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Improving implementation of NICE recommendations on end-of-life care

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www.thisinstitute.cam.ac.uk

Published by: The Healthcare Improvement Studies Institute, 2022

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Abstract

While the National Institute for Health and Care Excellence (NICE) sets out clear guidance relating to end-of-life care, evidence suggests that there is inconsistent uptake and implementation. This report documents an innovative partnership between The Healthcare Improvement Studies Institute at the University of Cambridge and NICE. We focus on four areas of end-of-life care and treatment provision: identifying people who may be approaching the end of life; initiating conversations about end-of-life care and treatment preferences; documenting preferences, for example through advanced care planning; and ensuring that people's preferences are made known to and acted on by other health and social care professionals. We sought to:

- identify and understand the key influences on implementation of end-of-life care guidance; and
- identify and prioritise interventions likely to help address implementation challenges.

Guided by a professional advisory group and by a patient and public advisory group with rich experience of these issues, our mixed-methods study included a survey, interviews with a range of stakeholders, and a consensus-building exercise adapted from the Delphi method. In the survey (106 responses) and interviews (21 stakeholder interviews plus 34 interviews with a subset of survey respondents), we identified multiple and complex challenges in implementing guidelines. With input from the advisory groups and through multiple iterations, we distilled the findings into 13 statements which we used to examine the importance of and prioritise various aspects of end-of-life care and treatment planning. With 475 participants in the initial round of consensus building, 11 of 13 statements reached consensus. The later rounds further identified potential components of a standardised record of preferences regarding end-of-life treatment and care, groups that should be empowered through new or improved training in advanced communication, and aspects of communication most important to include in advanced communication training for healthcare professionals. Our findings, which may be of interest to health and care professionals, suggest among other things an appetite for undertaking important—if sensitive—conversations in a timely fashion, even if the optimal circumstances for such conversations never quite present themselves. Finally, state agencies and voluntary sector bodies might find value in the priorities identified in our consensus building work.

Executive summary

Background

The importance of high-quality care for people approaching end of life is widely recognised, but in the United Kingdom (UK) practice is inconsistent. Despite the availability of guidance from the National Institute of Health and Care Excellence (NICE), there are wide variations in indicators of quality such as the opportunity to prepare personalised care plans that set out preferences for treatment and care at the end of life. Implementation challenges of this kind can lead to people either not receiving the care they need, or receiving inappropriate interventions that they do not want, that are costly for healthcare systems, and that are distressing for individuals and their informal carers.

This report describes an innovative programme of collaborative work led by The Healthcare Improvement Studies Institute (THIS Institute) at the University of Cambridge and NICE, focused on better understanding problems in implementation and identifying possible solutions. Using a range of research methods including qualitative interviews, a survey, and structured consensus-development processes, the programme sought to generate learning for NICE and other stakeholders on how to improve implementation of guidance, by:

- identifying and analysing the key influences on implementation of end-of-life care guidance (relating to the identification of people approaching end of life, the initiation and conduct of conversations with them about their preferences for treatment and care, the recording of these preferences, and their use by health and social care practitioners across the system); and
- consulting and seeking consensus across multiple relevant stakeholder groups on recommendations for the design and development of approaches and resources most likely to improve implementation of guidance.

The programme also acted as a ‘proof of concept’ for a model of collaboration between NICE and THIS Institute that could be readily transferred to other ‘implementation gaps’ faced by NICE. It demonstrated the viability of a rapid, replicable model for identifying the problems that underlie inconsistent or imperfect implementation of NICE’s guidance, taking a highly collaborative approach involving a range of affected stakeholders. The programme made use of the opportunities for rapid research and development offered by THIS Institute’s online Thiscovery platform, which facilitated much of the data collection.

Methods

The programme involved three stages: (1) qualitative interviews with key stakeholders to ensure a broad-based and up-to-date understanding of key issues in the field; (2) a survey of people preparing for end of life and health and social care practitioners, and further qualitative interviews with a subset of survey participants; and (3) a consensus-development exercise to identify the level of agreement regarding various approaches that might help to improve implementation of end-of-life care guidance.

Throughout the process, colleagues from NICE and THIS Institute worked closely on design, management and analysis. They were ably supported by a professional advisory group, comprising individuals from a range of relevant stakeholder organisations, and a patient and public advisory group, including a diverse group of people with experience of planning for end-of-life care, for themselves or others.

Results

In the first stage (key stakeholder interviews), a total of 21 interviews were conducted with individuals from organisations with an interest in the field of end-of-life care planning, including service providers, policy makers and patient representatives. The stakeholder interviews were used to obtain a breadth of perspectives and to inform the development of the survey and the interview topic guide in the second stage of the study.

The interviews offered rich data about the issues that affected the implementation of end-of-life care guidance. These included the medicalisation of death (for example, a strong tendency towards curative approaches where possible among some healthcare professionals), the challenges of making decisions about admissions and treatment in the absence of comprehensive information about the situation of an individual, and ignorance about legal provision in this area (for example, the status of various means of setting out personal preferences in advance and the provision of the Mental Capacity Act).

The second stage (survey and further qualitative interviews) elicited 106 survey responses (52 from individuals approaching end of life and others important to them; 54 from health or social care staff), and 34 further qualitative interviews. Across people planning for end of life and staff, the survey and interviews found broad agreement on several issues. For example, participants reported that:

- conversations about planning end-of-life treatment and care should be initiated earlier in the care pathway
- multiple groups are well placed to initiate such conversations
- a wide range of issues should be covered in conversations about planning end-of-life treatment and care

Participants planning for end of life described a mixed picture of experiences and practice. Few felt that staff were not sensitive or caring. However, while some reported respectful conversations that happened at the right time and clearly indicated what to expect next, others felt less prepared for and less empowered by the conversations. Health and social care staff participants suggested that not all felt they had access to the right tools and resources to enable them to have productive conversations about end-of-life treatment and care preferences, and that they were not confident that preferences documented would be drawn on effectively by other parts of the health and social care system.

In the third stage (consensus development regarding propositions for what is needed to improve care), the findings from the first two stages were used to develop a set of statements regarding good practice (for example, 'It is sometimes OK for a health or social care professional to raise the issue of planning for end-of-life treatment and care with someone, even if they don't know the person that well') and opportunities to support further improvement (for example, 'A single, standardised approach to documenting and recording end-of-life treatment and care preferences is needed'), drawing on input from the two advisory groups. Nearly 500 individuals were involved in at least one round of the consensus development exercise. Of 13 statements put forward, consensus was achieved on the importance of 11 of them. Further rounds of consensus building focused on three of the 11 statements in greater detail, asking participants about potential components of a single approach to documenting end-of-life treatment preferences, where efforts to empower various groups might best be concentrated, and which healthcare professional groups might most benefit from advanced communication training. These further rounds identified clear priorities for future action.

Implications

The findings of the study have implications for various groups. For practitioners, for example, the findings suggest that there is a strong appetite for undertaking important—if sensitive—conversations in a timely fashion, even if the optimal circumstances for such conversations never quite present themselves. The findings merit dissemination to the range of health and social care professionals who may find themselves in positions to initiate these discussions but who, our survey suggests, may not be certain that they are the best-placed person to do so. For organisations with interests in research, staff training and development of resources, the findings indicate priorities for further activity, including issues that might be covered in advanced communication training, and the need for (and the most important components of) a standardised record of preferences regarding end-of-life treatment and care.

Besides its substantive focus, the programme of work also served as a model of collaboration between NICE and THIS Institute that could be transferred to other areas. The programme took a little over a year from initiation to completion; it was characterised throughout by close partnership working between THIS and NICE, alongside collaboration with a range of interested organisations (particularly in the voluntary sector), underpinned by clear guidance from a professional advisory group and a patient and public advisory group. Challenges in the translation of guidance into practice and consistency of uptake are ubiquitous across the areas of practice covered by NICE guidance, presenting opportunities to apply the approach taken here to other challenges, and inform evidence-driven improvement of implementation of guidance.

Recommendations for practice and policy

1. Clinicians and other practitioners involved in planning end-of-life treatment and care should seek to have important conversations with patients about treatment and care at the end of life early, rather than waiting for an 'ideal' time, place or person.
2. These conversations should include gaining understanding about:
    a. Individuals' views on the balance between prolonging life as much as possible, versus maximising quality of life
    b. Which outcomes are most important to individuals considering end of life
3. Organisations in all care settings should provide training to a diverse set of practitioners in having important conversations about treatment and care at the end of life. This will empower them to feel confident to initiate the conversations routinely. Topics covered should include:
    a. initiating conversations about end-of-life treatment and care;
    b. exploring what matters to the person and people close to them, and what concerns they might have;
    c. respecting people's decisions about treatments they wish to receive when having conversations with them, in line with the Mental Capacity Act;
    d. facilitating and responding to questions, including signposting people to other sources of support;
    e. talking to the person about illness progression, including prognostic uncertainty
4. Organisations in all care settings should work with partners across the health and care community to ensure a shared, standardised record for recording the outcomes of discussions about treatment and care at the end of life, ensuring that it is easily interpretable by others and records key elements as follows:
    a. any outcomes that are most important to the person (for example comfort, day-to-day independence)
    b. any outcomes that the person particularly wants to avoid (for example increased dependency on others, being housebound)
    c. a brief account of the person's preferred balance between prolonging life and maximising quality of life
    d. specific treatments the person would not like to receive
    e. a recommendation (based on patient and clinical views) on whether cardiopulmonary resuscitation should be attempted if the person's heart stops
    f. whether the person has an Advance Decision to Refuse Treatment, Advance Directive (Scotland), or Advance or Anticipatory Care Plan
    g. whether the person has a legal proxy who can make decisions on their behalf, for example through Lasting Power of Attorney for Health and Welfare (England and Wales) or Welfare Power of Attorney (Scotland)
5. Policymakers should recommend, mandate or incentivise a shared, standardised record for recording the outcomes of discussions about treatment and care at the end of life, ensuring that it is easily interpretable by others and records the key elements listed under recommendation 4 above.
6. Policymakers should consider commissioning the development of a single integrated electronic system for recording end-of-life treatment and care preferences.

Key messages

- Different health and social care professionals find themselves in positions to initiate conversations about the end of life, but they may not feel confident to do so.
- People approaching end of life, those close to them and professionals agree that it is important to discuss end-of-life care preferences, even if the optimal circumstances for such discussion never quite present themselves.
- Professionals including general practitioners and staff in care homes may benefit from training and resources to talk about the end of life with their patients.
- Discussing end-of-life care preferences should focus on what matters to the individual, what they value in their life and what concerns they have.
- It is important to document individual preferences and to ensure that these preferences can be easily shared across the health and care system.
- People approaching end of life, those close to them and professionals agree on key components that should be included in accessible records. However, ensuring that these preferences can be easily shared across the health and care system is currently a challenge.

1. Introduction and background

The National Institute for Health and Care Excellence (NICE) has produced a range of guidance and quality standards on the provision of end-of-life care, including guideline NG142 on service delivery of end-of-life care for adults.[1-3]

The National Institute for Health and Care Excellence (NICE) has produced a range of guidance and quality standards on the provision of end-of-life care, including guideline NG142 on service delivery of end-of-life care for adults.[1-3] This guideline focuses on the organisation and delivery of services to provide care for people in the final weeks and months of life, and to support planning and preparing for this period with other people. The guideline lays out key steps including identification of people who may be approaching the end of their life, assessment of their needs, support for carers, and advance care planning.

Implementation of this guidance varies, with much more consistent practice in some settings and for some groups of patients than others. Available evidence suggests that variation includes inconsistencies in practice in identifying people at the end of life, in initiating helpful and open conversations about end-of-life care preferences, and in documenting these conversations in the form of personalised plans.[4, 5] The 2015 National Survey of Bereaved People (VOICES)[6] indicates that only 60% of people in their last three months of life knew that they were likely to die, and the SAMBA18 survey[7] found that a low proportion of people admitted to hospital with acute medical emergencies had advance care plans: 4.8% overall, and 7.1% among patients re-admitted to hospital within 30 days of a previous admission. The Priorities of Care (2014) for the dying person make clear that there should be an individualised plan of care,[8] supported by NICE quality standards.[3] Yet the National Audit of Care at the End of Life found that of the deaths that were recognised as likely to be imminent, there was documented evidence of an individualised care plan in only 67% and 71% of cases in the audit's first (2018/2019) and second (2019/20) rounds respectively.[9, 10] These figures do not account for patients whose deaths were not recognised as imminent or expected by hospital staff, where documented care plans were much lower (8% in the 2019/20 audit). These implementation problems can lead to people either not receiving the care they need or receiving inappropriate interventions that they do not want, that are costly for healthcare systems, and that are distressing for individuals and their informal carers.

Optimised solutions to these challenges have remained elusive. There has been no systematic study of the introduction of NICE's end-of-life care guidelines nor on the influences of the guidelines' implementation. In the absence of a sound evidence base on the causes of the gap between best practice and actual practice, interventions to improve implementation may be misdirected. A full understanding of the influences on implementation and how they may interact is vital to framing the problems appropriately and to informing the design of acceptable, effective, and long-lasting interventions. Achieving this goal requires engagement with the full range of affected stakeholders, both on the reasons behind implementation gaps and on how they might be addressed.

1.1 Introduction to the strategic partnership between THIS Institute and NICE

This report documents an innovative partnership between The Healthcare Improvement Studies Institute (THIS Institute) at the University of Cambridge and NICE, the agency responsible for balancing best care with value for money across the NHS and social care, providing rigorous, independent assessment of complex evidence to produce guidance and advice for practitioners. Together, the two organisations undertook a collaborative programme of rapid participatory research focused on the 'implementation gap' in end-of-life planning, treatment and care described above.

This research programme first sought to identify and better explain the influences on the implementation of recommendations around: identifying people who may be approaching the end of life; undertaking important conversations around people's end-of-life care preferences; advance care planning; and ensuring that preferences are documented and acted upon. Second, we sought to develop insights that might inform the development, selection, uptake and refinement of resources and tools to facilitate better and more consistent implementation of NICE guidance by examining, through a consensus building exercise, the acceptability, feasibility and desirable characteristics of possible approaches to improving practice.

This programme of work had the potential to improve knowledge of the challenges of implementation of NICE's guidance relating to care at the end of life, to inform interventions that might effectively address these challenges, and to develop and trial a collaborative approach that could in the future be extended to other implementation challenges faced by NICE in relation to its guidance and standards. Therefore, the aims of the project were:

1. To generate recommendations for NICE on improving implementation of its guidance on end-of-life care, accounting for published evidence and the views of relevant stakeholders.
2. To generate methodological learning about scalable, rapid participatory research study design that could be used to address other implementation challenges faced by NICE and other health and care system organisations.

