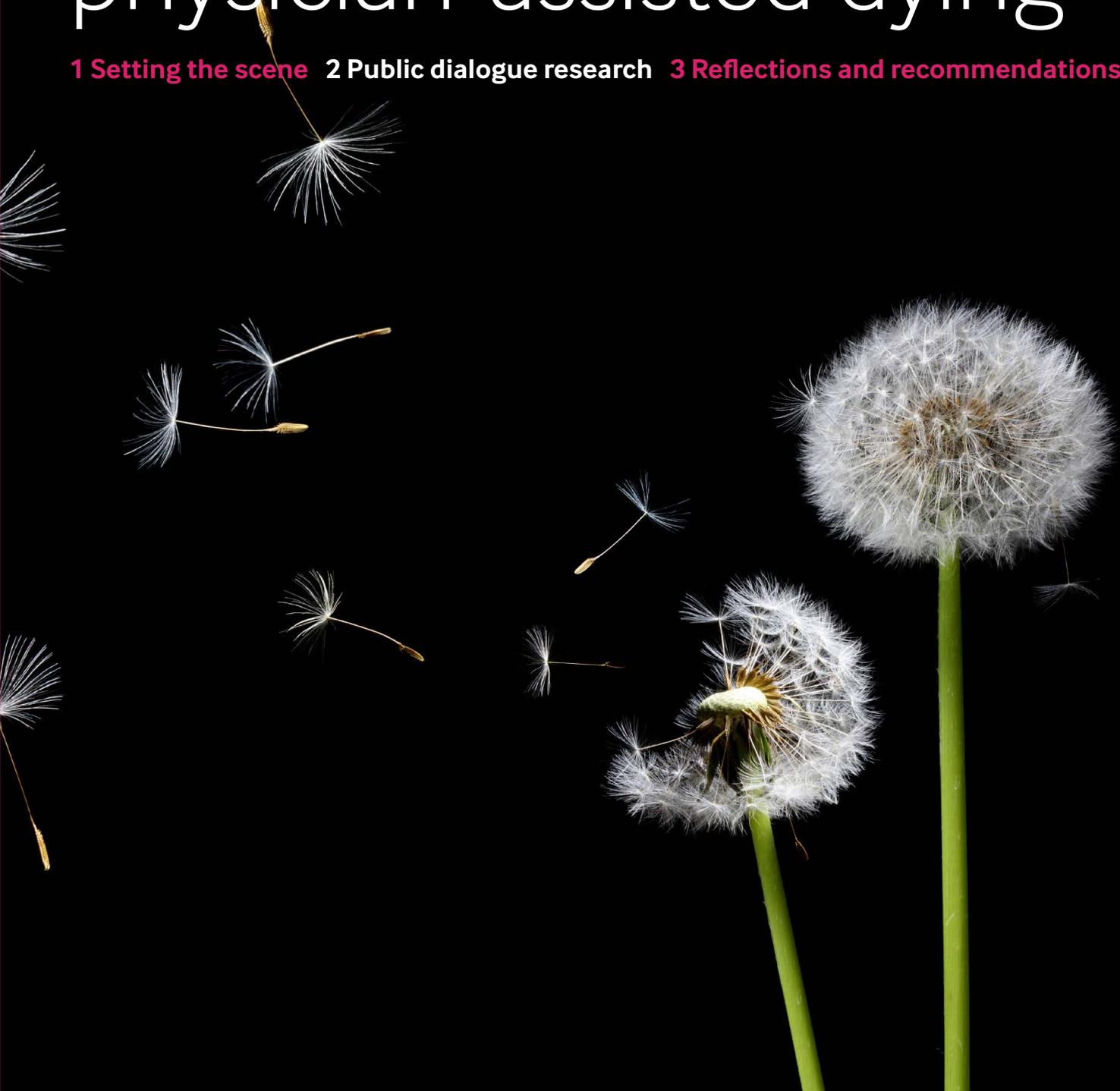# End-of-life care and physician-assisted dying

1 Setting the scene   **2 Public dialogue research**   **3 Reflections and recommendations**

Exploring public and medical attitudes to end-of-life care and physician-assisted dying
Public dialogue research

Contents

Acknowledgments

The research team would like to thank:

Foreword from the Project and Steering Group Chair

This second volume of the BMA project on end-of-life care and physician assisted dying contains the report by TNS BMRB of its independently conducted qualitative research covering a number of areas around end-of-life care and decisions at the end of life. The development of the project was overseen by a steering group of BMA members (listed in Volume 1) and the delivery was undertaken independently: the words and emphasis are those of the research team and not necessarily those of the BMA.

This research is one of the most significant pieces of qualitative research initiated by the BMA, with the aims not only of enriching our knowledge and understanding, but also informing discussion and debate within our Association and beyond. As part of our drive to embed new ways of working, the project has engaged with members not ordinarily active within the BMA, broadening our ways of developing policy and recommendations. At the same time we recognised that defining what is needed to assure the best possible end-of-life care could not be done without listening to the public and to patients – the research events with doctors being mirrored for the public.

The research findings merit detailed consideration. Some will be uncomfortable; some may feel less surprising. It is certain that campaign groups will select elements that support particular points of view – although the many issues are too nuanced and complex to be separated into isolated components and it would be wrong to take such an approach. These issues are of great importance for the profession and society. However it is worth noting that we found it more difficult to recruit doctors to participate in this research than we expected, notwithstanding these issues appearing on every annual representatives meeting agenda in recent times and being debated at seven of the last twelve meetings

So, what next? The first two volumes of this project provide a wealth of objective and subjective information and our next steps will be to develop a third and final volume of this report which, harnessing the contributions of members through the BMA's member engagement project, as well as external stakeholders, will make a number of recommendations for how end-of-life care should be improved. The findings on physician-assisted dying will be fed into future BMA discussions on the topic.

This report is the culmination of a huge amount of hard work and commitment on the part of the TNS BMRB team, and we are indebted to them for the development of this report. I hope that readers find it informative and thought-provoking, prompting and aiding the debate and discussion it was intended to generate.

Dr Ian Wilson
Project and Steering Group Chair
BMA Chair of the Representative Body

Executive summary

This research was commissioned to inform BMA discussion and debate, including that at the 2016 BMA Annual Representative Meeting, regarding perceptions and experiences of end-of-life care in the UK and the potential impact of the legalisation of physician-assisted dying on doctor-patient relationships. This qualitative research explores:

- Views on and experiences of the doctor-patient relationship and whether this changes when a patient has a terminal illness
- Patients' fears and concerns about the impact of serious/terminal illness and facing death
- Perceptions of the availability, accessibility and quality of end of life and palliative care in the UK
- Views about the potential impact of legalised physician-assisted dying on the doctor-patient relationship
- The professional and emotional impact of involvement in assisted dying upon doctors.

This large-scale qualitative research involved in-depth and informed discussions through 21 dialogue events with the public and doctors. A qualitative approach provided depth and detail about perceptions, views, experiences, feelings and motivations on these topics. Public dialogues are listening exercises which include a wide range of views and perspectives.

Ten half day dialogue events were held with the public and 11 with doctors in ten geographic locations across the UK and 269 members of the public and 237 doctors (506 people) took part. The events included sessions on:

- Doctor-patient relationships and hopes, fears and concerns about end of life and dying
- Perceptions and experiences of end-of-life care (public), and experiences of providing end-of-life care (doctors)
- The potential impact of the legalisation of physician-assisted dying on doctor-patient relationships (public and doctors) and professional and emotional impacts on doctors (doctors only).

