of life needs in advance. Some respondents thought that Covid-19 had been a catalyst for these conversations. Sadly, others described their difficulty and suffering when forced to be distant from dying relatives.



Philip Hardman/Marie Curie

2. We need to listen more closely to people about their own end of life preferences and recognise that these will differ from person to person and may change over time.

The findings are an important reminder that we need to listen to people about their own preferences for end of life care, and not make assumptions. Most importantly, we must recognise these will vary from person to person, and may change for an individual over time, particularly as they approach the point of death.

For example, many quality indicators for services are based on place of death with the preferred option of home. However, the survey results challenge the assumptions that have sometimes been made about patient needs, and preferences. Caring for people at home at the end of life often brings its own challenges – it may not meet the need for rapid pain control, access to equipment or trained carers,^{xxvi} and can bring disruption to the home environment,^{xxvii} whilst laying the burden of caring on family members, many of whom are elderly.^{xxviii} Many survey respondents feared becoming helpless and dependent, and suffering pain above all else, which may become more likely with disease progression and complex clinical needs.^{xxix} These issues, and others, may be difficult to mitigate in the home setting with the added problem of unprepared carers, although there are ongoing initiatives to better understand and support carers.^{xxx}

The survey results also indicate a strong preference for many people for quality of life over survival. This is significant in terms of indicating widespread support for the goals of palliative care, and challenges the provision of treatments at end of life which prioritise longevity over quality of life.^{xxxi} However, one of the consequences of not discussing terminal prognosis and

patient priorities can be excess treatment and unfulfilled needs,^{xxxii} although the vast majority of respondents say they are comfortable with these difficult conversations.

3. We need to treat end of life care as just as much of a priority as care and support at any other phase of people's life

The vast majority of respondents believe that End of life Care is of equal importance to any other NHS provision, and yet it is not wholly funded by the NHS and is not available to all. Nevertheless, over 70% of people believe that people at end of life are treated with dignity and respect. However, more than half of respondents were uncertain or disagreed that cultural and spiritual needs could be met.

Overall, the results of this survey demonstrate a range of broad, societally entrenched issues that require policy change and a public health approach. Some of these, such as peoples' preferences for end of life care including place of death, challenge our existing service configurations and should be further interrogated. Others, such as the clear gap between intention and completion in ACP require direct action.

Respondents' preferences for quality of life over survival is another important topic; our previous work has shown that too often patients' priorities and preferences are not taken into account, with the medical model assuming dominance. The end result is often avoidable harm from treatment toxicities and a misunderstanding by patients as to both the intention of treatment, and their terminal diagnosis. Suffering pain is the top fear of respondents so minimising needless side effects is important, as is communicating the symptom control expertise of specialist palliative care.

As ever, we should be mindful that perspectives may change as the disease trajectory progresses and levels of need increase. Those who identified as being in their last few years of life, or as caring for someone with terminal illness, had different perspectives to the general population.

Some of the results reinforce historical issues that are yet to be resolved, such as the barriers caused by palliative care and end of life terminology that may only be understood with experience. This is a language that needs to be understood throughout the life course in order to support future wishes, and the experiences of others.

Above all, a public health approach is needed to address these issues due to their effect on the whole population. The results show some differences to perceptions, specifically in Northern Ireland and Scotland, that are likely to be linked to cultural and religious values. Further work into understanding how social determinants influence preferences and outcomes is needed to cater for patient needs at an individual level.

Policy Recommendations

These survey findings have important implications for policy and practice around supporting people at the end of life. Marie Curie's key policy recommendations are:

Adopt a public health approach to encourage more open conversations about death and dying.

As well as tackling taboos, this approach should seek to improve public understanding of technical terms related to palliative and end of life care and increase public awareness of which health and care services are available, what they can offer, and how to access them at the end of life. It should also include action to encourage and support advance care planning in a willing population.

Offer everyone approaching the end of their life a conversation about their personal needs, wishes and preferences for the end of their life.

This conversation should cover all aspects of a person's care and support, and it should be conducted in accordance with best practice as set out in the What Matters Most Charter and ReSPECT process. Each person's advance care plan should be recorded, reviewed and updated when appropriate, and shared with and acted upon by all the professionals involved in their health and care.

Palliative and end of life care should be a priority for NHS funding.

Specialist and generalist palliative and end of life care is under-funded both inside and outside the NHS. Charitable hospices are the main providers of specialist palliative care

across the UK, yet only around 30% of their income currently comes from the NHS and statutory sources. The remainder is raised through community fundraising, charity shops and their own investments. A much more resilient and sustainable funding model is urgently needed to ensure rising future demand for these services can be met.

Commissioning palliative and end of life care services should be compulsory in every part of the UK.

Estimates suggest that while as many as 90% of people who die may have palliative care needs, only around 50% of people who die receive palliative care. Integrated care systems in England should be legally required to commission palliative care services for local populations, and these services should be available to dying people and their carers 24 hours a day, seven days a week.

End of life services should meet the cultural and spiritual needs of the whole UK population.

This requires concerted action to tackle inequities in access to and quality of care for groups such as people living in deprived areas, religious and ethnic minorities, LGBTQ+ people, homeless people, and people in prison. We need to listen to and learn from the voices of individuals and communities with direct experiences of inequality.

Outcome measures for end of life care services should reflect the success of services in meeting people's own preferences, and not make assumptions about what outcomes they want.

For example, our findings found that many people did not view dying at home as being an important priority for them, but many quality indicators for services are based on place of death with the preferred option of home. A more holistic approach is needed to measuring performance in end of life care that focuses on full range of a person's wishes, needs and preferences for the end of their life – and responds flexibly as these needs change over time.

Further research is needed into several areas related to our survey findings.

There is increasing evidence that home is not the preferred place of death for many and further evidence synthesis is required to explore this. Further work is also needed to understand how social determinants affect the preferences and outcomes of patients.

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