Specific project objectives were:

1. Accounting for a wide range of stakeholder perspectives, to identify and analyse the key influences on implementation of end-of-life care guidance in the following areas:
    a. identifying people who may be entering the last year of their life;
    b. initiating and conducting important conversations about preferences and plans for treatment and care towards the end of life;
    c. advance care planning, including recording of relevant conversations, preferences and plans;
    d. ensuring that plans and preferences are shared between necessary organisations and appropriately accessed and used by health and social care services, including in relation to access to end-of-life care services.

2. Using structured consensus building methods, to consult and seek consensus across stakeholder groups on recommendations for the design and development of approaches and resources that are most likely to improve implementation.

Stakeholders included: people who may be approaching the end of life or have planned ahead for this time; people important to them such as family, friends and informal carers; representatives from patient groups and other stakeholder organisations; and health and social care staff. The report identifies findings for NICE and other organisations with relevance for how best to improve implementation of its guidance on end-of-life care, accounting for the views of this wide range of relevant stakeholders.

2. Methods

In this section, we describe the methods used to meet the project objectives listed above. A survey and interviews with various stakeholders were used to address the first objective; a consensus-building exercise was used to meet the second objective. Each activity is elaborated below. The activities were also informed by an unpublished literature review undertaken by RAND Europe which is not reported here.

2.1 Key stakeholder interviews

As an initial step, to ensure we had a broad-based and up-to-date understanding of key issues in the field, we undertook interviews with key senior stakeholders. These included: those involved in end-of-life care practice in health and social care; voluntary sector organisations including campaigning organisations and those involved in disseminating information to the public; academics and others. Using purposive sampling, we identified relevant stakeholders in consultation with NICE and with our advisory groups (see section 2.4 below). The individuals approached included those who worked for or represented various health and care areas including emergency medicine, palliative care, critical care, and ambulance services. There were also individuals from Marie Curie, Resuscitation Council UK, ICUsteps, NHS England, Compassion in Dying, and National Voices. Finally, we approached individuals from organisations representing homeless people, people with Down's Syndrome, and the Court of Protection. All individuals were contacted by email to request participation in a 30-40-minute interview. Individuals who agreed to participate were asked to consent to the study via THIS Institute's online research platform, Thiscovery, and were then taken to an online booking page to schedule an interview at a convenient time.

Interviews were digitally recorded through the Thiscovery system. The research team also offered an 'offline' option, for individuals who did not want to register for Thiscovery or preferred to conduct interviews using other platforms (such as Zoom) or over the phone. For these options, a consent form was emailed to participants and interviews were scheduled through email or by phone. A Dictaphone was used to record interview audio for all interviews – for Thiscovery interviews, the recording was used as a backup and deleted after interview files were confirmed to be sent for transcription; for other modes, the audio file was the primary file used for transcription. Audio/video files were used to transcribe the interviews by a third-party transcription service. Once transcripts were returned and passed quality checks, the audio and video files were deleted from the secure server.

2.2 Survey and interviews with people preparing for the end of life and health and social care practitioners

Building on the first stage, we then sought to canvass the views of a wider range of individuals involved in planning end-of-life treatment and care, through an online survey and further qualitative interviews. Questions for both were developed based on key issues identified in the stakeholder interviews, alongside discussions with our advisory groups, within the research team and with NICE.

We sought to recruit participants in four groups: people approaching the end of life; those important to someone approaching the end of life; healthcare staff; and social care staff.

For the first two groups, we sought to recruit people who had had conversations about end-of-life treatment and care in the UK within the last two years. For the second two groups, we sought people who were involved in the planning or delivery of end-of-life treatment and care in the UK. Individuals who were not 18 years old or older, whose experience did not relate to the UK, or who were unable complete the consent form were not eligible to participate in the study.

We identified nearly 90 organisations as professional associations, charities or other groups with interest or involvement in end-of-life care, and enlisted their help in recruiting participants. Emails were sent to each organisation on behalf of Graham Martin, as principal investigator at THIS Institute, and Judith Richardson, as acting director of health and social care at NICE, requesting that organisations assist with recruitment by helping to publicise the study. Organisations primarily supported the study through social media such as Twitter, but also helped to share study information through newsletters, regular member bulletins, or email distribution lists. THIS Institute also put out a series of tweets related to the study, with slight modifications to target specific groups for both the survey and interviews. Potential participants were directed to a webpage on the Thiscovery platform that provided further information about the study.

We developed and administered the survey over the period December 2021 to March 2022. Data were collected using an online survey administered through the Thiscovery platform. Two versions of the survey were developed, with several overlapping questions and some divergent ones. For individuals planning end of life and the people important to them, questions focused primarily on their perspectives on conversations they had had regarding end-of-life treatment and care, including issues such as the timing, content, and who should initiate such conversations. For health and social care staff, we asked questions relating to identifying people who may be approaching the end of life, who should initiate conversations about end-of-life care and treatment preferences and when, the content and documentation of such conversations, and the sharing of decisions made with other parts of the system to ensure people's preferences were known to others who could then act on them appropriately. For both versions of the survey, a series of questions were asked relating to the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process and form for those who had related knowledge and experience. The ReSPECT process is a system widely used around the UK to create personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. The final versions of the two survey variants can be found in Appendices 1 and 2.

At the end of the survey, participants were asked if they would be interested in participating in an online interview with a member of the research team. Participants who agreed to be invited were emailed a link to a webpage with a participant information sheet as well as a link to complete a consent form and book an appointment. The interviews were semi-structured; the interview topic guide touched on many of the same issues as the survey: identifying who may be approaching the end of life, initiating and having conversations about treatment and care preferences, documenting preferences and ensuring that people's preferences are known and acted on across the health and social care systems.

All participants provided consent prior to taking part. Similar to the stakeholder interviews, interviews were conducted through the Thiscovery platform; all interviews were similarly transcribed through a third-party transcription service (see section 2.1 above).

2.3 Consensus building

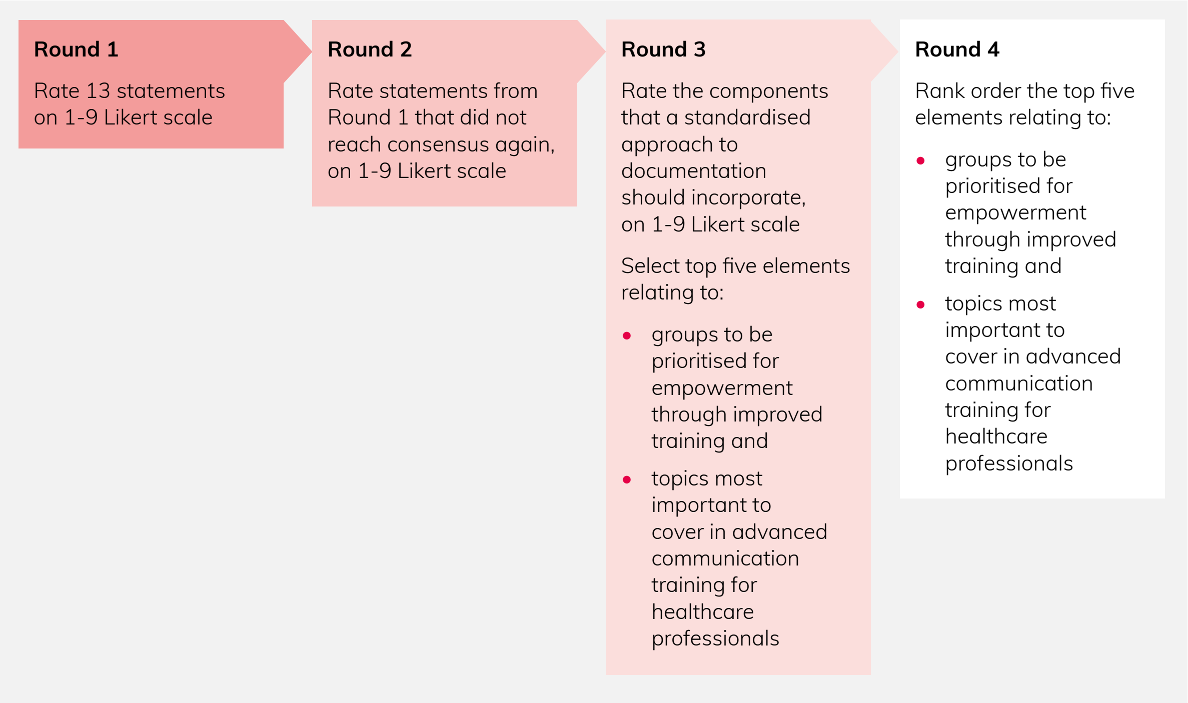
In the final stage of the study, we drew on the data collected in earlier stages to undertake a consensus building exercise, based on the Delphi approach[11, 12] to identify the level of agreement regarding the desirability and feasibility of various approaches that might help to improve implementation of end-of-life care guidance. The Delphi approach is a structured methodology, usually applied in in-person group settings, which seeks to build consensus by collating initial views and then allowing participants to reconsider their own views in light of the wider group's.

Individuals who had participated in the earlier activities, including the survey and stakeholder interviews, were invited to participate. In addition, a few individuals representing policy or regulatory organisations with relevance to end-of-life care provision identified in earlier study stages were invited to participate. Finally, one professional advisory group member distributed the link to individuals on a mailing list run by Compassion in Dying.

For the first round of the consensus building, we asked participants to select the group which most accurately reflected their interest in the area, from the following options: (1) a member of the public in the UK with experience planning for end-of-life treatment and care for myself; (2) a member of the public in the UK with experience planning for end-of-life treatment and care for someone important to me; (3) a healthcare professional in the UK; (4) a social care professional in the UK; (5) a representative of a policy or regulatory organisation in the UK with relevance to end-of-life care provision; or (6) a representative of an organisation in the UK with an interest in end-of-life care provision, such as a charity or professional association. The response to this question was used to identify the participant group of the respondent throughout the consensus building rounds. Due to smaller numbers of responses, group 3 and 4 and groups 5 and 6 were merged in the analyses. Participants thus covered four groups: people planning for their own end-of-life care; people important to someone planning their end-of-life care; health and social care professionals; and representatives of policy or regulatory organisations with relevance to end-of-life care provision and representatives of organisations such as a charity or professional association with an interest in end-of-life care provision.

The consensus-building portion of the study included two tasks over four rounds (Figure 1). The first task (rounds 1 and 2) was to rate the importance of a series of statements related to improvements to implementation of end-of-life guidance. The second task (rounds 3 and 4) was dependent on the outcome of the first, and was designed to examine in more detail issues raised in four of the statements from the first round by identifying priorities for implementation. If any of these four statements reached consensus after the first two rounds, a related follow-up question would be included in this second task.

Figure 1. Description of the four rounds of the consensus building exercise



Round 1

Rate 13 statements on 1-9 Likert scale

Round 2

Rate statements from Round 1 that did not reach consensus again, on 1-9 Likert scale

Round 3

Rate the components that a standardised approach to documentation should incorporate, on 1-9 Likert scale

Select top five elements relating to:

- groups to be prioritised for empowerment through improved training and
- topics most important to cover in advanced communication training for healthcare professionals

Round 4

Rank order the top five elements relating to:

- groups to be prioritised for empowerment through improved training and
- topics most important to cover in advanced communication training for healthcare professionals

For the first round, participants were asked to rate the importance of 13 statements relating to various aspects of planning for end-of-life treatment and care. They were asked to use a nine-point scale, ranging from 1 (not important at all) to 9 (extremely important). For the second round, for each statement, participants were presented with their own original rating, the overall mean rating for all participants, and the mean rating for participants in their group. They were then asked to re-rate each statement in light of this information.

Rounds 3 and 4 allowed us to elaborate further on the statements and ask participants to prioritise various elements related to each statement. This task asked participants, first, to select the top five priorities (round 3) and then to rank them against one another (round 4).

Prior to beginning the study, the threshold for rating statements consensus was set at 70%, which meant that any statement where at least 70% of the respondents rated either 7, 8, 9 or 1, 2, 3 reached consensus that an item was or was not important, respectively.

2.4 Advisory groups

Throughout the course of the study, we were greatly aided by two groups: a professional advisory group comprising individuals from organisations with a role in end-of-life care policy and implementation; and a patient and public advisory group comprising people with direct experience of planning for end-of-life care, either for themselves or for someone important to them, and others involved in supporting these groups. We approached several organisations to ask if they could identify individuals who could serve on the professional advisory group, or help recruit people for the patient and public advisory group. Table 1 lists selected members of the professional advisory group, and the organisations involved.

Table 1. Selected professional advisory group members

Name	Title	Organisation
Julie Armstrong-Wilson	Lead Nurse and Operational Manager	The National Gold Standards Framework Centre
Chris Bassford	Consultant in Intensive Care Medicine Clinical Lead for Critical Care Medicine	University Hospitals of Coventry and Warwickshire NHS Trust
Upeka de Silva	Policy Officer	Compassion in Dying
Fliss Murtagh	Professor of Palliative Care	Associate Director of the Wolfson Palliative Care Research Centre
	Member	RCP Joint Steering Committee for Palliative Medicine
	Academic Training Programme Director	North & East Yorkshire and Northern Lincolnshire
Amy Proffitt	President	Association for Palliative Medicine
Anna Spathis	University Lecturer in Palliative Medicine	University of Cambridge
Mehrunisha Suleman	Director of Medical Ethics and Law Education	Ethox Centre, University of Oxford

The patient and public advisory group included eight members with a diverse range of experiences and backgrounds: Molly Bartlett, Sonya Brown, Annette Furley, Jean Gaffin, Rebecca Langley, Deirdre McIlelan, Francis Tienga Ngale, and Robin Ward.

Each group met three times over the course of the study and gave input into the development of research instruments including the questionnaire and interview topic guide, advised on the recruitment of participants, discussed emergent findings from the survey, provided input into the development of the consensus building statements, and advised on the dissemination of study findings to effectively reach target audiences.

2.5 Ethics approval

The study protocol, which included all research activity above, was approved by the University of Cambridge Psychology Research Ethics Committee.

2.6 Analysis

For the survey, basic descriptive statistics were calculated for demographic questions as well as multiple choice questions related to various aspects of end-of-life conversations (mean and percentage of total).

For the qualitative interviews (including the initial stakeholder interviews and the subsequent interviews alongside the survey), a coding framework was first developed using the primary areas of enquiry from the interview topic guide. Two members of the research team used the coding framework to independently code three interviews. After comparing coding for the interviews, codes were slightly modified and additional codes were added to the coding framework. The remaining interviews were coded by one member of the research team. Interviews were coded in NVivo 12, and the software was used to generate a matrix used for framework analysis[13] where each matrix row represented an interviewee, and each column was an area of end-of-life care planning that we were particularly interested in.

For the consensus building, the mean ratings were calculated for all participants and for each of the four groups: people planning for their own end-of-life care; people important to someone planning their end-of-life care; health and social care professionals; and organisation representatives. For rounds 3 and 4, again the mean rating was calculated for questions that asked participants to rate statements (between 1 and 9). For questions that asked participants to select their top 5 statements, we calculated for each statement the total number of participants who had included that statement among their top 5 choices. Finally for questions that asked participants to rank statements (between 1 and 5) we assigned points to the statement based on rank – 5 points for rank 1, 4 points for rank 2, 3 points for rank 3, 2 points for rank 4, and 1 point for rank 5 – such that higher points reflect higher ranking. We calculated the total points for each statement. Analyses were performed in R and Microsoft Excel.