Stimulus material was provided to enable more informed discussions. Participants in the public and medical events were divided equally on to four discussion tables. For the doctors, each table included a mix of genders, grades and specialisms. In the public workshops, tables 1-3 consisted of a mix of demographic groups. Table 4 was populated by those with recent experience of bereavement in the last two years but not within the last six months. Measures were taken to emotionally support participants through these discussions and positive feedback was received from doctors and the public.

The public workshops were recruited to reflect the UK general public and the doctors' workshops to reflect the UK doctor population. However, it is important to emphasise that this is qualitative research, and the sample is not intended to be representative or statistically generalisable to the wider UK population.

TNS BMRB's inductive analytical approach used to interrogate the data has been developed and honed over many years and is highly systematic, robust and reliable. Our analysis is presented below and broken into five key sections: doctor-patient relationships; hopes, fears and concerns about end of life

and dying; perceptions and experiences of end-of-life care; providing end-of-life care; and the potential impact of legalisation of physician-assisted dying on doctor-patient relationships.

Doctor-patient relationships

Doctor-patient relationships are perceived to be special and characterised by trust. The public have high levels of trust in doctors and this trust is 'there to be lost', unlike with other professionals where it first must be gained. However, in practice experiences can vary and doctor-patient relationships are shaped by a number of factors including ease of access, level of continuity, attitude of doctors and other medical staff, and notably length and quality of time spent with a doctor.

Doctors were found to recognise the high level of trust and high expectations the public have of them. There is some recognition among the public and doctors that traditional doctor-patient relationships (often perceived of as a family GP) are diminishing as people no longer see the same GP when they visit their surgery.

The intensity of doctor-patient relationships vary by medical specialism, being more intense between patients and district and Macmillan nurses, palliative care doctors, and geriatricians, oncologists and medical students. This is often linked with the length of time spent with these professionals and perceived quality of this time. The relationship is often perceived to be less intense and more functional, or transactional, between patients and out-of-hours doctors, surgeons, and consultants. There was wide variation of the experience of intensity of relationships with GPs.

Doctors perceive the relationship to change when a patient has a terminal illness and becomes more intense as the patient becomes more vulnerable and the role of the family and doctors' relationships with them become more important.

We found that patients often want to feel engaged in their health care – to be treated as a person not a condition – but views differ regarding how to achieve this with some people taking a more collaborative and others a more proactive approach. Some patients are content to take a passive approach to their healthcare.

Hopes, fears and concerns about end of life and dying

The public do not often think about end of life and dying. Talking about end of life and dying is not seen as part of our culture and it is an uncomfortable topic for most people, many of whom have not discussed this with spouses and close family members. Many people had not made any practical arrangements for their end of life (e.g. wills, insurance, or care plans) and people prefer to plan for life rather than death. However those with recent experience of bereavement, older people and those from higher social grades were more likely to have thought about practical arrangements.

The public's main fears about end of life and dying concern: pain; the impact on their family and loved ones during end-of-life care and after their death; choice; dignity; being a burden; and fear of the unknown. The public hope for a quick death in their sleep which is painless, where they get to choose when their family and loved ones are present, the location (often at home or in a hospice) and that they have a good quality of life, personalised care, are not alone and have their finances sorted out.

The doctors identified many of the hopes and fears the public have. However they were less likely to mention the impact on the family and loved ones of end-of-life care and the death of the patient, which was a major concern for the majority of the public. Some doctors thought the public were overly optimistic about their hopes for a good death (e.g. being able to choose the location of care and death).

Perceptions and experiences of end-of-life care

The public without recent experience of bereavement know very little about end-of-life care, what it consists of, how to access it or its availability. However many have low expectations and their main sources of information are the media and television. Those with recent experience of end-of-life care for a loved one were mixed in their views about its quality and reported wide geographic variation and variation between urban and rural locations.

Being treated as a person, rather than a number or medical condition, is seen as central to the provision of good end-of-life care for the public. This included having choice about treatment and location of care, engagement as desired by the individual with their treatment and care, and being encouraged and enabled to live as 'normally' as possible. Privacy and access to loved ones as desired were also important. Seven other factors were important in the provision of good end-of-life care, particularly factors one to three:

- (1) timely access to medical services (including pain management)
- (2) choice of location of care and death (and a preference for being in a hospice or the community)
- (3) access to the level of information desired by the patient (and for information to be consistent)
- (4) good communication (between the patient, doctors, services and the family)
- (5) good planning and coordination of services (and for this to be personalised)
- (6) emotional support (secular and spiritual, and for the patient and family – during and after end-of-life care)
- (7) help with financial and legal issues (particularly for older people).

Those with recent experience of bereavement reported that the quality of end-of-life care currently varies widely. There was no clear pattern of quality of end-of-life care across geographic areas, with mixed reports given by participants in all the event locations. It is currently working well where patients are treated as a person, have good access to medical services, the right level of information, and there is good communication and coordination of services. Being able to choose the location of care and the provision of emotional support are working less well, and currently financial and legal support are lacking. Respondents also often reported that there is a lack of support for families and loved ones. Recently bereaved respondents reported that end-of-life care is working less well where patients are not treated as a person, have poor access to services, less choice of location, coordination is poor and emotional support is lacking. They reported that in some areas the provision of information, communication and financial and legal advice are particularly poor.

Provision of end-of-life care

Doctors also reported that there is wide variation in the quality of end-of-life care provision between areas, within areas and between rural and urban locations. Doctors reported concerns about medical services (particularly when end-of-life care is started too late or doctors see it as a failure); some locations (particularly out of hours and community care); communication (particularly when doctors are not confident in talking about end-of-life care and dying and where family relationships are poor); and coordination of care (particularly when it is assumed this is happening or that palliative teams will see to holistic needs).

For many doctors, end-of-life care is primarily a concern for palliative doctors, oncologists and GPs. Patients' holistic needs are seen as secondary to physical treatment, palliation and pain management and dependent upon whether there is time available. There is a reliance on nurses to attend to these needs. Discussing end of life and dying is never easy and can be distressing for doctors, but is often seen as part of the job. However there is a desire for more training, particularly among students and younger doctors.

Doctors were asked to discuss four key challenges in providing end-of-life care. Pain at end of life is a key concern for the public. Doctors view this as something which can be managed but not eliminated entirely but have concerns about administration within the profession and other professionals' lack of confidence in this area. A prognosis is almost always requested by the patient and/or family but doctors reported that it is almost impossible to give the level of detail desired and this impacts on the doctor-patient relationship. Doctors were often polarised about the profession's ability to assess mental capacity – with some being confident in the procedures and others reporting them to be open to wide interpretation and this being of concern. Doctors reported that it is difficult to identify and treat depression in end-of-life care settings. Some doctors lacked confidence in this area and it emerged as a key concern for doctors from the discussions.

The potential impact of physician-assisted dying on doctor-patient relationships

Respondents were asked to imagine a hypothetical scenario in which physician-assisted dying had been legalised for people who requested it and met certain criteria, and to consider the impact of this on doctor-patient relationships. Many public respondents found it difficult to articulate their views on this topic as it was usually not something they had considered or discussed before. The doctors were more likely to come with pre-formed views and many found it difficult to separate their views on this topic from their wider views on physician-assisted dying and whether it should be legalised.

Most of the public were not aware of much of the background information provided in this session about physician-assisted dying. Most of the public, and many doctors, were shocked and surprised by the information provided about complications, failure and length of time it can take to die, and many of the public were discouraged by this information.