3. Results

3.1 Key stakeholder interviews

We conducted 21 initial stakeholder interviews (not including the in-depth interviews that followed the survey) with individuals from various backgrounds, including those with experience in palliative care practice and discussing plans for end-of-life care and people from voluntary and campaigning organisations with an interest in this area. The stakeholder interviews were used to obtain a breadth of perspectives and to inform the topics that should be included in the survey and in-depth interview guide in the second stage of the study.

The interviews provided rich data from various perspectives. For example, we asked interviewees about overall challenges in terms of ensuring that people's preferences are known, shared, and acted on. People described their sense of how the palliative care approach was often at odds with a 'culture of healthcare to cure', to 'intervene to save lives'.

> 'If you can't cure, it's to control, and then [palliative care] feels like a failure, and that's a mindset shift. You need to be able to hold in your head success being something other than cure or control in order to address it.'

These contrasting mindsets could, in some participants' views, deter both healthcare professionals and patients from opening conversations about end-of-life treatment and care options, and result in planning for end of life beginning much later than optimal. The notion that it was countercultural to integrate enabling a good experience of death within good care was expressed across various specialties and patient groups. For emergency and urgent care, one interviewee described the challenge of culture change, and how practitioners such as paramedics and emergency physicians are tasked with assessing a situation very rapidly and making a decision in haste:

> 'We're in a way fighting against our historic traditional foundations of a lifesaving organisation. We're trying to create a culture change.'

This culture shift was also articulated in terms of the lack of end-of-life care options and planning for people experiencing homelessness, especially those who for whatever reason are not on a recovery path. Stakeholders in this area discussed how it was often very difficult to consider parallel planning which included palliative care services, and that it was viewed as 'giving up', especially for relatively young individuals.

Relatedly, interviewees elaborated on how the culture of medicine was at times at odds with patient preferences. For example, some interviewees described situations where a person's capacity was questioned simply because they did not agree with their clinicians, or chose to refuse treatment. These occurrences were, according to participants, not uncommon, despite clear legislation in the form of the Mental Capacity Act that deems that a person must be assumed to have capacity unless otherwise established.

Many interviewees commented on how the end-of-life and dying process had become overly medicalised – that there is general unawareness, even among healthcare professionals, of what 'ordinary dying' looks like, and that there is almost an expectation that clinical intervention is needed at the end of life. One participant described a common 'fixation where clinical services can solve it all' when in fact personal interests or other aspects of day-to-day life, not medical intervention, might offer the best source of fulfilment during the end-of-life period. These perspectives, compounded by healthcare professionals' lack of confidence in managing the dying process at home, were seen to influence healthcare professionals' judgements about whether to move people from their homes or care facilities to hospital settings. If there was any degree of uncertainty, any prospect of extending life through clinical intervention could lead healthcare professionals to favour a hospital admission.

Several interviewees brought up areas of confusion that made difficult end-of-life care situations even more challenging – for those planning end-of-life care and health and social care professionals alike. These included which advance planning documents are legally binding and which are not, as well as confusion surrounding the status of documented preferences regarding attempted cardio-pulmonary resuscitation as medical recommendations rather than legally binding documents (unless expressed in an Advance Decision). Participants also described lack of understanding surrounding the Mental Capacity Act and when a person loses capacity about the rights (or lack thereof) of family members, particularly in instances when the wishes of family members are not aligned with healthcare professionals seeking to act in the person's best interest, or where there are differences of opinion regarding what the patient her/himself would have wanted.

> '[There is a] huge disjuncture between the law and medicine, how little doctors understand the law, how frequently doctors end up in court giving evidence and being cross examined, and displaying their total ignorance about some of what are supposed to be the fundamentals of law in this country – to do with taking into account the person's own values, wishes, feelings and beliefs, to do with the importance attached to autonomy, not simply to sanctity of life, and to do with basics like no, family are not the decision maker, the person giving the treatment is the decision maker...'

Finally, some participants brought up the lack of clarity and consistency around end-of-life care terminology – including what is covered by palliative care, how it is different from end-of-life care, and the timing of each.

In terms of service provision, a particular challenge from professionals' perspective was the tension between eliciting patient preferences and the reality of the availability of resources to meet people's needs, and how conversations need to be bounded by system capacity (and communicated clearly). One interviewee commented on the accessibility of palliative care services for people with non-cancer conditions compared to well-established pathways for cancer patients.

> 'I think one of the initial challenges was, historically, planning for end of life and palliative care has been focussed around cancer and there has been inequity with non-cancer conditions. So, services would have been developed in that way and commissioned from that perspective .... [Palliative care] covers all of the different service areas so it's part of a care pathway for all of those conditions. So, it's taken quite a number of years for people to recognise that it's part and parcel of many care pathways from a service provision perspective.'

There were also calls for a system approach for end-of-life and palliative care services given the 'interrelationships and coordination that needs to happen'

3.2 Survey

We received 106 responses to the survey: 52 responses from individuals approaching the end of life or someone important to them, and 54 from health or social care staff. Demographic data are shown by group in Table 2. Below we report on the survey results by these two groups.

Table 2. Demographic information for survey respondents, by group

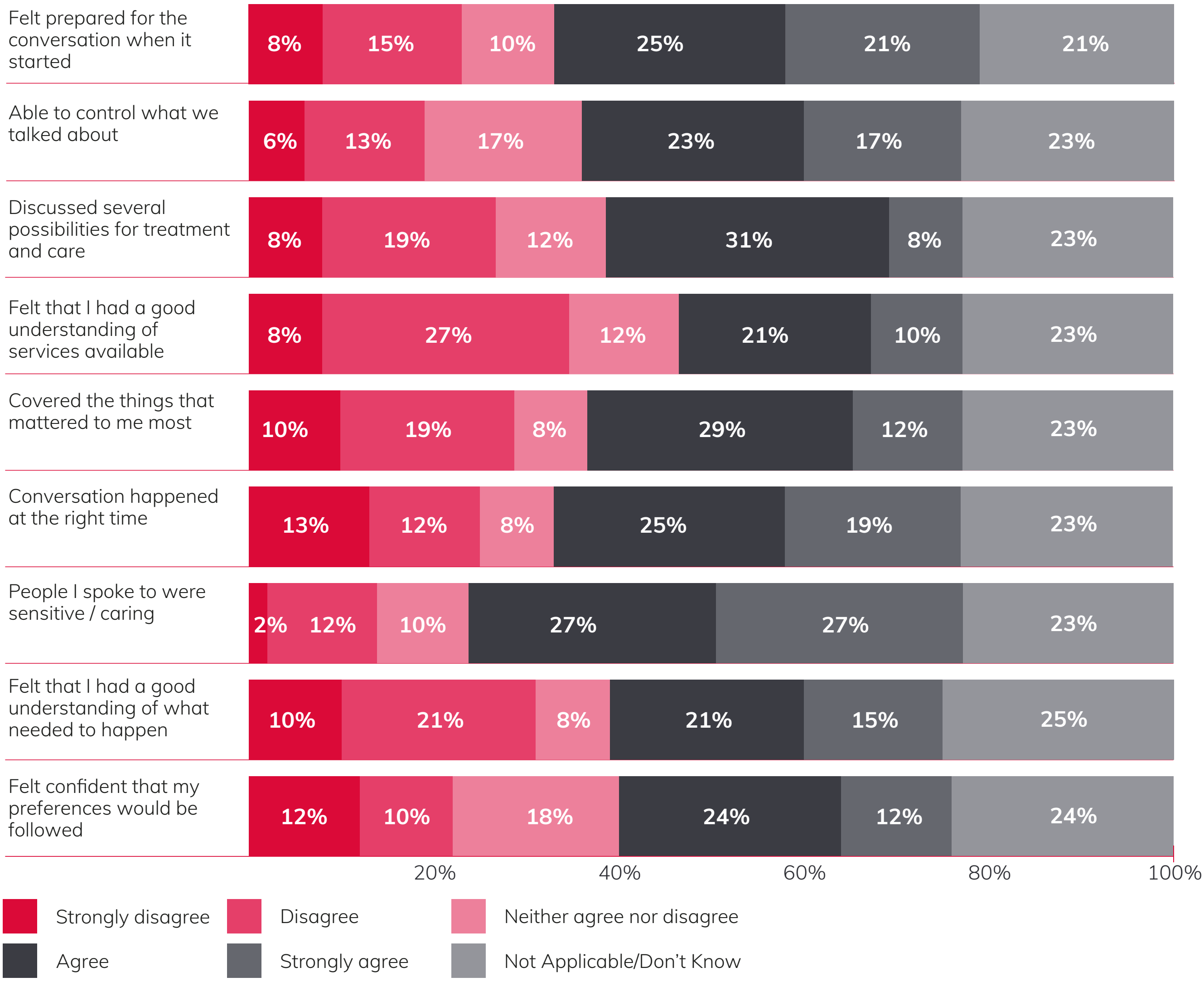
Characteristic	Individuals approaching end of life and those important to them	Health/social care professionals (n=54)
	(n=52) Number (Percent)	(n=54) Number (Percent)
Sex		
Female	38 (73%)	45 (83%)
Male	13 (25%)	9 (17%)
Prefer not to say	1 (1%)	0 (0%)
Age		
18-35	4 (8%)	7 (13%)
36-45	4 (8%)	10 (19%)
46-55	7 (13%)	19 (35%)
56-65	15 (29%)	10 (19%)
66-75	12 (23%)	1 (2%)
76-85	7 (13%)	0 (0%)
86-95	1 (2%)	0 (0%)
Prefer not to say	2 (4%)	7 (13%)
Ethnicity		
English / Northern Irish / Scottish / Welsh / British	48 (92%)	43 (80%)
Irish	0 (0%)	1 (2%)
Any other white background	2 (4%)	3 (6%)
White and Asian	1 (2%)	2 (4%)
Indian	0 (0%)	2 (4%)
Chinese	0 (0%)	1 (2%)
Any other ethnic group	0 (0%)	1 (2%)
Prefer not to say	1 (2%)	2 (4%)

3.2.1 People approaching the end of life and people important to them

Of the 52 responses from people approaching the end of life or people important to them, 15 (29%) reported that the individual planning end of life had cancer, 24 (46%) that they had a long-term life-limiting physical condition other than cancer, 4 (8%) that they had dementia, 1 (2%) that they had a mental health condition, and 3 (6%) that they had another form of disability (not learning disability). Thirty of the 52 were people important to the person at the end of life, including family, friends or informal carers (referred to in shorthand as 'Carers' in some of the graphs below); just over half (16 out of 30, 53%) of them had been assigned lasting power of attorney and 13 had not (1 did not reply).

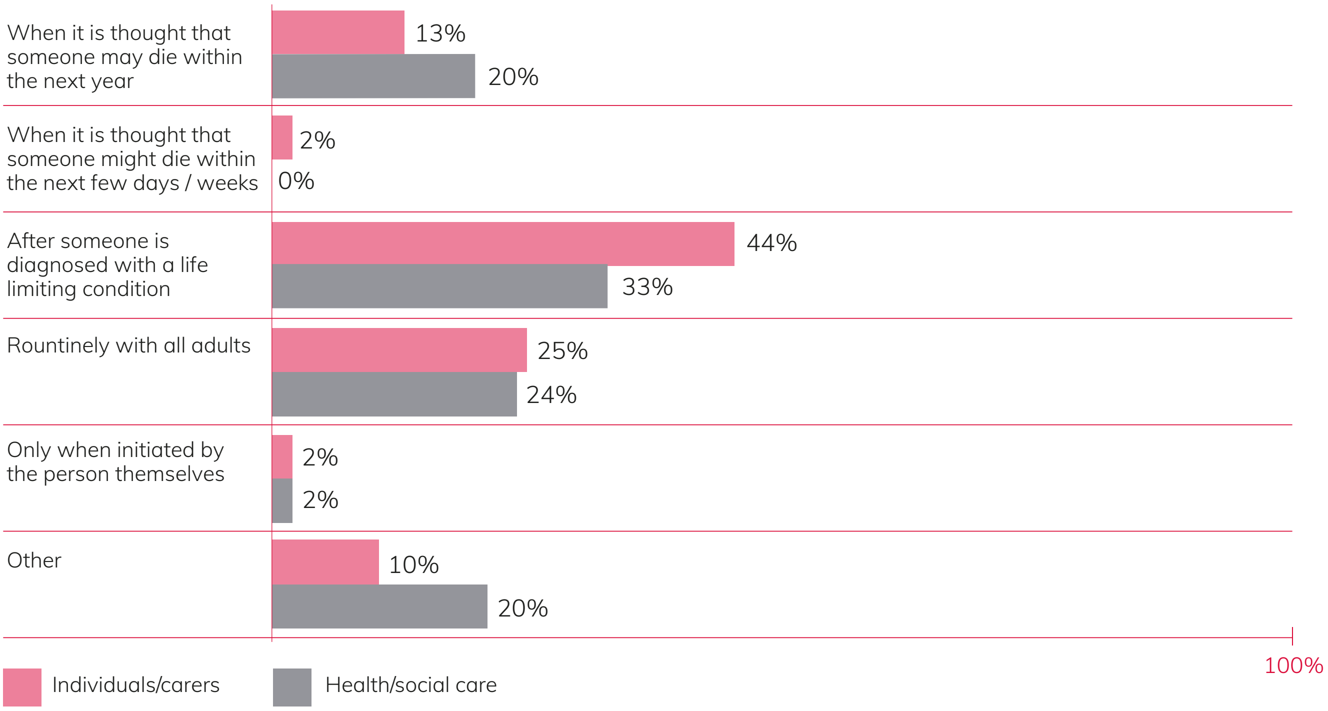
We asked participants to what extent they agreed with various statements relating to aspects of end-of-life conversations (see Figure 2 for summary). Around half of participants agreed or strongly agreed that they felt prepared for the conversation when it started and that the people they spoke to were sensitive and caring (n=24, 46% and n=28, 54%, respectively). Only 31% (n=16) of participants agreed or strongly agreed they had a good understanding of services available to them and 35% (n=18) agreed or strongly agreed that they felt confident that they preferences would be followed, reflecting the findings of other national surveys and audits.

Figure 2. Percent of survey response ratings to statements regarding various aspects of end-of-life care conversations among people approaching the end of life and those important to them, n=52



In terms of the timing of conversations, most individuals approaching end of life and those important to them felt that the best time to have an initial conversation with a member of health or social care staff would be 'soon after someone is diagnosed with a condition that may shorten their life, or other factors are present that might increase their risk of dying' (n=23, 44%) or 'routinely with all adults, regardless of current age, health, or medical condition' (n=13, 25%) (see Figure 3), suggesting strong support for initiating conversations earlier.

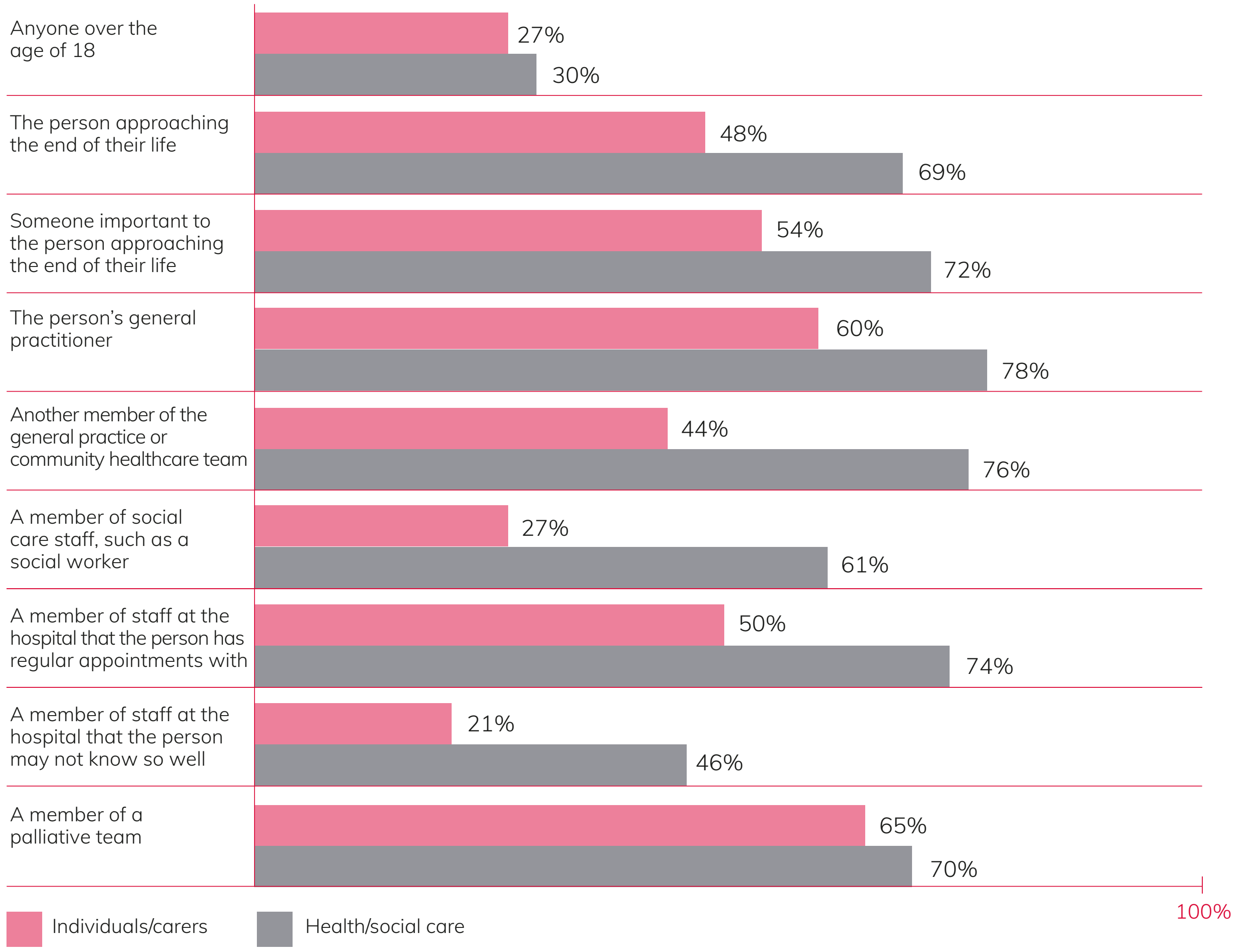
Figure 3. Percent of responses for 'When do you think is the best time to have a conversation [about planning end-of-life treatment and care]?', n=52 for individuals/carers and n=54 for health and social care professionals



Note: Two individual/carers responding Don't Know/Not Applicable not displayed

In terms of who is best placed to initiate a conversation, participants felt that a member of a palliative care team specialised in end-of-life care (n=34, 65%), the person's GP (n=31, 60%), someone important to the person approaching the end of life, such as a family member or close friend (n=28, 54%), or a member of staff at a hospital that the person has regular appointments with (n=26, 50%) would be appropriate (see Figure 4).

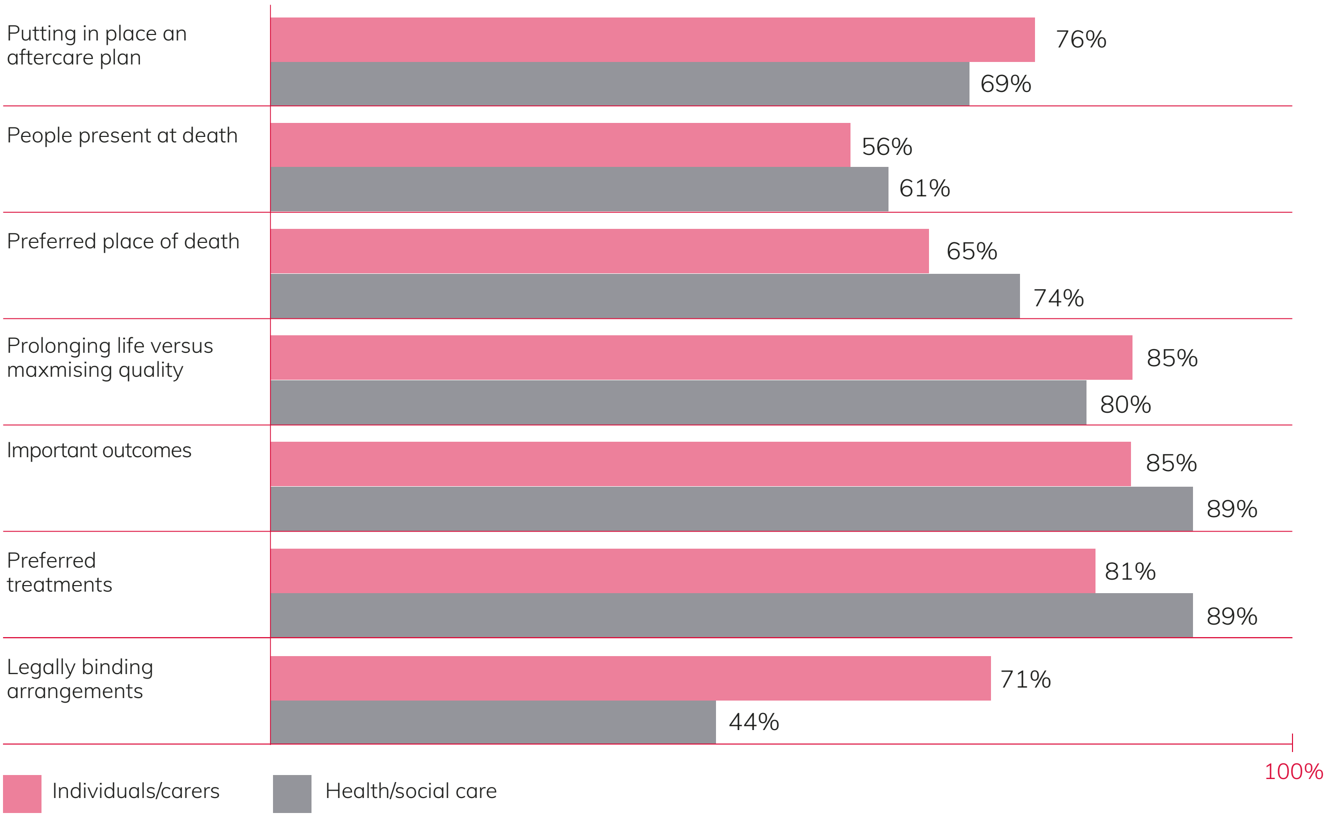
Figure 4. Percent of responses by group for 'Who do you think should initiate a conversation [about planning end-of-life treatment and care]?', n=52 for individuals/carers and n=54 for health and social care professionals



Note: Does not include 2 Don't Know responses. Multiple selections were allowed for this question.

Finally, we asked participants to rate the importance of discussing and documenting various aspects of end-of-life treatment and care with health or social care staff. Figure 5 shows the percentage of respondents rating each aspect as 'very important'. Participants rated most highly 'My views on the balance between prolonging life as much as possible, versus maximising quality of life' (n=44, 85% rated very important), 'Which outcomes are most important to me' (n=44, 85%), and 'What specific treatments I would or wouldn't like to receive' (n=42, 81%). Discussing and documenting preferences on who should be present at death and preferred place of death were seen as very important by the majority of respondents as well, although a lower proportion of respondents rated them as very important (n=29, 56% and n=34, 65% rated very important, respectively).

Figure 5. Percent by group responding Very important to each of the of the following potential foci of conversations about planning end-of-life treatment and care, n=52 for individuals/ carers and n=54 for health and social care professionals.



When asked what resources people found most helpful, participants mentioned those produced by Compassion in Dying (n=4), Macmillan (n=4), Marie Curie (n=2), and Dignity in Dying (n=2) in their free-text responses. Responses suggested that these resources were mostly accessed online. But people also mentioned their healthcare, hospice care, or in-home care team as critical sources of knowledge. Finally, there were some references to NHS leaflet resources, the ReSPECT form, and authors such as Kathryn Mannix and Atul Gawande.

In open-text responses, people shared what they felt would be most helpful to them. The most common theme was information – people wanted clear and easy-to-navigate information in various forms, such as a leaflet describing important considerations for end-of-life discussions, information on local services and contact information, and specific information such as what care packages are and how to best use them or an information pack specific to residents in care homes. Discussions with their healthcare professional or specifically someone from the palliative care team were also commonly mentioned. Finally, a few participants noted the importance of honesty in conversations.

3.2.2 Health and social care professionals

Among 54 health and social care respondents, most reported working in acute care (n=22, 41%) followed by community healthcare (n=7, 13%), hospice (n=6, 11%) and social care (n=5, 9%) (see Table 3). There were 17 doctors (13 consultants or GPs, 4 junior doctors or doctors in training, 24% and 7% respectively). Over a third were nurses (n=19, 35%) and 3 of the 54 (6%) were advanced nurse practitioners. Few participants were social workers (n=4, 7%) or social care workers (n=2, 3%) (see Table 4).

Table 3. Reported area of work for health and social care respondents, n=54

Area of work	Number (Percent)
Social care	5 (9%)
Primary care or general practice	2 (4%)
Community healthcare	7 (13%)
Acute care	22 (41%)
Secondary mental healthcare	1 (2%)
Hospice	6 (11%)
Charity sector	2 (4%)
Other	8 (16%)
No response	1 (2%)
Total	**54**

Table 4. Reported professional role for health and social care respondents, n=54

Professional role	Number (Percent)
Doctor – consultant or GP	13 (24%)
Doctor – junior or in training	4 (7%)
Nurse	19 (35%)
Allied health professional	1 (2%)
Social worker	4 (7%)
Social care worker	2 (4%)
Advanced nurse practitioner	3 (6%)
Registered manager	3 (6%)
Other	5 (9%)
Total	**54**

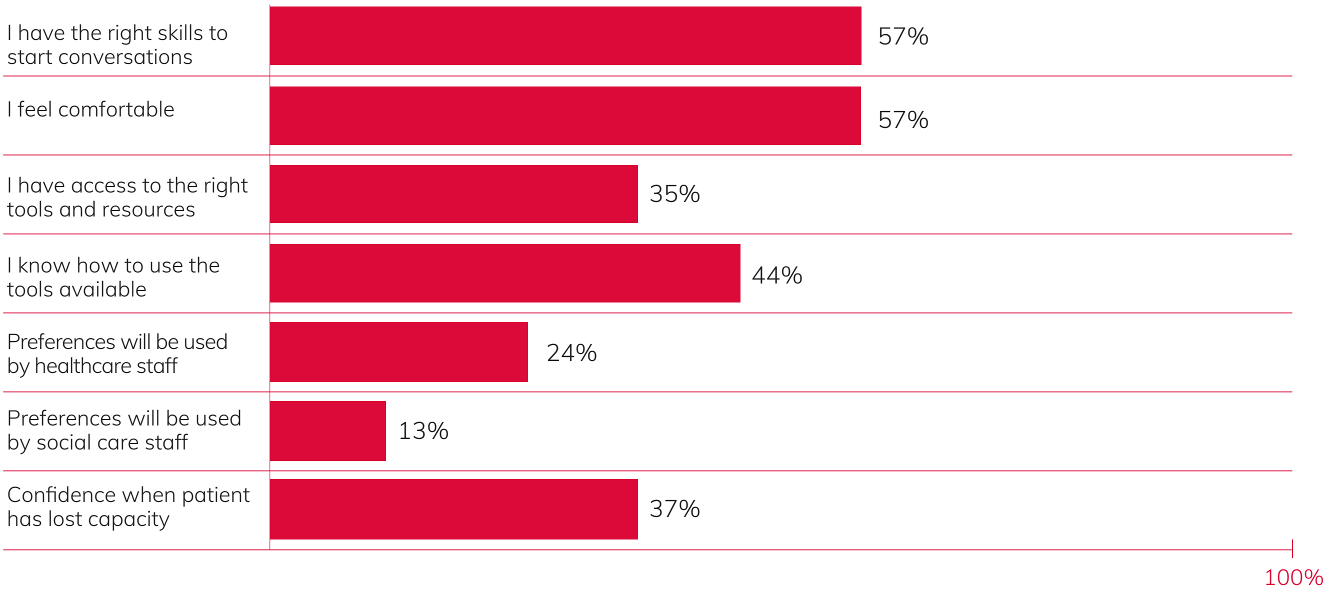
We asked health and social care professionals similar questions to those asked of the first group, allowing some comparison of responses between groups. In terms of conversation timing, most respondents felt that it was most appropriate to have the conversation soon after someone is diagnosed with a condition that may shorten their life (n=18, 33%), or routinely with all adults (n=13, 24%) (Figure 3). This group was more likely to take the view that initiating a conversation when someone might die within the next year would be appropriate (n=11, 20% versus n=7, 13% for people approaching the end of life and people important to them) (Figure 3). Eleven of 54 (20%) responded ‘other’; open text responses from these participants emphasised that timing may vary by individual. One wrote that the timing ‘depends on the person, the family, culture, acceptance’ while another felt that ‘it has to be based on trust and respect and confidence in the professional... but also needs to be done when the person is ready themselves.’ Other respondents suggested that a conversation is an offer that should be made regularly – ‘to make a future appointment to discuss’ or ‘to return to the topic when and if they wish’.