Overall, the public presented a balanced range of views and potential positive and negative impacts on the doctor-patient relationship. Doctors were more likely to focus on the potential negative impacts on the relationship than the public. For the public and some doctors, physician-assisted dying could mean doctors are more able to provide a 'good' death, choice to patients and improve communication about end of life and dying. However the public and doctors raised concerns that physician-assisted dying could increase fear of doctors and hospitals; cause conflict between doctors, patients and families; damage doctors' relationships with families where there are disputes and disagreements; and change the fundamental role of doctors if they were able to 'kill'. The public expressed particular concern for vulnerable groups whose fear of doctors may increase, (particularly the frail, elderly and disabled as well as religious groups and those opposed to assisted dying) but this was only raised after prompting rather than spontaneously. However the public and doctors reported that the impact would depend on the process in place (and particularly that there are adequate safeguards), who was involved (and whether this was a separate and specialist branch of medicine or not), and whether there were financial motivations.

The public and doctors reported that the impact of physician-assisted dying on the view of doctors in society would strongly depend on the media's coverage of this issue – as well as the method, process and safeguarding procedures, and particularly the extent of doctors' involvement. There was a high degree of fear among doctors about media coverage of this topic for their profession. However some doctors thought it would become accepted over time. The positive and negative impacts on the view of doctors in society raised by the public and doctors reflected the same categories raised in the discussions about the impact on the relationship itself, and these discussions often blurred.

There was a lack of consensus among the public and doctors about the potential impact of three options given for who could decide eligibility for physician-assisted dying: the treating doctor, a doctor with no clinical relationship to the individual, or a judge on the basis of information provided by doctors. No option stood out for either group. However the public responded more negatively to the idea of a judge

making the decision than the doctors, and the doctors responded more negatively to the idea of the treating doctor making the decision than the public. As a consequence both the public and the doctors suggested an alternative whereby eligibility for assisted dying could be decided by a panel, committee or ombudsman – this would share the burden of the responsibility for the decision, protect doctors from litigation, better protect patients from coercion, and be more likely to reach a better decision.

Doctors thought there would also be emotional and professional impacts on themselves, their colleagues and the profession, and they more often reported negative than positive impacts. Many reported feeling uncomfortable about the idea of themselves or their profession being involved in physician-assisted dying and many did not see it as consistent with their understanding of their role as doctors – however this was not universal and some felt it was part of their role.

1. Introduction

1.1. Background to this research

In 2015, the British Medical Association (BMA) commissioned TNS BMRB to undertake qualitative research with the public and doctors to inform debate at the 2016 BMA Annual Representative Meeting (ARM) regarding perceptions and experiences of end-of-life care and palliative care in the UK and the potential impact of the legalisation of physician-assisted dying on doctor-patient relationships.

This research involved in-depth and informed discussions through public dialogue events with the public and doctors and sought to understand the factors that influence opinion among the public and a range of doctors. The methodology used means this research takes the debate further than the existing quantitative research and member opinion.

It is important to emphasise that this is qualitative research and the sample of 269 members of the public and 237 doctors is not intended to be representative or statistically generalisable to the wider UK population. The research is designed to enable us to explore the key research questions and to explore *how* and *why* questions in greater depth.

1.2. Research objectives

The primary aims of this research are to explore the following:

- Patients' fears and concerns about the impact of serious/terminal illness and facing death
- Perceptions of the availability, accessibility and quality of end-of-life and palliative care in the UK
- Views about the potential impact of legalised physician-assisted dying on the doctor-patient relationship
- The professional and emotional impact of involvement in assisted dying upon doctors.

A fifth research objective was added during the project to provide context to the other discussions:

- Views on and experiences of the doctor-patient relationship and whether this changes when a patient has a terminal illness.

1.3. Structure of the report

This report follows an interim report and two presentations to the steering group, to give the full findings of the research. The report first outlines the methodology of this research in detail and describes the sampling approach and our robust analysis process. It then reports the findings from the public and doctors on doctor-patient relationships; hopes, fears and concerns about end of life and dying; perceptions and experiences of end-of-life care in the UK; perceptions and experiences of providing end-of-life care in the UK; and the potential impact of legalisation of physician-assisted dying on doctor-patient relationships before summarising our key insights.

The topic guides and stimulus used in the workshops can be found in the appendix.

2. Research design

2.1. Methodology

A qualitative approach was taken and used to explore the research objectives. Qualitative research is used to explore specific areas of interest and provide greater depth than survey research by exploring how and why questions. It provides greater understanding of perceptions, opinions, feelings and motivations and allows us to explore peoples' experiences in detail. Qualitative methodologies are ideal for exploring complex, sensitive and emotive topics such as end-of-life care and physician-assisted dying as this can be done in small, moderated groups where people can share and explore their views and experiences.

Qualitative research involves small sample sizes and samples which reflect the general population. However it should be noted that qualitative findings are not statistically representative or generalisable to the general population; instead they provide rich insights and depth on the topic of interest.

The key stages of the research are outlined in the diagram below.

Figure 1: The key stages of the research

2.1.1. Public dialogues

TNS BMRB ran 21 dialogue events in locations across the UK. We held 10 events with members of the public and 11 events with a range of doctors. It is important to note that the events were dialogues rather than deliberative events. In deliberative workshops, participants are incrementally informed about the area of study throughout the session. Researchers would be interested in tracking how attitudes change with the presentation of new materials. Public dialogues do not seek to change participants' views and attitudes. This methodology enables researchers to listen to a broad range of views from a wide range of people to uncover their thoughts, opinions, attitudes and feelings about a topic area and helps researchers to understand how these views are formed. Public dialogues are a listening exercise and findings from the research are often fed into policy development.

We held conversations with members of the public and doctors to understand opinions and perceptions and how they are formed around the issues of end-of-life care and the potential impact of physician-assisted dying on the doctor-patient relationship. The discussions were expressly not concerned with the pros and cons of physician-assisted dying, nor whether it should be legalised.
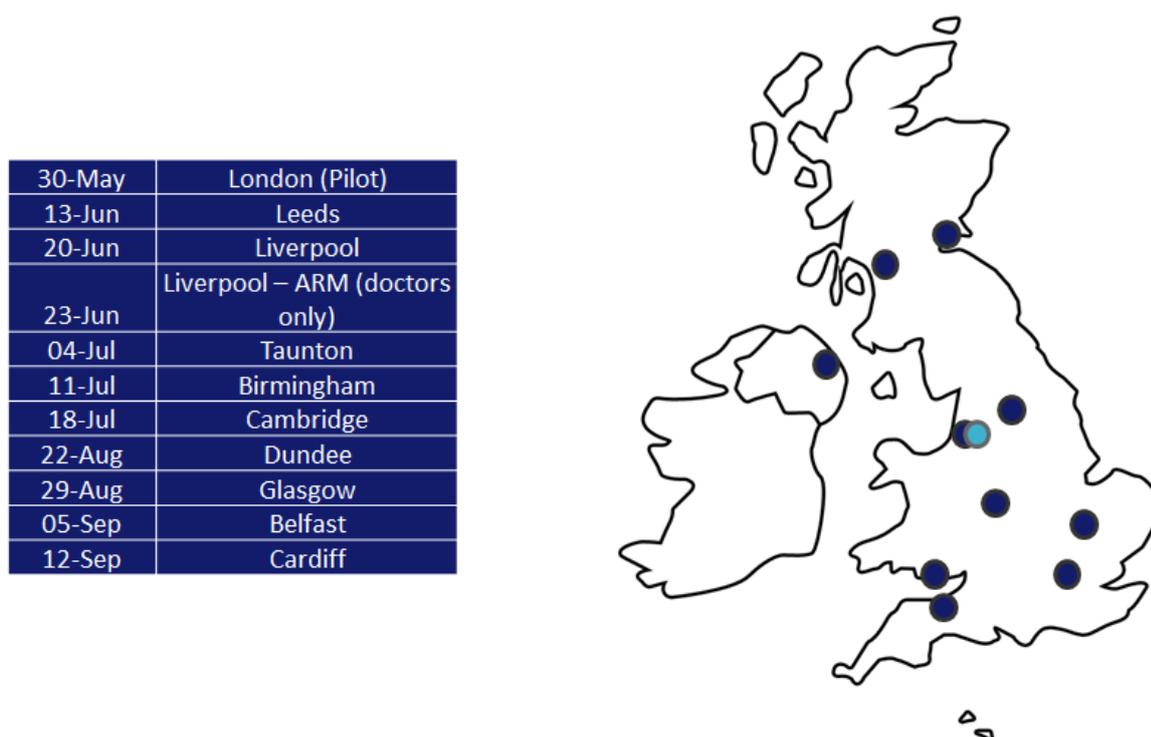
2.1.2. Locations

The ten public and 11 medical events were held in ten different geographic locations across the UK. This enabled us to explore whether there was any geographic variation in responses and any significant differences between healthcare systems.

Events were held in six locations in England, two in Scotland, one in Northern Ireland and one location in Wales. In ten locations, events were held with the public and doctors. As indicated in the table below, and extra doctors only event was held on 23rd June at the BMA ARM in Liverpool.

A pilot event was held in May in London to test the topic guides and stimulus materials. Minor revisions were made afterwards to make them clearer and easier to use for participants and to improve the flow of the conversations.

Figure 2: Locations of the public dialogue events

30-May	London (Pilot)
13-Jun	Leeds
20-Jun	Liverpool
23-Jun	Liverpool – ARM (doctors only)
04-Jul	Taunton
11-Jul	Birmingham
18-Jul	Cambridge
22-Aug	Dundee
29-Aug	Glasgow
05-Sep	Belfast
12-Sep	Cardiff

2.1.3. Structure of the events

The events for the public and doctors were held separately to explore their views independently and because mixing these groups would have meant introducing power dynamics and imbalances based on levels of knowledge about the subject areas. The public events were 3.5 hours long and held in the mornings from 09:30-13:00. The doctors' events were nearly 4 hours long and held in the afternoons from 13:45-17:30.

The public and medical events began with an introductory plenary session to outline the aims and purpose of the research, structure of the day, guidelines for the discussions and housekeeping information. Both events closed with a final plenary session to feedback the headline findings from each

table so that participants could have the opportunity to hear what other tables had discussed and to see whether the discussions in the room varied.

The events then consisted of the three discussion sessions shown in the diagram below. The topic guides were designed so that groups could build rapport before broaching the most sensitive topics in these events.

Figure 3: The structure of the events

Public Welcome Plenary	**Doctors** Welcome Plenary
Session 1 • Relationships with doctors & health services • Understanding, hopes, fears and concerns about illness and dying	**Session 1** • Relationships with patients • Understanding, hopes, fears and concerns about illness and dying
Session 2 • Perceptions / experiences of end of life care	**Session 2** • Providing end of life care
Session 3 • Doctor assisted dying and doctor-patient relationships	**Session 3** • Doctor assisted dying and doctor-patient relationships • The professional and emotional impact upon doctors
Closing Plenary	Closing Plenary

The doctors were divided equally on to four tables and each contained a mix of gender, grade and speciality. This enabled the participants to share and compare and contrast experiences. In the public events, participants were divided up on to four tables. Three tables were populated by a mix of the general public and included a range of gender, age and social grade. Table 4 was populated by 6-7 people who had recently experienced bereavement of a family member or loved one, within the last two years but not within the last 6 months. Within the last six months would potentially have been upsetting for the respondent and the other members of the table so respondents were excluded during the recruitment on this basis. During recruitment, table 4 respondents were asked whether they would be comfortable talking about their experience of bereavement in a small group of 6-7 people.

A different topic guide was used for table 4 (the recently bereaved group) in session 2. Whilst tables 1-3 discussed their perceptions of end-of-life care, table four initially discussed their recent experiences of end-of-life care and the services their loved one had used and experienced. All four tables designed what a good approach to end-of-life care should look like. Tables 1-3 spent more time designing a good EOLC approach. In the first workshops, participants on table 4 were asked to talk about the services their loved one had used and received and their experiences of these. However this could be upsetting for respondents and was also found to be time consuming to allow all members of the table to share their stories. Therefore, to make this session easier and less burdensome for respondents and to maximise the

time available to evaluate services, participants in the later sessions were asked to write down the key details of their loved ones' experiences on paper and could then share aloud only the information they were most comfortable with and the moderators focussed the discussions on what worked well and less well.

In the doctors' second session, participants were asked about their views and experiences of providing end-of-life care, and were prompted on a number of key issues and challenges, namely: access, what works well and less well, pain management, giving a prognosis, assessing mental capacity, identifying depression, meeting patients' needs and holistic needs, and how doctors feel about discussing death and dying with patients.

The third session explored the potential impact the legalisation of physician-assisted dying would have on the doctor-patient relationship. It was made clear to respondents that the topic of this session was not whether physician-assisted dying should be legalised or not, and that they would not be discussing the pros and cons of it. Respondents were asked to imagine a hypothetical scenario in which physician-assisted dying had been legalised for people requesting it and who meet certain criteria and to think about the impact of this on the relationship. Respondents were then asked to consider some different ways in which eligibility could be decided and the impact each of these might have on the doctor-patient relationship. Respondents were informed about the focus of the discussion in this session in the introductory plenary and again at the start of session 3. The doctors were also asked about whether there would be any professional and/or emotional impacts on doctors and the profession.

Stimulus was provided throughout the sessions to encourage more informed debate on these topics. The topic guides show where the stimulus materials were introduced and used in the discussions. These materials can be found in the appendix.

There were a number of challenges involved in developing the large-scale public conversations about these sensitive medical issues and experiences. To ensure that discussion was open and candid, small group discussions of 6-7 people were held within the larger workshop space. In this way we were able to hear and consider all views while facilitating a large group of participants. For members of the public, it ensured there was full and active participation with no one person dominating the discussion. For doctors, as with other professionals, they are well informed on the subject matter and smaller groups fostered discussion and debate and allowed all participants to have their say. To ensure sustained participation and avoid fatigue, the public and medical events were each half a day in length. Public dialogues can be held over a full day. However we felt with a sensitive topic area the shorter length would allow a greater engagement and allowed us to hold the public and doctor events both on one day.

When designing the research it was important to consider the emotional wellbeing of participants and the researchers involved. To support the wellbeing of the participants we put in place a number of measures. Tissues were provided at all tables and leaflets for a relevant support organisation. These were actively handed to respondents who were upset during the session. During the events, a space was made available outside for participants to take a break whenever they needed to and this was explained at the start of the session. Where possible, table 4 (the bereaved group) was moderated by TNS BMRB researchers who had training and experience in counselling. The changes described above were also made to session 2 for table 4 to make the session easier for respondents. It was checked during recruitment as to whether respondents had any disabilities to accommodate for these in the venues. It was also checked as to whether respondents had a family member or loved one in end-of-life or palliative care.