In terms of who is best placed to initiate a conversation about end-of-life treatment and care preferences, health and social care professionals recognised that several groups could be well placed to initiate such conversations: most selected were the person’s GP (n=42, 78%), another member of the general practice or community healthcare team (n=41, 76%), a member of staff at a hospital that the person has regular appointment with (n=40, 74%), someone important to the person approaching the end of life (n=39, 72%), and a member of the palliative care team (n=38, 70%). Less popular was a member of staff at a hospital that the person may not know so well (n=25, 46%) (see Figure 4). All in all, health and social care professionals had more positive views about the appropriateness of most of the identified groups in initiating conversations, compared to people planning for end of life and those important to them.

With regard to the content of conversations, most health and social care professionals felt that outcomes were most important to discuss (n=48, 89% rated very important), as well as people’s views on the balance between prolonging life versus maximising quality of life (n=43, 80%) (Figure 5). Discussing putting in place legally binding arrangements and identifying who should be present at death were also seen as important, although a smaller proportion of respondents rated them as very important, n=24 (44%) and n=33 (61%) respectively. Health and social care professionals’ views on the importance of legally binding arrangements diverged from those of people approaching the end of life and people important to them (n=37, 71% of whom felt that discussing legally binding arrangements was very important).

In terms of accessing up-to-date records of people’s preferences, respondents indicated that it was relatively difficult to access such records: 19 (35%) responded ‘Very difficult’ or ‘Quite difficult’, 10 (19%) responded ‘Neither easy nor difficult’, and 8 (15%) responded ‘Quite easy’ or ‘Very easy’.

Figure 6. Percent responding Strongly agree to each of the of the following aspects of discussing end-of-life treatment and care preferences with patients or service users, n=54



In terms of discussing end-of-life treatment and care preferences with patients or service users, over half (57%, n=31) of respondents strongly agreed that they had the right skills to start conversations and over half (57%, n=31) felt comfortable having those discussions. Only 35% (n=19) of respondents felt that they had access to the right tools and resources to have productive conversations, and 44% (n=24) strongly agreed that they knew how to use the tools available for documenting these preferences. About a quarter (24%, n=13) of respondents felt that the preferences expressed by people would be used by healthcare staff providing end-of-life treatment and care, and only 13% (n=7) strongly felt that the preferences would be used by social care staff providing end-of-life care. Finally, 37% (n=20) of respondents strongly felt that they were confident in making treatment decisions when a patient has lost capacity (Figure 6).

In terms of resources for discussing and planning end-of-life treatment and care with patients or service users that respondents had found useful, the breadth of resources cited was striking. People again mentioned Kathryn Mannix's books as being helpful as well as using the ReSPECT process and form. There were resources that both staff and individuals approaching the end of life drew from, including Compassion in Dying, Dying Matters, and Marie Curie resources, but also others such as SAGE & THYME for communication training and the Gold Standards Framework that were identified by health and social care professionals specifically. Several health and social care professionals mentioned resources that they had developed themselves, including a webinar '*to help staff understand why it is important we record* [a patient's wishes] *in our risk assessments*' and masterclasses to help professionals improve their confidence in end-of-life conversations.

When asked what would be most helpful in identifying people approaching the end of life, having conversations about their end-of-life treatment and care preferences with them, or recording and sharing these preferences, many respondents (n=16) mentioned having a nationally shared record across care services. In addition, several participants mentioned communication training, for example 'advanced communication to navigate difficult conversations' and 'how to start conversations with people who are not necessarily at the end of their life, but in the last year of their life'. Finally, time was a common theme – time to form relationships with the patient and family and time to be able to have conversations without feeling behind on other clinical work.

3.3 In-depth interviews

To enrich and supplement the survey data, we asked participants if they would be interested in participating in a qualitative interview. We conducted 34 interviews with individuals recruited this way (in addition to the 21 stakeholder interviews reported in section). They included 14 health or social care providers, 7 individuals planning the end of life, and 13 carers or people important to those at the end of life. The interviews provided rich detail of people's experience with end-of-life treatment and care as well as professionals' experience with planning and delivery of end-of-life treatment and care.

We asked people to describe what were important considerations for initiating or having a conversation about a person's end-of-life care and treatment preferences. Important aspects that facilitated good conversations included: having sensitivity about what is important to someone, prioritising relationship building, making sure individuals feel in control, portraying real care through empathy and compassion, and giving people the time they need (even when time was pressing). Others included the importance of courage in communicating difficult but important news, and the need to convey the positive things that could arise from good planning without sugar-coating the reality of the prognosis.

> 'You have to be prepared to say, "going into hospital you might get better, but actually it's a possibility you may not ever be well enough to come out of hospital and could die there."'

> 'They [hospice workers] were so good, they provided me with the suction machine, they showed me how to use it, and they said, "you know, this is how you use it, this is when you use it, but you know that it's not going to stop him from dying but it will make him much more comfortable when he is dying."'

With regard to content of the conversation, participants emphasised the importance of making known how the conversation would be documented, making clear if preferences may not be possible due to resources or other reasons, and also acknowledging that one session is often not enough to discuss everything.

Healthcare professionals shared specific approaches they took to initiate conversations, with a few sharing the specific questions that they often asked to patients and their families to gain understanding of everyone's perspectives. Some interviewees described in detail how they guided people through conversations and specific phrases that they found helpful to broach the idea that the patient may not get better and that there were limitations to what could be done.

Most participants agreed that advanced communication skills were critical and that observing conversations was a valuable way of learning how to facilitate conversations better. Healthcare professionals acknowledged that the completion of an advance planning document and the necessity of doing so could get in the way of communicating with a person and understanding what is important to them and their loved ones.

3.3.1 Building on the insights from the survey and interviews

The survey and interview data highlighted challenges in end-of-life care planning in various areas. Certain issues were particularly apparent, from both interview and survey data and from both health and social care professionals and people planning end of life and those important to them.

Among both groups, there was no doubt about the importance of planning for the end of life, and for initiating conversations early. Health and social care professionals in particular agreed that a variety of people were well placed to initiate conversations; there was less agreement among people planning end-of-life care and those important to them, but still this group felt that a wide variety of people were well-placed. Broadly, though, the two groups appeared to agree that this is a matter of personal preference, and that individual circumstance in terms of who happens to have the time, information, and skills to have a conversation is more important than role or specialty. Some of the challenges identified by participants were not readily amenable to intervention: while both groups recognised the importance of finding time to undertake conversations properly, and many health and social care professionals reported going out of their way to do so, resourcing pressures made it difficult.

Both groups, however, also identified opportunities for improving quality of care around identifying people approaching end of life, initiating conversations with them, having fruitful and sensitive conversations, documenting people’s preferences, and ensuring they are shared with and taken up by others in the health and care system. In consultation with our advisory groups, we collated these views on potential opportunities and priorities for improvement, and took them forward into the next stage of our study: consensus building.

3.4 Consensus building

Invitations to participate in the consensus building exercise were issued to those who had participated in earlier stages of the research and indicated willingness to be contacted about further stages. The exercise was also advertised on social media and by collaborating organisations with an interest in the field. Additionally, we approached further stakeholder organisations with a particular interest in end-of-life care to supplement those included in the first stage of the work.

Rounds 1 and 2

In the first round of consensus building, participants were asked to rate the importance of 13 statements developed by the research team based on responses to the survey and interviews, with input from NICE and both advisory groups (see Table 5 for list of the statements included and rationale for their inclusion). There were 475 participants in the first round; the increase in participants compared to the earlier survey appeared to be due primarily to responses to advertisement of the consensus building exercise on the Compassion in Dying mailing list.

Table 5. Statements and their rationale for rounds 1and 2 of the consensus building exercise.

	Statement	Rationale
1	Healthcare staff should initiate conversations and document preferences about end-of-life treatment and care planning routinely, including for people who are not yet approaching end of life – for example during regular check-ups with a GP or practice nurse, or when attending hospital appointments.	Interview data suggest that conversations about end-of-life treatment and care preferences often take place too late or not at all. This statement proposes that routine conversations should be occurring, suggesting that they happen regularly regardless of patients' conditions.
2	It is sometimes OK for a health or social care professional to raise the issue of planning for end-of-life treatment and care with someone, even if they don't know the person that well.	Survey respondents showed preferences for who should initiate end-of-life planning conversations, i.e. healthcare professionals that they know and see regularly. However, qualitative data suggest that conversations about end-of-life treatment and care preferences often take place too late or not at all. If endorsed, this statement may have value in showing health or social care professionals that it is OK to raise this issue even if they don't know them that well.
3	It is better for a health or social care professional to raise the issue of end-of-life treatment and care with someone even if it's not quite the ideal time than for no-one to raise it at all.	When asked whether the initial conversation happened at the right time, survey responses were mixed. This statement seeks to address initiating end-of-life planning conversations given challenges with identification of patients approaching the end-of-life. If endorsed, it may have value in showing health or social care professionals that it is OK to raise this issue even if they have some doubts.
4	We need to empower a wider range of people, including staff, people preparing for end of life and others, to initiate conversations about end-of-life treatment and care, for example by providing them with better skills and knowledge.	Survey and interview data suggest wide ranging views on who is appropriate and qualified to initiate end-of-life care planning conversations. Among healthcare professional respondents, there was strong agreement that one thing that prevented health and social care staff from having productive conversations was the belief someone else may be best placed to have them. Yet, when asked who is appropriate to initiate these conversations, responses suggested that any healthcare professional would be appropriate. *If consensus is reached, ranking exercise in round 3 to identify/prioritise groups to be empowered.*
5	Too many different guides and protocols about how to have conversations about people's preferences around end-of-life treatment and care are available – a single guide to having conversations would be better.	Conversations planning for a person's end-of-life care and treatment preferences can happen at different time points in the period before a person's death. While the individual's specific health condition or healthcare needs may be different, there are common elements (e.g. style, structure) of these conversations that could be included in a unified approach. *If consensus is reached, ranking exercise in round 3 to identify/prioritise elements of conversations.*
6	Efforts to discuss and document end-of-life treatment and care preferences should cover what matters to the individual and what they value in their life.	While survey respondents rated both preferred treatments and outcomes as very important to discuss and document, interviews with health and social care professionals suggest that end-of-life care planning conversations start by understanding what is most important to the person approaching end of life. There was also some suggestion that specific directions about treatments that should and should not be given are more easily upheld if an individual loses capacity. However, we also heard from patients who found that conversations were sometimes carried out as 'tick-box exercises'. These statements seek to see whether there is consensus on whether conversations should be values-based and/or decision-based.
7	Efforts to discuss and document end-of-life treatment and care preferences should cover specific treatment and care preferences.	

8	People approaching end of life are not fully aware of what cardiopulmonary resuscitation (CPR) involves or who makes the recommendation – more consistent messaging is needed.	While survey respondents rated preferred treatments as very important to discuss and document, interviews with health and social care professionals suggest that there is often too much focus on the CPR 'decision' during these conversations, to the neglect of wider considerations around end-of-life treatment and care. If endorsed, this statement may have value in showing that individuals and people who care about them should have a clear understanding of when there may be a CPR recommendation to make and when there is not.
9	People approaching end of life do not have a clear understanding of what good-quality and poor-quality end-of-life treatment and care look like – more work is needed to ensure that people have clear information about what to expect at the end of life, and know where to access support when things go wrong.	Qualitative data suggested that individuals and their carers continue to have poor experiences at the end of life. Several carers spoke of difficulties providing care at the end of life in the home setting including access to pain medication and limited home visits. Understanding of what can be expected and potential issues with care and treatment access in various settings may need to be improved through better communication. There were a few examples where this communication occurred early and throughout the end-of-life period.
10	Training on advanced communication skills should be provided to support healthcare professionals in initiating and conducting conversations about end-of-life treatment and care preferences.	Many survey respondents found advanced communication skills training particularly helpful to initiate sensitive or difficult conversations with patients, even given a short amount of time. They provided a very long list of resources they found helpful in this regard, making clear that there is not currently a unified approach. *If consensus is reached, ranking exercise in round 3 to identify/prioritise elements of training.*
11	A single, standardised approach to documenting and recording end-of-life treatment and care preferences is needed.	Some healthcare professionals commented on how other healthcare provider notes were sometimes written in an unclear or ambiguous way. Others commented on the length of some documentation and the need for summary statements, and on important items that were not always available. Individuals and people important to them desired some feedback to confirm that their wishes had been documented or updated. *If consensus is reached, ranking exercise in round 3 to identify/prioritise what should be recorded.*
12	A single integrated electronic system for recording end-of-life treatment and care preferences is needed.	Multiple respondents suggested that a record, interoperable across settings (e.g. community, hospital, ambulance), has been or would be helpful to ensure an individual's preferences were known across the healthcare system. Qualitative data suggest that a lot of time is currently spent by some individuals to make sure patients' wishes are known in different settings, i.e. by calling GP offices, etc. While other forms of recording preferences (e.g. 'message in a bottle' – a note of personal and medical information kept by individuals in the refrigerator, so that it can be easily located by ambulance staff in an emergency) are likely to be needed as a back-up, there was strong support for an integrated system, and a sense that uptake of the NHS app driven by Covid may provide an opportunity to take this forward.
13	Accessing and using people's care plans when making decisions about treatment should be routine practice in all healthcare activities.	There were concerns among some participants that consideration of preferences around end-of-life treatment and care was patchy among healthcare professionals when making treatment decisions. If endorsed, this statement may have value in emphasising that these preferences should be considered routinely by all healthcare professionals when making decisions about treatment when a patient lacks capacity to give consent.

In the first round, 11 of the 13 statements reached consensus, meaning that at least 70% of participants rated the statement 7, 8 or 9 – i.e. the highest three levels of agreement with the statements. Two statements did not reach consensus and were therefore subject to a second round of rating. These were:

- Too many different guides and protocols about how to have conversations about people's preferences around end-of-life treatment and care are available – a single guide to having conversations would be better (58.2% agreement across all groups). [Statement 5]
- Efforts to discuss and document end-of-life treatment and care preferences should focus on specific treatment and care preferences (60.7% agreement across all groups) [Statement 7]

In this second round, 283 of the 475 participants (59.6%) from the first round participated, and while numbers agreeing with each statement increased slightly, neither statement 5 nor statement 7 reached consensus, with 60.8% and 64.9% agreement respectively achieved after the second round.

Table 6 shows the final overall and group-level rates of agreement for all statements. As expected, there was variation across the group-level rates of agreement. For example, for statement 1, 'Healthcare staff should initiate conversations and document preferences about end-of-life treatment and care planning routinely, including for people who are not yet approaching end of life – for example during regular check-ups with a GP or practice nurse, or when attending hospital appointments', there was consensus among people planning their own end-of-life care, people important to them, and health and social care professionals, but only 60.9% of policymakers or representatives of organisations with interest in end-of-life care planning rated its importance as 7, 8 or 9.

Table 6. Final overall and group-level rates of agreement for consensus building statements.

	Statement	People planning their own end-of-life care	People planning end-of-life care of others important to them	Health and social care professionals	Policymakers and representatives of organisations with interest in end-of-life care	All
		n=278	n=133	n=38	n=26	n=475
1	Healthcare staff should initiate conversations and document preferences about end-of-life treatment and care planning routinely, including for people who are not yet approaching end of life – for example during regular check-ups with a GP or practice nurse, or when attending hospital appointments.	76.8%	71.0%	70.3%	60.9%	73.9%
2	It is sometimes OK for a health or social care professional to raise the issue of planning for end-of-life treatment and care with someone, even if they don't know the person that well.	79.4%	77.1%	78.4%	87.0%	79.1%
3	It is better for a health or social care professional to raise the issue of end-of-life treatment and care with someone, even if it's not quite the ideal time, than for no-one to raise it at all.	84.5%	84.6%	78.4%	82.6%	83.9%
4	We need to empower a wider range of people, including staff, people preparing for end of life and others, to initiate conversations about end-of-life treatment and care, for example by providing them with better skills and knowledge.	94.2%	92.4%	91.9%	95.7%	93.6%
5	Too many different guides and protocols about how to have conversations about people's preferences around end-of-life treatment and care are available – a single guide to having conversations would be better.	60.8% (62.1%)	60.0% (53.9%)	69.2% (56.8%)	53.3% (39.1%)	60.8% (58.2%)
6	Efforts to discuss and document end-of-life treatment and care preferences should focus on what matters to the individual and what they value in their life.	94.9%	94.7%	94.6%	100.0%	95.1%
7	Efforts to discuss and document end-of-life treatment and care preferences should focus on specific treatment and care preferences.	65.5% (64.0%)	61.0% (54.2%)	61.5% (59.5%)	80.0% (60.9%)	64.9% (60.7%)
8	People approaching end of life are not fully aware of what cardiopulmonary resuscitation (CPR) involves or who makes the recommendation – more consistent messaging is needed.	86.2%	81.5%	86.5%	82.6%	84.8%

9	People approaching end of life do not have a clear understanding of what good-quality and poor-quality end-of-life treatment and care look like – more work is needed to ensure that people have clear information about what to expect at the end of life, and know where to access support when things go wrong.	91.7%	86.2%	86.5%	95.7%	89.9%
10	Training on advanced communication skills should be provided to support healthcare professionals in initiating and conducting conversations about end-of-life treatment and care preferences.	90.6%	87.8%	78.4%	95.6%	89.1%
11	A single, standardised approach to documenting and recording end-of-life treatment and care preferences is needed.	79.3%	72.9%	78.4%	73.9%	77.2%
12	A single integrated electronic system for recording end-of-life treatment and care preferences is needed.	82.9%	73.9%	81.1%	78.3%	80.0%
13	Accessing and using people's care plans when making decisions about treatment should be routine practice in all healthcare activities.	94.2%	93.1%	89.2%	82.6%	93.0%

Notes: Statements 5 and 7 underwent two rounds in the first part of consensus building.
Figures shown in parenthesis reflect ratings from Round 1.

3.4.2 Rounds 3 and 4

In the second part of the consensus-building exercise, participants were asked to rate or rank additional elements related to three statements that had achieved consensus in the first part of consensus building. All 475 participants from round 1 were invited to round 3 and 273 (57%) responded.

Four of the statements included in rounds 1 and 2 were considered for inclusion in rounds 3 and 4: statement 4 ('We need to empower a wider range of people, including staff, people preparing for end of life and others, to initiate conversations about end-of-life treatment and care, for example by providing them with better skills and knowledge'), statement 5 ('Too many different guides and protocols about how to have conversations about people's preferences around end-of-life treatment and care are available – a single guide to having conversations would be better'), statement 10 ('Training on advanced communication skills should be provided to support healthcare professionals in initiating and conducting conversations about end-of-life treatment and care preferences') and statement 11 ('A single, standardised approach to documenting and recording end-of-life treatment and care preferences is needed'). In consultation with the advisory groups, the team identified that each of these statements could benefit from further examination in terms of the specific elements that required action: for example, the types of groups to be prioritised for empowerment (statement 4) or the best guide to use to inform conversations (statement 5). However, since statement 5 did not reach consensus in rounds 1 and 2, it was not included in rounds 3 and 4. Therefore rounds 3 and 4 included further interrogation of three statements.

First, building on statement 11 from rounds 1 and 2 ('A single, standardised approach to documenting and recording end-of-life treatment and care preferences is needed'), participants were asked to identify the components that such a standardised approach to documentation should incorporate (using the same nine-point scale, with 1 = Not important at all and 9 = Extremely important). All items reached consensus with ratings as 7, 8 or 9 between 81.3% and 99.3% (Table 7). Of these, there were 7 items where overall consensus was above 95%:

- Any outcomes that are most important to the person (for example comfort, day-to-day independence) – 98.6% consensus
- Any outcomes that the person particularly wants to avoid (for example increased dependency on others, being housebound) – 98.2% consensus
- The person's preferred balance between prolonging life and maximising quality of life – 99.3% consensus
- Specific treatments the person wouldn't like to receive (for example artificial ventilation, antibiotics for life-threatening infections) – 96.3% consensus
- The recommendation (based on patient and clinical views) on whether cardiopulmonary resuscitation should be attempted if the person's heart stops – 97.8% consensus
- Whether the person has an Advance Decision to Refuse Treatment, Advance Directive (Scotland), or Advance or Anticipatory Care Plan? – 98.9% consensus
- Whether the person has a legal proxy who can make decisions on their behalf, for example through Lasting Power of Attorney for Health and Welfare (England and Wales) or Welfare Power of Attorney (Scotland)? – 98.9% consensus

Table 7. Overall percent of respondents rating 7, 8 or 9 for each element relating to statement 11 (components to be included in a standardised approach to documenting end-of-life care preferences), n=273.

How important is it to record:	People planning their own end-of-life care	People planning end-of-life care of others	Health and social care professionals	Policy and stakeholder organisation representatives	All
	n = 169	n = 73	n = 17	n = 14	N = 273
Health information – diagnoses	89.9%	81.9%	100.0%	100.0%	**89.0%**
Health information – communication needs	87.0%	94.4%	94.1%	100.0%	**90.1%**
Any outcomes that are most important to the person (for example comfort, day-to-day independence)	98.2%	98.6%	100.0%	100.0%	**98.6%**
Any outcomes that the person particularly wants to avoid (for example increased dependency on others, being housebound)	97.6%	98.6%	100.0%	100.0%	**98.2%**
The person's preferred balance between prolonging life and maximising quality of life	99.4%	98.6%	100.0%	100.0%	**99.3%**
Specific treatments the person wouldn't like to receive (for example artificial ventilation, antibiotics for life-threatening infections)	97.6%	95.9%	88.2%	92.9%	**96.3%**
The person's preferred place of death	79.2%	83.6%	88.2%	85.7%	**81.3%**
Preferences on managing symptoms when experiencing pain	92.3%	95.9%	88.2%	100.0%	**93.4%**
Preferences on managing symptoms when experiencing breathlessness	86.9%	94.5%	82.4%	100.0%	**89.3%**
Preferences on managing symptoms when experiencing anxiety or agitation	84.6%	93.2%	82.4%	100.0%	**87.9%**
The recommendation (based on patient and clinical views) on whether cardiopulmonary resuscitation should be attempted if the person's heart stops	97.0%	100.0%	94.1%	100.0%	**97.8%**
Names of other people important to the person, and their contact details in case of emergency	93.5%	95.9%	94.1%	100.0%	**94.5%**
Names of health and social care professionals involved in the person's care	75.6%	86.3%	100.0%	100.0%	**81.3%**
Whether the person has an Advance Decision to Refuse Treatment, Advance Directive, or Advance or Anticipatory Care Plan?	98.8%	100.0%	100.0%	92.9%	**98.9%**
Whether the person has a legal proxy who can make decisions on their behalf, for example through Lasting Power of Attorney for Health and Welfare (England and Wales) or Welfare Power of Attorney (Scotland)?	98.8%	98.6%	100.0%	100.0%	**98.9%**

Second, building on statement 4 from rounds 1 and 2 ('We need to empower a wider range of people, including staff, people preparing for end of life and others, to initiate conversations about end-of-life treatment and care, for example by providing them with better skills and knowledge'), which achieved strong consensus across groups (93.6% rating as 7, 8 or 9), in round 3, we asked participants to choose five groups of people that should be prioritised in efforts to improve skills and knowledge from a list of 11 groups (Table 8), and then, in round 4, we asked participants to prioritise the top five groups selected in round 3. The top five groups selected in round 3, in order by highest to lowest rank in round 4, were: general practitioners, staff in care homes, palliative care staff, specialist nurses, and healthcare staff working in the community setting.

Table 8. Total number of participants that selected each group among their top 5 choices (statement 4 in round 3).

Of the following groups, which ones do you think are the most important to empower through new or improved training or information?	People planning their own end-of-life care	People planning end-of-life care of others	Health and social care professionals	Policy and stakeholder organisation representatives	All
	n = 169	n = 73	n = 17	n = 14	N = 273
General practitioners	125	60	9	10	**204**
Staff in care homes	115	49	10	8	**182**
Healthcare staff working in the community, such as nurses, therapy staff and pharmacists	86	43	8	9	**146**
Palliative care staff	96	35	6	9	**146**
Specialist nurses, such as heart failure and COPD nurse specialists	77	33	9	4	**123**
The general public	77	32	9	4	**122**
Community social care and social work staff	63	33	6	7	**109**
Emergency and acute medicine department staff	69	28	6	5	**108**
Specialist hospital doctors other than surgeons, such as neurologists and nephrologists	43	20	4	5	**72**
Ambulance staff	36	9	4	3	**52**
Surgeons (for example to inform preoperative assessments)	32	9	6	4	**51**

Third, building on statement 10 from rounds 1 and 2 ('Training on advanced communication skills should be provided to support healthcare professionals in initiating and conducting conversations about end-of-life treatment and care preferences'), which achieved strong consensus across groups (89.1% rating as 7, 8 or 9), in round 3, we asked participants to choose five most important topics that such training should focus on from a list of 10 topics (Table 9), and then, in round 4, we asked participants to prioritise the top five topics selected in round 3. The top five topics selected in round 3, in order by highest to lowest rank in round 4, were: exploring what matters to the person and people close to them, and what concerns they might have; initiating conversations about end-of-life treatment and care; respecting people's decisions about treatments they wish to receive when having conversations with them, in line with the Mental Capacity Act; facilitating and responding to questions, including signposting people to other sources of support; and talking to the person about illness progression, including prognostic uncertainty.

Table 9. Total number of participants that selected each topic among their top 5 choices (for statement 10 in round 3).

Of the following topics, which ones do you feel are most important to include in advanced communication training for healthcare professionals?	People planning their own end-of-life care	People planning end-of-life care of others	Health and social care	Policy and stakeholder	All
	n = 169	n = 73	n = 17	n = 14	N = 273
Exploring what matters to the person and people close to them, and what concerns they might have	123	60	12	11	206
Initiating conversations about end-of-life treatment and care	123	53	9	9	194
Facilitating and responding to questions from the person preparing for the end of life and people close to them, including signposting people to other sources of support	110	43	10	9	172
Respecting people's decisions about treatments they wish to receive when having conversations with them, in line with the Mental Capacity Act	102	47	9	8	166
Talking to the person about illness progression, including prognostic uncertainty	75	31	12	7	125
Exploring what death might look like and discussing fears about dying	61	27	3	8	99
Establishing a shared understanding of the person's current situation	61	24	8	5	98
Establishing a shared management plan	62	25	6	5	98
Checking that the person is comfortable with the content and pace of the conversations	56	30	7	2	95
Dealing with challenging scenarios at the end of life	45	15	9	5	74

4. Discussion

While NICE sets out clear guidance relating to end-of-life care, evidence on uptake suggests that this is inconsistently implemented, and affected by challenges in identifying people approaching end of life, discussing and documenting their preferences with them, and ensuring that these preferences inform the treatment and care provided. Guided by a professional advisory group and by a patient and public advisory group with rich experience of these issues, our mixed-methods study sought to rapidly ascertain the views of a wide range of stakeholders on how these challenges might best be addressed. Our stakeholder interviews helped to clarify the nature of the challenges and inform data-collection instruments for subsequent activities. The survey and further accompanying qualitative interviews provided insight into the practical difficulties that most impeded implementation, and started to source ideas about putative solutions. The consensus building exercise, covering the full gamut of stakeholders involved in the process, identified the interventions most likely to help to improve implementation, and suggested priorities for coordinated activity relating to awareness-raising, education and training, and documentation and record-keeping. It also provided strong endorsement, from the perspective of people approaching end of life, those important to them, and health and social care professionals alike, that conversations about end-of-life care planning are to be welcomed and encouraged, and that the priority should be to have the conversation (which could be initiated by a range of professionals, or the patients themselves), rather than to wait for an ideal time to have it.

Through the survey and interviews, we were able to identify multiple and complex challenges, particularly in the areas of initiating conversations about end-of-life care and treatment preferences, documenting preferences such as through advance care planning, and ensuring that people's preferences are made known and acted on by other health and social care professionals. From specific activities and planning for care at the frontline to the broader commissioning system, these challenges spanned different levels of activity and settings that provide care to people approaching the end of life.

In our consensus building process we took the variety of issues and challenges and attempted to distil findings into statements that could reflect the importance of and prioritise various aspects of end-of-life care and treatment planning. Of the 13 statements we put to participants in the consensus building process, 11 reached consensus overall, and agreement across the four groups of participants was also largely strong. There was consensus around the importance of raising the issue of planning for end-of-life treatment and care despite it not being the perfect timing or other ideal conditions. People agreed that healthcare staff should routinely offer to have the conversation, and that a wider range of people should be empowered to initiate such conversations. The third and fourth rounds of consensus building identified GPs, care home staff, palliative care staff, specialty nurses as well as community-based providers as groups who might particularly benefit from such efforts at empowerment. There was consensus on the need for advanced communication skills training to support healthcare professionals in initiating and conducting conversations about treatment and care at the end of life. The third and fourth rounds of consensus building clarified what was seen as particularly important: exploring what matters to the person and carers at the end of life, initiating conversations about end-of-life treatment and care, respecting people's decisions about treatment in line with the Mental Capacity Act, facilitating and answering questions, and talking to the person about illness progression and prognostic uncertainty. There was consensus that there should be a standard approach to documenting and recording preferences and a single integrated electronic system for recording and sharing people's preferences. All of the components put forward as candidate components of such records reached high consensus.