To support the wellbeing of the researchers a sounding board was provided for discussion on any potential impacts or issues raised, and TNS BMRB provides an employee access programme, at no cost to staff, should further support be required.

2.1.4. Feedback from participants

The formal and informal feedback about the events from both members of the public and the doctors was very positive. This was monitored throughout the fieldwork period and used to improve the events.

Some members of the public provided informal feedback to moderators but were not asked for formal feedback. However many reported spontaneously that they had enjoyed the events and sharing their experiences, particularly those who participated on table 4 where some reported to moderators that they appreciated the opportunity to share their stories with people with similar experiences.

All of the doctors were given a form to provide formal feedback at the end of each event. The feedback form was designed and administered and the data collated by the BMA. A majority of doctors rated the events overall and our researchers' practice as excellent. The letter[1] inviting doctors to an event made it clear that the pros and cons of legalising physician-assisted dying would not be a topic of conversation; this was also reiterated during the plenary session at the beginning of each event. However, this was clearly a disappointment to some doctors, which is likely to be reflected in the ratings of the events. Data from these surveys can be found in the appendix.

2.2. Sampling

Ten dialogue events were held with the public and 11 with doctors, meaning 269 members of the public and 237 doctors took part in this research – 506 people in total. We aimed to recruit 24 members of the public and 18-24 doctors per event, and therefore exceeded our recruiting targets.

2.2.1. Public sampling

The public workshops were recruited to reflect the UK general public. We aimed to recruit 24 people per event (6 per table) and over recruited by four people per event in case of drop outs on the day to ensure that the events ran smoothly. The locations of the events ensured that England, Scotland, Wales and Northern Ireland were represented. Quotas were set for age, gender and social grade to ensure a mix of respondents and respondents with a mix of qualifications were recruited[2]. Ethnicity, work status, disabilities and whether people described themselves as being committed to a religion were also monitored. In Wales, two Welsh speakers were recruited to be able to consider whether this impacted upon their use of medical services[3].

The public recruitment was managed by TNS BMRB's specialist in-house field team. There are rigorous, independently audited quality controls applied to our recruitment. To ensure a mix of social demographics a free find process was used for the public recruitment. Free find methods include on the street recruitment and door knocking. To avoid recruiting a self-selecting group, participants were not initially told the research would concern physician-assisted dying. Participants were told the research was for the BMA and about end-of-life and palliative care in the UK. Participants were informed at the start of the workshops that the impact of physician-assisted dying on doctor-patient relationships would form part of the discussion.

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[1] This was not included in the invitation letters for the initial event, although it was mentioned during the plenary session.

[2] Qualification levels ranged from no formal qualifications through to higher degrees. Literacy was not assessed. However, people were asked to bring reading glasses as there would be stimulus material to read. In case anyone had any difficulty reading the materials, when given out they were also read out by the moderator.

[3] They spoke Welsh and English as the workshops were conducted in English.

Participants were informed during recruitment and were reminded at the events, that participation was voluntary and that they could withdraw, take a break or refuse to answer any question at any time. Participants were ensured of the confidential and anonymous nature of the research and that any information given would be used for research purposes only; permission for audio recording was gained at the start of the event. Only the TNS BMRB team has access to and listened to the recordings.

As a thank you for their time, participants were gifted £80 for attending the event which was paid via a debit card which could be used in any cashpoint.

Figure 4: Public sampling frame

Public Events 24 people per event (6x4 tables) (+4 over recruits per event – +1 each age group, +1 for Table 4)			
	England [6]	Wales [1]	Scotland [2]	N Ireland [1]
Age	Approximately equal mix • 18-30 – 8 [+1] • 31-59 – 8 [+1] • 60+ - 8 [+1]			
Gender	• 50% Male • 50% Female			
Social Grade	• 50% ABC1 • 50% C2DE			
Bereavement	• 6 [+1] - recent experience of the death of a loved one within the last 2 years, but not within the last 6 months			
Welsh speakers	• 2 (in Cardiff only)			
Qualifications	• Recruit a mix			
Ethnicity, work status, disabilities, religion	• Monitor			

Figure 5: Public achieved sample

Public Events – Achieved sample	
London (pilot)	27
Leeds	26
Liverpool	28
Taunton	28
Birmingham	28
Cambridge	27
Dundee	24
Glasgow	25
Belfast	29
Cardiff	27
TOTAL	**269**

2.2.2. Doctor sampling

The doctors who participated in the research were recruited by the BMA conference unit. Members were randomly selected to reflect the UK doctor population. This was in terms of practice, grade, gender and specialism. This group was then sent a hard copy invitation by post with a follow up email a week later. The process was repeated, excluding the preceding samples, and any category that was fully recruited, until the events had the required registrations. BMA steering group members were excluded from selection. Each event was over recruited by 50% in case of drop outs on the day, particularly as the event was held on a Saturday. The doctors were informed that the event would concern end-of-life care and the impact of physician-assisted dying on the doctor-patient relationship.

This group proved more difficult to recruit than anticipated, and invitations were sent to larger groups than expected in order to recruit the required numbers. Doctors who did not attend indicated various reasons for this on enquiry, including work commitments (including not knowing whether they would be scheduled to work on that date); existing social or family commitments; or the topic not being relevant to their work and therefore not a priority for them. It was our impression that the doctors who did participate were skewed towards those with an interest in end-of-life care. Therefore these participants may offer a different perspective to doctors more generally.

Despite the reasons cited above, recruitment levels were higher than for other deliberative or dialogue events the BMA has held on other topics. The tables for the achieved medical sample can be found in the appendix.

Figure 6: Doctor sampling frame

Doctor Event Quotas 24 per event (4x6) (+ 50% over recruits)			
Branch	**Grade/Type**	**Gender**	**Speciality**
GP [6]	Partner/Principal [3] Non partner (salaried/locum/sessional) [3]	Female [3] Male [3]	General medical practice
Consultant [5]	N/A	Female [2] Male [3]	At least 6 from the specialties of: geriatric medicine, neurology, palliative care, pain medicine, psychiatry, oncology.
SAS [2]	N/A	Female [2] Male [2]	
Junior doctor [7]	Specialty training junior [5]	Female [3] Male [2]	
	Foundation year 1 or 2 [1] GP trainee [1]	Female [1] Male [1]	N/A
Medical student [3]	N/A	Female [2] Male [1]	N/A
Retired [1]	N/A	Female or Male	N/A

Figure 7: Doctors achieved sample

| Doctors' Events – Achieved sample	
London (pilot)	25
Leeds	23
Liverpool	19
Liverpool – BMA ARM	20
Taunton	20
Birmingham	19
Cambridge	22
Dundee	20
Glasgow	20
Belfast	22
Cardiff	27
TOTAL	**237**

2.3. Analysis Process

TNS BMRB's analytical approach has been developed and honed over many years and is highly systematic, robust and reliable. Our procedures and process ensure that the extraction and interpretation of findings are grounded and based on the raw data rather than on researchers' impressions.

Our approach is inductive. This means we build up our analysis from the raw data rather than sorting the findings into pre-determined categories. All of the workshop discussions were audio recorded and thorough notes were also taken by a BMA note-taker sitting at each table. All of the audio files have been listened to by our researchers to verify the notes taken and add layers of detail. The researchers collected quotes and summarised the key themes emerging from each discussion topic for each table. The summaries from each topic at each table were then charted into a matrix to enable the identification of emergent key themes and construct thematic frameworks.