The two statements that did not reach consensus also deserve brief note. Participants were not, overall, convinced that the problem of implementation was the existence of too many, competing guides and protocols about how to have conversations about end-of-life care options. Nor did they agree that conversations should focus on specific treatment and care preferences (as opposed to broader values and preferences). There was overall agreement that conversations (not necessarily the documentation) were key to understand what matters most to the person at the end of life. This perhaps reflects a quandary that was evident in the qualitative interview data: that while specific directives could offer a clear steer to (and in some situations a legally binding obligation on) those providing care in the future if the individual were to lose capacity, they could not readily capture all possible eventualities and the complexities of situations in which such decisions would need to be made. On the other hand, there was strong agreement that recommendations on cardiopulmonary resuscitation and any Advance Decision to Refuse Treatment, Advance Directive, or Advance or Anticipatory Care Plan in place should be covered by a standardised approach to documenting the information and preferences captured in conversations about end-of-life treatment and care. In addition, there was strong agreement that specific treatments the person wouldn't like to receive (for example artificial ventilation, antibiotics for life-threatening infections) should be included in documentation. The role of skilled staff and others in ensuring that written records do justice to individuals' preferences, and communicate recommendations in a form that is clear to staff treating them later, is therefore vital.

4.1 Key implications

The findings of our study have implications for several stakeholder groups working in the field of end-of-life care planning. The statements set out in the consensus-development exercise are not, in the main, new or radical, but the earlier stages of the research highlight that realising these ambitions remains challenging. In some instances, the clear endorsement of these points by the wide range of groups involved in the process may offer important confirmation of their importance, and encourage practitioners to put them into practice. For example, the data from qualitative interviews, the survey and the consensus building exercise strongly suggest that there is an appetite for undertaking important—if sensitive—conversations in a timely fashion, even if the optimal circumstances for such conversations never quite present themselves. This finding merits targeted dissemination to the range of health and social care professionals who may find themselves in positions to initiate these discussions but who, our survey suggests, may not be certain that they are the best-placed person to do so. Other major deterrents for health and social care professionals in initiating discussions included lack of time, lack of confidence in leading them, and lack of knowledge about what to cover and what might follow. While time pressures on health and social care professionals are not readily relieved, our work also offers insight into what might be most helpful in addressing issues of confidence and knowledge. Both state agencies and voluntary sector bodies might find value in the priorities identified in our consensus building work around the groups who could most benefit from empowerment, and the areas of focus for training in communication skills around end-of-life treatment and care planning.

Another important contribution of our work is in identifying the potential components of a standardised record of preferences regarding end-of-life treatment and care – an ambition which, our survey and qualitative interviews suggest, is an important priority if the decisions reached during important conversations about end-of-life treatment and care preferences are to be acted on and respected, and not 'lost in the system'. All of the proposed components were taken from approaches which are already in use. The findings suggest that a comprehensive record is needed, one which includes details about the patient's condition; what outcomes the patient values or wishes to avoid; their overall goals of care; specific preferences about symptom management; a recommendation about CPR; and details about emergency contacts and any legal arrangements which have been made. Stakeholders from across care settings have already been involved in the development and iteration of ReSPECT (which already includes most of these components) and our findings will be directed back to these stakeholders. Results of the consensus building exercise suggest that additional standardised modules with further detail on symptom management are needed for those at the end of life. All of these components could be mapped onto the shared care record or the NHS app, in order to ensure accessibility of the recommendations at all times and to all people.

The approach taken in this study was the result of close collaboration between NICE's implementation team and THIS Institute. The intention was to develop a rapid, replicable model for identifying the problems that underlie inconsistent or imperfect implementation of NICE's guidance, taking a highly collaborative approach involving the range of affected stakeholders, and making use of the opportunities for rapid research and development offered by THIS Institute's Thiscovery platform. The study as a whole took a little over a year from initiation to completion; the approach taken could readily be transferred to other areas of NICE guidance. The study has been characterised throughout by joint working between THIS Institute and NICE, alongside collaboration with a range of interested agencies (particularly in the voluntary sector), and underpinned by clear guidance from a professional advisory group and a patient and public advisory group. At the same time, NICE has been engaged in a review of its strategy, priorities and operations, including in relation to implementation.

4.2 Strengths and weaknesses of the study

Strengths of this study include its responsive nature, its commitment to collaborative working, including important contributions from the advisory groups, and the wide range of participants involved, particularly in the consensus-building exercise. The study also has important limitations. Its focus was relatively high level: it did not involve, for example, examination of specific guidance documents or tools and views on their quality and usefulness. Initial stakeholder interviews focused less on the identification of people approaching end of life and more on later stages in the pathway, and so issues relating to identification featured less heavily in later stages of the study. Participants in all stages were self-selecting – they were likely to have an interest in the end of life and experience in talking about it. The number of participants in the survey stage was modest and interviewees were predominantly white. The representativeness of the sample is thus limited. While the numbers participating in the consensus-building exercise were greater, the routes towards recruitment (for example, through charities with an interest in promoting understanding of and proactive engagement in end-of-life care issues) may mean that the views of those participating are not typical of the wider population.

At all stages in the study, participation from professionals from social care backgrounds was relatively limited. The focus on generating insights at speed mean that the full potential of the data generated by the study has not yet been fully explored; we intend to undertake further analyses of these data and produce further outputs for consideration by peer-reviewed journals in due course.

4.3 Recommendations for practice and policy

We offer the following recommendations for practitioners, providing and commissioning organisations, and policymakers in the field.

4.3.1 Recommendations for practice

Recommendations for individual practitioners:

1. Clinicians and other practitioners involved in planning end-of-life treatment and care should seek to have important conversations with patients about treatment and care at the end of life early, rather than waiting for an 'ideal' time, place or person.
2. These conversations should include gaining understanding about:
    a. Individuals' views on the balance between prolonging life as much as possible, versus maximising quality of life
    b. Which outcomes are most important to individuals considering end of life

Organisations in all care settings should:

3. Provide training to practitioners in having important conversations about treatment and care at the end of life. This will empower them to feel confident to initiate the conversations routinely. Topics covered should include:
    a. initiating conversations about end-of-life treatment and care;
    b. exploring what matters to the person and people close to them, and what concerns they might have;
    c. respecting people's decisions about treatments they wish to receive when having conversations with them, in line with the Mental Capacity Act;
    d. facilitating and responding to questions, including signposting people to other sources of support;
    e. talking to the person about illness progression, including prognostic uncertainty
4. Work with partners across the health and care community to ensure a shared, standardised record for recording the outcomes of discussions about treatment and care at the end of life, ensuring that it is easily interpretable by others and records key elements as follows:
    a. any outcomes that are most important to the person (for example comfort, day-to-day independence)
    b. any outcomes that the person particularly wants to avoid (for example increased dependency on others, being housebound) a brief account of the person's preferred balance between prolonging life and maximising quality of life
    c. specific treatments the person would not like to receive
    d. a recommendation (based on patient and clinical views) on whether cardiopulmonary resuscitation should be attempted if the person's heart stops

  e. whether the person has an Advance Decision to Refuse Treatment, Advance Directive (Scotland), or Advance or Anticipatory Care Plan
  f. whether the person has a legal proxy who can make decisions on their behalf, for example through Lasting Power of Attorney for Health and Welfare (England and Wales) or Welfare Power of Attorney (Scotland)

4.3.2 Recommendations for policy

5. Policymakers should recommend, mandate or incentivise a shared, standardised record for recording the outcomes of discussions about treatment and care at the end of life, ensuring that it is easily interpretable by others and records key elements as follows:
    a. any outcomes that are most important to the person (for example comfort, day-to-day independence)
    b. any outcomes that the person particularly wants to avoid (for example increased dependency on others, being housebound)
    c. a brief account of the person's preferred balance between prolonging life and maximising quality of life
    d. specific treatments the person would not like to receive
    e. a recommendation (based on patient and clinical views) on whether cardiopulmonary resuscitation should be attempted if the person's heart stops
    f. whether the person has an Advance Decision to Refuse Treatment, Advance Directive (Scotland), or Advance or Anticipatory Care Plan
    g. whether the person has a legal proxy who can make decisions on their behalf, for example through Lasting Power of Attorney for Health and Welfare (England and Wales) or Welfare Power of Attorney (Scotland)
6. Policymakers should consider commissioning the development of a single integrated electronic system for recording end-of-life treatment and care preferences.

5. Conclusion

We employed a multi-method approach including a survey, interviews, and a consensus-building exercise to identify and understand key influences on implementation of end-of-life care guidance and build consensus in areas of end-of-life treatment and care planning primarily related to conversations and documentation of people's preferences. Including people approaching the end of life, people important to them such as family and carers, health care and social care staff, we incorporate the perspectives of a diverse set of groups. In the consensus building exercise, participants further identified potential components of a standardised record of preferences regarding end-of-life treatment and care, groups that should be empowered through new or improved training in advanced communication, and topics most important to include in advanced communication training for healthcare professionals.

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Appendices

Appendix 1: Questionnaire (groups ii and iii – people planning for end-of-life care and those important to them)

Version 1.2

1. Have you had a conversation with health or social care staff about planning end-of-life treatment and care?

Response options (multiple choice – can select one only):

a. Yes – my own end-of-life treatment and care
b. Yes – the end-of-life treatment and care of someone important to me
c. Yes – both my own end-of-life treatment and care and that of someone important to me
d. No

Participants who respond with options a or c proceed to question 2a.
Participants who respond with option b are routed to question 2b.
Participants who respond 'No' are routed to question 3.

2a. To what extent do you agree or disagree with each of the following statements about the conversations you have had with health or social care staff about planning for your end-of-life treatment and care?

Five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus 'Don't know' option. Optional free text box for further comment.

If you have had more than one conversation about your own care, please answer the questions while considering the first time you had a conversation like this.

- I felt prepared for the conversation when it started.
- I was able to control what we talked about during the conversation.
- We discussed several possibilities for treatment and care as I approach the end of my life.
- At the end of the conversation, I felt that I had a good understanding of different services available to help with my end-of-life treatment and care.
- The conversation covered the things that mattered to me most about my end-of-life treatment and care.
- The conversation happened at about the right time.
- The person or people I spoke to was sensitive and caring during the conversation.
- At the end of the conversation, I felt that I had a good understanding of what needed to happen next to ensure that my end-of-life care preferences would be met.
- I felt confident that, as far as possible, my preferences would be followed as I approach the end of life.

Participants are then routed to question 3.

2b. To what extent do you agree or disagree with each of the following statements about the conversations you have had with health or social care staff about planning end-of-life treatment and care for someone important to you?

Five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus 'Don't know' option. Optional free text box for further comment.

If you have had more than one conversation, please answer the questions while considering the first time you had a conversation like this.

- I felt prepared for the conversation when it started.
- The person important to me and I were able to control what we talked about during the conversation.
- We discussed several possibilities for treatment and care of the person important to me as they approach the end of their life.
- At the end of the conversation, I felt that I had a good understanding of different services available to help with the end-of-life treatment and care of the person important to me.
- The conversation covered the things that mattered most about end-of-life treatment and care to the person important to me.
- The conversation happened at about the right time.
- The person I spoke to was sensitive and caring during the conversation.
- At the end of the conversation, I felt that I had a good understanding of what needed to happen next to ensure that the end-of-life care preferences of the person important to me would be met.
- I felt confident that, as far as possible, the preferences of the person important to me would be followed as they approach the end of life.

3. When do you think is the best time to have an initial conversation with a member of health or social care staff about end-of-life care preferences?

Response options (multiple choice – can select only one):

☐ Routinely with all adults, regardless of current age, health, or medical conditions
☐ Soon after someone is diagnosed with a condition that may shorten their life, or other factors are present that might increase their risk of dying
☐ When it is thought that someone might die within the next year
☐ When it is thought that someone might die within the next few days to weeks
☐ Only when initiated by the person themselves, regardless of their stage of life
☐ I do not think that people should have conversations about end-of-life care preferences
☐ Don't know
☐ Other (with free text box)

4. Who do you think should initiate a conversation about end of life treatment and care preferences?

Response options (multiple choice – can select more than one):

☐ Anyone over the age of 18
☐ The person approaching the end of their life
☐ Someone important to the person approaching the end of their life, such as a family member or close friend
☐ The person's general practitioner
☐ Another member of the general practice or community healthcare team, such as a practice nurse or district nurse
☐ A member of social care staff, such as a social worker
☐ A member of staff at a hospital that the person has regular appointments with (for example, at planned visits to the outpatients clinic)
☐ A member of staff at a hospital that the person may not know so well (for example, for unplanned care in the accident and emergency department)
☐ A member of a palliative care team, specialised in end-of-life care
☐ Don't know
☐ Someone else (with free text box)

Free text box for further comment

Participants who responded to question 1 with options a, c or d proceed to question 5a. Participants who responded to question 1 with option b are routed to question 5b.

5a. How important is it to you to discuss and document each of the following aspects of end-of-life treatment and care with a member of health or social care staff?

Four-point Likert scale (Unimportant, Not very important, Important, Very important) plus 'Don't know' option. Free text box to add other things not listed.

- Putting in place an advance care plan (ACP)
- Who should be present with me at the time of my death
- My preferred place of death and how to achieve it
- My views on the balance between prolonging life as much as possible, versus maximising quality of life
- Which outcomes are most important to me – for example my comfort, my independence, my continued ability to interact with others, or my ability to make decisions for myself
- What specific treatments I would or wouldn't like to receive – for example ventilation to help me stay alive, or cardiopulmonary resuscitation to try to revive me if my heart stops or I stop breathing
- A legally binding arrangement for how care and treatment are provided (for example lasting power of attorney or an advance decision to refuse treatment)

Participants are then routed to question 6.

5b. How important is it to you that each of the following aspects of end-of-life treatment and care are discussed and documented for the person important to you with a member of health or social care staff?

Four-point Likert scale (Unimportant, Not very important, Important, Very important) plus 'Don't know' option. Free text box to add other things not listed.

- Putting in place an advance care plan (ACP)
- Who should be present with them at the time of their death
- Their preferred place of death and how to achieve it
- Their views on the balance between prolonging life as much as possible, versus maximising quality of life
- Which outcomes are most important to them – for example their comfort, or their day-to-day independence
- What specific treatments they would or wouldn't like to receive – for example ventilation to help them stay alive, or cardiopulmonary resuscitation to try to revive them if their heart stops or they stop breathing
- A legally binding arrangement for how care and treatment are provided (for example lasting power of attorney or an advance decision to refuse treatment)

6. Are there any resources (such as information leaflets or guides) for discussing and planning end-of-life care for yourself or someone important to you that you have found particularly useful? Please give details here.

Free-text box

7. What would be most helpful to you in planning for end-of-life treatment and care for yourself or someone important to you?

Free-text box

8. Have you or someone important to you used the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process to help in planning end-of-life care? If so, would you be happy to answer some extra questions about this?

To include an image of the ReSPECT form as an aide-memoire for participants.

Response options (multiple choice – can only select one):

☐ I haven't used ReSPECT
☐ I have used ReSPECT and would be happy to answer some questions about it
☐ I have used ReSPECT but would prefer not to answer questions about it

Participants who select 'I haven't used ReSPECT' or 'I have used ReSPECT but would prefer not to answer questions about it' are routed to question 16.

Participants who select 'I have used ReSPECT and would be happy to answer some questions about it' proceed to question 9.

We are interested in knowing more about your experience with ReSPECT.

9. Please can you tell us when you had your ReSPECT conversation?

☐ During an emergency admission to hospital
☐ When I or the person important to me was given a new diagnosis in hospital, or in an outpatient setting
☐ At my GP practice (or the GP practice of the person important to me) while attending specifically to plan for future treatment and care
☐ At my GP practice (or the GP practice of the person important to me) while attending for another reason
☐ Other (free-text box)

10. With whom did you have the ReSPECT conversation?

☐ With my GP (or the GP of the person important to me)
☐ With a hospital doctor
☐ With a specialist nurse
☐ With someone else (free-text box)

11. How satisfied were you with the ReSPECT conversation overall?

☐ Very satisfied
☐ Quite satisfied
☐ Neither satisfied nor dissatisfied
☐ Quite dissatisfied
☐ Very dissatisfied

Please add any comments on your response here:

Free-text box

12. Did you feel you had the opportunity to express your views during the ReSPECT conversation?

☐ Very much so
☐ Somewhat so
☐ A little
☐ Not at all
☐ Not sure

Please add any comments on your response here:

Free-text box

13. Did you feel that the recommendations recorded in the ReSPECT form reflected your wishes, or the wishes of the person important to you?

☐ Very much so
☐ Somewhat so
☐ A little
☐ Not at all
☐ Not sure

14. What, if anything, do you think is good about the ReSPECT process?

Free-text box

15. What, if anything, could be done to improve the ReSPECT process?

Free-text box

16. We are almost at the end of the questionnaire. Is there anything else you would like to comment relating to planning end-of-life treatment and care preferences?

Free-text box

17. We are conducting interviews with some survey participants. The interview itself should take no more than 30-45 minutes. Would you be interested in being invited to participate in an interview?

☐ Yes
☐ No

Finally, we would like to ask some questions about you and your background. You do not have to answer any of these questions.

18. What is your sex?

Response options (multiple choice – can select only one):

☐ Female
☐ Male
☐ Prefer not to say

19. What is your age?

Response options (multiple choice – can select only one):

☐ 18-35
☐ 36-45
☐ 46-55
☐ 56-65
☐ 66-75
☐ 76-85
☐ 86-95
☐ 96 or over
☐ Prefer not to say

20. What is your ethnic group?

Response options (multiple choice – can select only one):

☐ White – English / Northern Irish / Scottish / Welsh / British
☐ White – Irish
☐ White – Gypsy or Irish Traveller
☐ White – Any other white background
☐ Mixed/multiple ethnic groups – White and Black Caribbean
☐ Mixed/multiple ethnic groups – White and Black African
☐ Mixed/multiple ethnic groups – White and Asian
☐ Mixed/multiple ethnic groups – Any other mixed background
☐ Asian/Asian British – Indian
☐ Asian/Asian British – Pakistani
☐ Asian/Asian British – Bangladeshi
☐ Asian/Asian British – Chinese
☐ Asian/Asian British – Any other Asian background
☐ Black / African / Caribbean / Black British – African
☐ Black / African / Caribbean / Black British – Caribbean
☐ Black / African / Caribbean / Black British – Any other Black/African/Caribbean background
☐ Other ethnic group – Arab
☐ Other ethnic group – Any other ethnic group
☐ Prefer not to say

21a. Previous research has suggested that some groups of people may be at risk of unequal access to end-of-life care. We would therefore like to collect some information about you and your background. Which, if any, of the following statements apply to you?

Response options (multiple choice – can select more than one):

☐ I have cancer
☐ I have a life-limiting physical condition other than cancer
☐ I have dementia
☐ I am lesbian, gay or bisexual
☐ I am transgender
☐ I have a learning disability
☐ I have a mental health condition
☐ I have another form of disability not covered above
☐ I am or have been homeless
☐ I live or have lived in a secure or detained setting, such as a prison or detention centre
☐ None of these

21b. Previous research has suggested that some groups of people may be at risk of unequal access to end-of-life care. We would therefore like to collect some information about the person important to you. Which, if any, of the following statements apply?

Response options (multiple choice – can select more than one):

☐ They have cancer
☐ I have a life-limiting physical condition other than cancer
☐ I have dementia
☐ I am lesbian, gay or bisexual
☐ I am transgender
☐ I have a learning disability
☐ I have a mental health condition
☐ I have another form of disability not covered above
☐ I am or have been homeless
☐ I live or have lived in a secure or detained setting, such as a prison or detention centre
☐ None of these

For carers only:

22. Have you been assigned lasting power of attorney (or welfare power of attorney)?

☐ Yes
☐ No
☐ Prefer not to say

Appendix 2: Questionnaire (groups iv and v – health and social care staff)

Version 1.1

1. Please indicate which of these statements most accurately describes your role in helping people with their preferences for end-of-life treatment and care.

Response options (multiple choice – can select one only):

a. I am involved in helping people to plan for their end-of-life treatment and care, but not in delivering it.
b. I am involved in delivering treatment and care to people towards the end of their lives, but not in helping people plan for this process.
c. I am involved in both helping to plan end-of-life treatment and care, and delivering it.
d. I am not involved in planning or delivering end-of-life care and treatment.

Participants who select options a and c proceed to question 2.
Participants who select options b and d are routed to question 8.

Questions for participants with experience of initiating and having conversations with people nearing the end of life

2. Have you been involved in a conversation with someone about planning their end-of-life treatment and care in the last two years?

Response options (multiple choice – can select one only):

☐ Yes
☐ No

3. To what extent do you agree with the following statements about identifying people nearing the end of life and initiating conversations with them about their end-of-life treatment and care preferences?

Five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus ‘Don’t know’ option. Optional free text box for further.

- I am confident that I can correctly identify people who may be entering the last year of life.
- I feel confident in my ability to initiate conversations with people approaching end of life about their treatment and care preferences.
- For at least some people, I am the right person to initiate a conversation about end-of-life treatment and care preferences.
- I feel I know what is most important to discuss with people approaching end of life.
- For each question: five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus ‘Don’t know’ option. Optional free text box for further comment.

4. Are there any approaches or resources for trying to identify people who might be approaching the last year or months of their life that you have found particularly useful? Please give details here.

Free text box

5. Are there any approaches or resources for discussing and planning end-of-life treatment and care with patients or service users that you have found particularly useful? Please give details here.

Free text box

6. Are there any approaches or resources that you have found particularly useful for ensuring that people's preferences for end-of-life treatment and care are recorded, shared and used by others? Please give details here.

Free text box

7. What would be most helpful to you in identifying people approaching end of life, having conversations about their end-of-life treatment and care preferences with them, and recording and sharing these preferences?

Free text box

8. When do you think is the best time for a health or social care professional to have an initial conversation with a patient or service user about end-of-life care preferences?

Response options (multiple choice – can select only one):

- ☐ Routinely with all adults, regardless of current age, health, or medical conditions
- ☐ Soon after someone is diagnosed with a condition that may shorten their life, or other factors are present that might increase their risk of dying
- ☐ When it is thought that someone might die within the next year
- ☐ When it is thought that someone might die within the next few days to weeks
- ☐ Only when initiated by the person themselves, regardless of their stage of life
- ☐ I do not think that people should have conversations about end-of-life care preferences
- ☐ Don't know
- ☐ Other (with free text box)

9. Who do you think should initiate a conversation about end of life treatment and care preferences?

Response options (multiple choice – can select more than one):

☐ Anyone over the age of 18
☐ The person approaching the end of their life
☐ Someone important to the person approaching the end of their life, such as a family member or close friend
☐ The person's general practitioner
☐ Another member of the general practice or community healthcare team, such as a practice nurse or district nurse
☐ A member of social care staff, such as a social worker
☐ A member of staff at a hospital that the person has regular appointments with (for example, at planned visits to the outpatients clinic)
☐ A member of staff at a hospital that the person may not know so well (for example, during unplanned care in the emergency department)
☐ A member of a palliative care team, specialised in end-of-life care
☐ Don't know
☐ Someone else (with free text box)

10. To what extent do you agree or disagree with each of the following statements about discussing end-of-life treatment and care preferences with patients or service users?

Five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus 'Don't know' option. Optional free text box for further comment.

- I feel I have the right skills to start conversations with people about their end-of-life treatment and care.
- I feel comfortable discussing people's end-of-life treatment and care preferences with them.
- I have access to the right tools and resources to have productive conversations with people about their end-of-life treatment and care preferences.
- I am confident that I know how to use the tools available for documenting these preferences.
- I am confident that the preferences expressed by people will be used by healthcare staff providing end-of-life treatment and care.
- I am confident that the preferences expressed by people will be used by social care staff providing end-of-life care.
- I am confident in making treatment decisions when a patient has lost capacity (e.g. as per the Mental Capacity Act, when to refer to Court of Protection, etc.)

11. To what extent do you think the following issues are important in preventing health and social care staff from having productive conversations about people's end-of-life care preferences?

Four-point Likert scale (Unimportant, Not very important, Important, Very important) plus 'Don't know' option.

- Uncertainty over whether someone is approaching end of life
- Uncertainty about the law (in relation to capacity, refusal of care, decisions about best interests) regarding decisions about treatment and care at the end of life
- Lack of time to have a productive conversation
- Lack of confidence in raising sensitive issues
- Lack of knowledge about what to discuss
- Lack of knowledge about the options and services available
- Uncertainty over what to do with what is discussed
- Uncertainty over whether and how the information will be acted on by others in the health and social care system
- Belief that someone else may be best placed to have conversations of this kind
- Difficulty in identifying individuals in particular groups who may be approaching end of life (free text box stating which group/s)
- Other (with free text box)

12. How important is it to plan ahead with a patient or service user about each of the following aspects of end-of-life treatment and care?

Four-point Likert scale (Unimportant, Not very important, Important, Very important) plus 'Don't know' option. Free text box to add other things not listed.

- Putting in place an advance care plan (ACP)
- Their preferences for who should be present with them at the time of their death
- Their preferred place of death and how to achieve it
- Their views on the balance between prolonging life as much as possible, versus maximising quality of life
- Which outcomes are most important to them – for example their comfort, their day-to-day independence, their continued ability to interact with others, or their ability to make decision for themselves
- What specific treatments they would or wouldn't like to receive – for example ventilation or cardiopulmonary resuscitation to try to revive them
- A legally binding arrangement for how care and treatment are provided (for example lasting power of attorney or an advance decision to refuse treatment)
- Other

Participants who responded to question 1 with options a and d are routed to the ReSPECT questions, starting question 17.

Participants who responded to question 1 with options b and c proceed to question 13.

13. How challenging do you find the following issues when trying to ensure that people's preferences about end-of-life treatment and care are shared with and used by other practitioners

Four-point Likert scale (Not at all challenging, A little bit challenging, Quite challenging, Very challenging) plus 'Don't know' option. Optional free text box for further comment.

- People's preferences regarding their end-of-life treatment and care are not recorded appropriately in the first place.
- The records we have regarding people's end-of-life treatment and care preferences are not routinely updated, and so may be out of date.
- The records we have regarding people's end-of-life treatment and care preferences are not always shared with the right people and organisations.
- The records we have regarding people's end-of-life treatment and care preferences are not acted upon at the right time, for example regarding admissions, place of death or access to hospice and palliative care
- Other (free text box)

14. When caring for someone who is approaching the end of their life, how easy do you find it to access up-to-date records of their preferences?

Response options (multiple choice – can only select one):

☐ Very difficult
☐ Quite difficult
☐ Neither easy nor difficult
☐ Quite easy
☐ Very easy
☐ Not sure

Please comment on the reasons for your answer (free text box)

15. Are there any approaches or resources for accessing and making use of people's preferences for treatment and care towards the end of life that you have found particularly helpful? Please give details here.

Free-text box

16. What would be most helpful to you in accessing and making use of people's preferences when delivering treatment and care to people approaching end of life?

Free-text box

17. Have you or someone important to you used the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process to help in planning end-of-life care? If so, would you be happy to answer some extra questions about this?

To include an image of the ReSPECT form as an aide-memoire for participants.

Response options (multiple choice – can only select one):

a. I haven't used ReSPECT

b. I have used ReSPECT and would be happy to answer some questions about it

c. I have used ReSPECT but would prefer not to answer questions about it

Participants who select options a or c are routed to question 21.
Participants who select option b proceed to question 18.

18. To what extent do you agree with the following statements about the ReSPECT process?

Five-point Likert scale (Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree) plus 'Don't know' option. Free text box for further comment alongside each of the three statements.

☐ It helps me to identify people who would benefit from planning about care and treatments towards the end of life

☐ It helps me to conduct useful conversations with people about care and treatment towards the end of their lives

☐ It helps me to document recommendations about people's preferences for care and treatment towards the end of their lives

☐ It helps me make better decisions about someone's care in an emergency

19. What, if anything, do you think is good about the ReSPECT process?

Free-text box

20. What, if anything, could be done to improve the ReSPECT process?

Free-text box

21. Is there anything else you would like to comment relating to identifying people approaching end of life, having productive conversations about their preferences, and delivering treatment and care to them?

Free-text box

22. We are conducting interviews with some survey participants. The interview itself should take no more than 30-45 minutes. Would you be interested in being invited to participate in an interview?

☐ Yes
☐ No

Finally, we would like to ask some questions about you and your background. You do not have to answer any of these questions.

23. Which of the following areas do you work most in?

Response options (multiple choice – can only select one):

☐ Social care
☐ Primary care or general practice
☐ Community healthcare
☐ Acute care
☐ Secondary mental healthcare
☐ Other (with free text box)

24. Which of the following best describes your professional role?

Response options (multiple choice – can only select one):

☐ Doctor – consultant or GP
☐ Doctor – junior or in training
☐ Nurse
☐ Healthcare assistant or nursing assistant
☐ Allied health professional
☐ Social worker
☐ Social care worker
☐ Other (with free text box)

25. What is your sex?

Response options (multiple choice – can select only one):

☐ Female
☐ Male
☐ Prefer not to say

26. What is your ethnic group?

Response options (multiple choice – can select only one):

☐ White – English / Northern Irish / Scottish / Welsh / British
☐ White – Irish
☐ White – Gypsy or Irish Traveller
☐ White – Any other white background
☐ Mixed/multiple ethnic groups – White and Black Caribbean
☐ Mixed/multiple ethnic groups – White and Black African
☐ Mixed/multiple ethnic groups – White and Asian
☐ Mixed/multiple ethnic groups – Any other mixed background
☐ Asian/Asian British – Indian
☐ Asian/Asian British – Pakistani
☐ Asian/Asian British – Bangladeshi
☐ Asian/Asian British – Chinese
☐ Asian/Asian British – Any other Asian background
☐ Black / African / Caribbean / Black British – African
☐ Black / African / Caribbean / Black British – Caribbean
☐ Black / African / Caribbean / Black British – Any other Black/African/Caribbean background
☐ Other ethnic group – Arab
☐ Other ethnic group – Any other ethnic group
☐ Prefer not to say

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