All researchers working on the project then attended a brainstorming session which focussed on the key themes and variation by sub groups. Researchers drew on the data collected from their tables (notes and audio) and their observations. This stage of analysis focusses on identifying important features within the data: defining concepts, mapping the range and nature of phenomena, creating typologies, finding associations, undertaking sub-group analysis, and providing explanations. The key themes from the brainstorm were then explored further and used to construct the presentations and report.

Figure 8: The analysis process
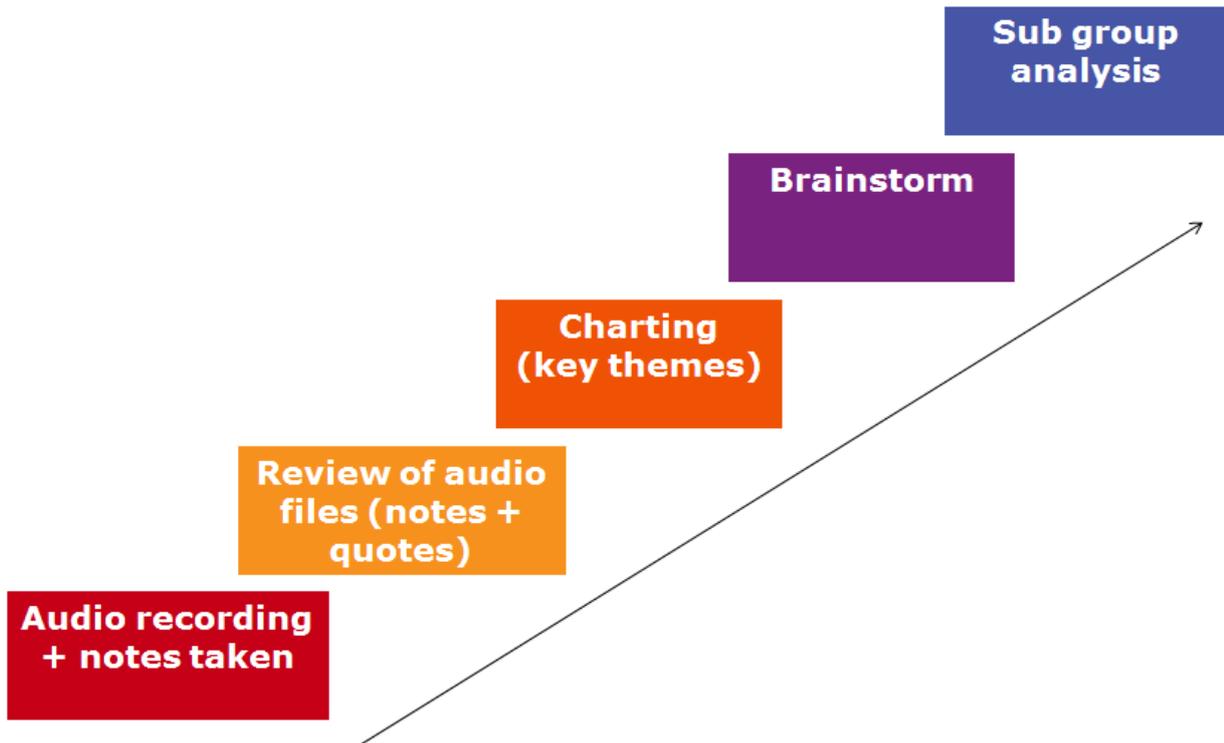
Our analysis is presented below and broken into five key sections: doctor-patient relationships; hopes, fears and concerns about end of life and dying; perceptions and experiences of end-of-life care; providing end-of-life care; and the potential impact of legalisation of physician-assisted dying on doctor-patient relationships.

3. Doctor-patient relationships

In the first session of the workshops, the public and doctors were invited to discuss their views on and experiences of the relationships between the public and doctors and health services. Participants were asked to describe their relationships with doctors and their GP and to consider whether there is anything distinctive and special about the doctor-patient relationship and how the doctor-patient relationship might change and develop following a terminal diagnosis. Doctors were asked how they think the public perceives this relationship. Members of the public were also asked about how involved they feel in their healthcare.

3.1. What characterises doctor-patient relationships?

For the public, the cornerstone of the doctor-patient relationship was an inherent **trust** of doctors and medical professionals. This **trust was 'there to be lost'** rather than earned, unlike with other types of professionals. Whilst there were some participants who described experiences which had diminished their trust in doctors somewhat – for the most part, this high degree of trust was seen to be a **distinctive and special** feature of the doctor-patient relationship. Doctors were seen to be a highly regarded profession in general, and their medical expertise was felt to make them particularly **authoritative** figures.

> *"There's no substitution for medical knowledge, going to the actual expert. They're very helpful. I would sooner speak to someone than type a search term into Google."* (Public, Table 2)
>
> *"Much as I don't know some of the doctors in my own (GP) surgery, I would trust them implicitly. In terms of trust, I would put them at the top of the tree."* (Public, Table 1)
>
> *"They're probably up there. I guess people put them on a pedestal until they prove that they're not worthy of that pedestal - I guess and there's very few that aren't."* (Public, Table 2)

Although trust formed the cornerstone of the doctor-patient relationship for many among the public, there was still a degree of variation in terms of how well members of the public perceived their own personal relationships with doctors to be working. In particular, **continuity** was a key issue for the public that had potential implications for the doctor-patient relationship, particularly with GPs. There was broad agreement that being able to meet with the same GP on an ongoing basis formed the foundation for a stronger and more positive doctor-patient relationship. However, where there was an absence of continuity in these relationships, this was seen to begin to undermine some the default trust that was placed in doctors. Older participants in particular felt that this was part of a broader shift away from the idea of a 'family doctor' – and participants often felt that this lack of continuity was an increasingly common feature of the doctor-patient relationship.

> *"It's so different now to when I was a child. I had a family doctor back then - but now I can't really build a relationship, as I see different ones all the time. There's 5-6 doctors at my practice and I don't always get to see my doctor."* (Public, Table 2)

"It's important to feel that you're getting one continuous person. You feel more at ease, and it feels like a natural progression. They're with you until you feel better - rather than restarting over and over. I would just stop if I had to keep repeating myself." (Public, Table 1)

Another key factor that was seen to influence the doctor-patient relationship was **access**. The ease with which it was possible for a patient to make an appointment with their GP or a specialist, and the length of **time** that this process took, was seen to have a direct impact on the overall quality of the doctor-patient relationship. Where it was seen to be a difficult or protracted process in order to secure a meeting with a doctor, this was commonly cited as having negative implications for the relationship, and a source of some frustration.

"I always struggled a bit when I was referred to a consultant. I had to waste a lot of time in chasing up appointments and getting it all sorted." (Public, Table 1)

Once an appointment had been arranged, the **amount of time** spent during an appointment was another important factor shaping doctor-patient relationships. When assessing the quality of the relationship they had with their doctors, participants often considered the **length** of their appointments. Patients who used more specialist services appreciated the longer appointment times they had with doctors to discuss their conditions in detail, whereas ten minute appointments with GPs were sometimes perceived as rushed and insufficient to establish a strong relationship. The length of an appointment was often seen to correspond to its overall **quality**, and patients were negative about experiences where they felt the doctor **rushed** them and/or looked at their computer screen rather than engaging with them. However some respondents acknowledged the time pressures GPs face and sympathised with them about this and their workload.

"It's important to me that when I visit my GP I don't feel rushed to get out. If I'm there for an appointment and doctors spend their time looking at a screen rather than at me, it seems as if they're not listening." (Public, Table 2)

"I felt I was more comfortable with this doctor, it was more a business in [location] they were constantly rolling in patients but here, they just seem to have more time for you…" (Public, Table 4)

Participants also noted that the **attitude** of staff within the wider environment of the hospital or GP surgery (such as nurses and receptionists) could also play an important role in shaping the doctor-patient relationship. Where receptionists or administrators were seen to be unwelcoming or unhelpful this reflected badly on the overall experience of visiting the doctor – and had the potential to influence how the medical relationship developed in that setting.

"I feel really uncomfortable when receptionists insist on asking about what my symptoms are. It just feels inappropriate for them to ask given that they are not doctors or nurses." (Public, Table 4)

The public's expectations of doctors, and how **intense** a relationship they expected to form with them, was also affected by the specific **role or specialism** of a doctor. Less intense relationships with doctors tended to be perceived as functional or practical ones – in which the focus was on seeking a resolution to a particular condition or treatment, in a way that was sometimes perceived to be more transactional. Doctors working as locums, in out-of-hours services, or in highly technical roles such as surgeons, were therefore perceived to have some of the least intense relationships with members of the public.

"All I ever see is locums, you never get to see the doctor you saw the last time. There's not any continuity, and so you need to get them up to speed quickly and reinform them of who you are and what the problems are." (Public, Table 2)

Conversely, participants identified more intense relationships developing with doctors who were involved in the treatment of chronic or long-term conditions, as there was more likely to be a prolonged relationship with these doctors. Those who had experience of a recent bereavement also identified doctors involved in the provision of end-of-life care (such as those working in palliative care, and some oncologists and geriatricians) as doctors with whom relationships were particularly strong and intense.

> *"The palliative team could not have done more. They were lovely to our family. After my mum died, the nurses still treated the body like a person, like a human being. Her dignity was still there and it was incredibly important."* (Public, Table 4)

General practice is a role where there is perceived to be a high level of variation in the intensity of relationships members of the public expect and experience.

Figure 9: The public reported that the intensity of relationships with medical professionals depends on their role
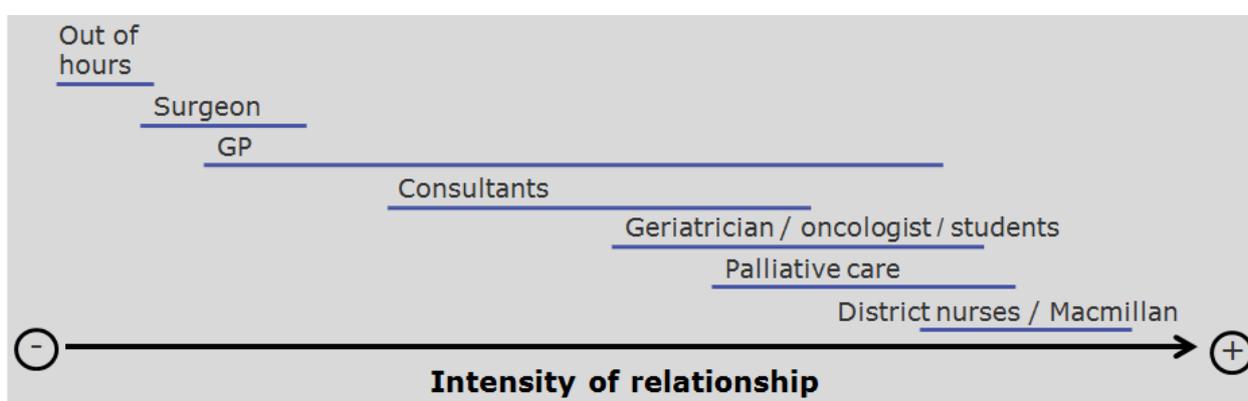
3.2. How doctors think patients perceive the relationship

Doctors understood and **reflected** much of what patients perceived about the doctor-patient relationship. Doctors were keenly aware of the high levels of trust that the public places in them. In some instances it was felt that patients placed **too much trust** in doctors and had **unrealistic expectations** about what it might be possible to do in terms of curing or treating their conditions and asking what the doctor would do in their position or for their personal opinion. Doctors felt that this sometimes presented a challenge. In particular, doctors who saw their role as being to assist patients in making the best choice about their healthcare, rather than to dictate the best course of action, were concerned that some of their patients at times sought to leave important decisions about their care entirely up to doctors.

> *"Patients put a lot of trust in us. I still get patients and families saying 'whatever you think best' but you have to help them make decisions"* (Doctor).

Doctors recognised the desire of patients for **continuity** in relationships, and also agreed that this continuity is an important element of a strong doctor-patient relationship. Like the public, doctors felt that in many instances it is becoming increasingly difficult to maintain this kind of sustained relationship over a number of years, and felt that this reflected a broad change in healthcare practice and an increase in workloads over recent years. GPs were often particularly sensitive to the view that things had changed over time, but doctors in hospital settings also recognised this trend and the difficulties of maintaining a strong relationship.

> *"People don't see the same doctor, our surgery is so overrun, they're coming back complaining about the practice more than they used to."* (Doctor)

"As a hospital doctor I see patients in clinics - and there is not much time. I see them every 6 months, at most – and it is a big responsibility to build a relationship and empower the patient in a short amount of time." (Doctor)

3.2.1. After a terminal diagnosis

Doctors felt that the doctor-patient relationship undergoes a **change** once a terminal diagnosis is given, due to the increasing **vulnerability** of the patient and the complex emotions involved. It was felt that in these circumstances the role of the doctor tends to shift from simply providing treatment to taking on a more **supportive** and mediating role. Additionally, the relationship with the **family** and loved ones was felt to become more important and more intense in these cases.

"A terminal diagnosis changes the relationship dramatically. You spend a lot of time in that person's house, in their bedroom. You get more of a sense of who they are; more open service, call me, we'll call you. Our training encourages us to talk about spiritual side of things, which changes the relationship." (Doctor)

"Often the setting of care has changed, and the more ill they become, the more they stay in their own home. Consultation can become a 3-way discussion with the spouse or partner as well, and there is dynamic movement of where that care takes place." (Doctor)

3.3. Involving patients in their healthcare

The public expressed quite **a range of views** about the degree to which they seek to be actively involved in managing their own healthcare. Some people felt that it was important for them to **proactively** take the lead in order to develop a positive relationship with their doctors. Some participants described how they would actively search for information (either online or through other people and sources) about symptoms and conditions before coming to discuss them with a doctor.

"I think now with the internet you sometimes self-diagnose yourself. I Google everything to see what comes up. You're maybe a bit more clued up and anticipate what they [doctors] are going to come back to you with. That wasn't possible before and you went with whatever they said. People are a bit more inquisitive and will check for alternatives. That's mostly for the good, but maybe not always." (Public, Table 1)

Younger patients were sometimes more keen to take this **proactive** approach and seek out information using internet sources which they trusted. Equally, those with previous negative experiences, or who were less trusting of doctors generally, were also among the more proactive. These people tended to feel that by coming to an appointment prepared with information they would be better placed to take control of their own healthcare and ensure they were getting the right and best treatment for themselves. This kind of approach was partly dependent on the personality of the doctor and patient involved. However it was seen to be harder to have this kind of proactive relationship with more senior and less accessible doctors (e.g. consultants and surgeons). Some doctors felt that while a proactive approach was often to be welcomed, patients who felt they knew better than the doctor were said to be difficult to deal with and reflected a different, more combative type of relationship.

"I would like to believe that I am completely involved with my health care decisions. I feel that it is important for me to stand up for myself because at the end of the day, doctors are only human as well." (Public, Table 4)

Other patients were less proactive in their relationship with doctors, but still felt that it was important to feel involved in the management of their healthcare. These patients often sought a more **collaborative** relationship with doctors. Unlike those who felt that it was important for patients to be proactive, these individuals trusted doctors to engage with them in regards to their care – and to discuss possible courses

of action. These participants included some of those with more experience of long-term contact with a particular doctor (for example those who had been diagnosed with chronic conditions), and who felt that this continued contact led to a more open, discursive relationship in which it was possible for doctor and patient to work together to manage the condition. This kind of **collaborative** approach was again partly dependent on the personality and experiences of the doctor and patient involved – a 'bad attitude' on either side (generally meaning resistance to involvement) could jeopardise the development of this kind of relationship.

> *"We need to give them credit; research is so far advanced that if you give them symptoms, it could be anything, could have malaria or the flu. I don't mind them looking things up because their job is so difficult. I feel part of the discussion and I'm happy with that."* (Public, Table 2)

A third group of patients were those who were content to take a more **passive** role in their healthcare, seeking primarily to follow the explanations and prescriptions and instructions that were provided to them by doctors. These patients often had high levels of trust in doctors and felt that it was not necessary for them to play an active role in their healthcare. These patients sometimes placed a higher expectation on doctors, and held them in higher regard than participants who felt the need to push proactively for more engagement with doctors. The public tended to talk about their own elderly parents who adopted a passive role. This seemed to be generational and increasingly the public were talking more collaborative or proactive roles with their GP.

> *"I trust them to make the decision for me as to what's best for my care. If the doctor says to take these tablets, I will!"* (Public, Table 3).

4. Hopes, fears and concerns about end of life and dying

In the second part of the first session the public and doctors discussed their views regarding end of life and dying. The public were asked to describe their hopes and fears about their end of life and dying, and doctors were asked to discuss their perceptions of the public's hopes and fears. Both groups were asked to come to a consensus on their tables about their (or the public's) three greatest fears and concerns. The public discussed what they thought constitutes a 'good death', and were asked about the information sources that informed their perceptions of end of life and dying.

4.1. Thinking and talking about and planning for end of life and dying

Participants reported that they **do not often think about end of life and dying**, or discuss the subject with their spouse, family or friends, or in society more generally. People prefer to think and talk about life rather than death. End of life and dying was seen to be a topic which many people found **uncomfortable**, and something that was relatively **taboo**, even among family and loved ones. The discussion of end of life and dying was seen to be something that does not feature regularly in the British culture. Life is the focus of popular culture - and death and dying, when they are discussed, are usually portrayed negatively and/or sensationally. Some participants responded to their discomfort by using **humour** in order to be able to talk about the subject more openly in the groups.

> *"If I think about not being around and not being around for my kids, it makes me feel sick. I lost my own mum and dad, it was the hardest thing - so I just block myself from thinking about it."* (Public, Table 1)
>
> *"It's a scary prospect because nobody knows what happens afterwards. My mum says – 'if I lose my marbles, shoot me.' That was her end of life plan."* (Public, Table 2)

For most participants there was **uncertainty about many of the practicalities** around end of life and dying. Participants raised questions about when wills should be drawn up, the value of life insurance, and other practical arrangements that one might make in advance. Very few people spontaneously raised medical arrangements such as advanced plans. It was felt that people (even in later life) often spent more time 'planning for life' than 'planning for death'. In the instances where participants had spoken with family members or loved ones about end of life and dying it was often in relation to more general fears rather than specifics about managing the process or practical arrangements and steps that could be taken. Whilst some people had thought about financial and funeral arrangements, few respondents had thought about end-of-life care plans and preferences in any detail.

> *"I haven't made any provisions, but have discussed it with my close family. Some people, like my sister and my wife would struggle if I wasn't here."* (Public, Table 3)

Although overall the public tended to avoid confronting the issues of end of life and dying where possible, **some groups within the population had given the topic some more serious consideration**. Those with recent experience of a bereavement tended to have given more thought to these issues, and had

often been prompted to consider how the management of their deceased loved one's care might have implications for their own care, or that of others who might be nearing the end of their life. Equally, older participants (generally those aged over 60) and those from higher social grades tended to be more likely to have given thought to some of the practical arrangements. In part this was driven by a greater familiarity with the different practical steps that might be taken (compared to younger participants), but also by a more serious contemplation of the need for these kinds of measures. To a lesser extent, some participants were more conscious if they came from a family or cultural background which had traditionally been more 'open' in discussing the subject of end of life and dying.

> *"A certain generation probably talk about it more. Both my sets of grandparents have got their money saved for their funerals, their choices for everything they want …They feel comfortable talking about it, but it would make us upset and sad. Personally, I think me and my brother, younger people like us, would probably not want to think about it."* (Public, Table 3)

In order to engage the public further with these issues, it might be necessary to develop a communications campaign encouraging people to discuss end of life and dying with their family and loved ones and to make advanced plans.

4.2. The public's hopes, fears and concerns

The public groups were asked to explore their hopes, fears and concerns about end of life and dying. The hopes, fears and concerns reported were broadly **similar across all of the tables and locations**, with key themes frequently occurring on the majority of tables. Hopes and fears were broadly similar across genders, age groups, social grades and other demographic variables as well as locations.

Figure 10: The public's hopes, fears and concerns about end of life and dying

Hopes, fears and concerns – public

Pain * Impact on family & loved ones * Leaving family * How family will cope during EOL * Lack of choice * Loss of dignity * Fear of the unknown * Being a burden * Poor quality of life * Lack of / poor care from medical staff * Not being treated like a person * Lack of control * Cost & quality of care homes * Being alone * Having dementia * Loss of bodily control * Loss of mental health * The cost of care * There being no NHS in the future * Loss of social life * Family and friends not visiting * Loss of intimacy with partner**

Quick / in my sleep * Painless * Family being there/ choice about when loved ones are there * At home / in a hospice * Good quality of life * Finances sorted * Dignified * Choice / being able to make decisions * Being in control * Wishes respected * Respected as an individual * the ability to communicate * Being prepared * Able to say goodbye to loved ones * Able to achieve final wishes

The participants were asked to come to a consensus about their three greatest fears and concerns and again a small group of concerns were repeatedly identified. The **most common fears** among the public were **pain, impact on family and loved ones** (particularly spouses and children), **leaving family**

members and loved ones, and how loved ones would cope during their end of life (particularly spouses). Other issues which were frequently raised were lack of choice (particularly regarding the location of their care and death), loss of dignity (due to symptoms and side effects, and particularly in front of loved ones), fear of the unknown, and being a burden (particularly to spouses and children).

> *"Daughter says she'll take care of me in my old age, but that's the last thing I want to happen. If I need help, it's either got to be professional care or to be terminal. I don't want anyone having to do that for me … I would hate to put any of my family through that, the strain of helping me".* (Public, Table 1)
>
> *"I think a lot of people are afraid of losing themselves. People who get diagnosed with a terminal condition often feel it makes them a different person, becomes a part of their identity….they want to be able to stay 'themselves' as much as possible."* (Public, Table 1)

The public's **most common hopes** for their end of life and dying were that it would be **quick** and in their sleep, **painless**, and that they would have a choice about if and when their **family** and loved ones were present, although most people often wanted family and loved ones to be there. Other issues which were frequently raised were location (and often that they could be at home or in a hospice), having a good quality of life (which often meant being able to continue 'as normal' as much as possible) and that their finances would be sorted out as desired.
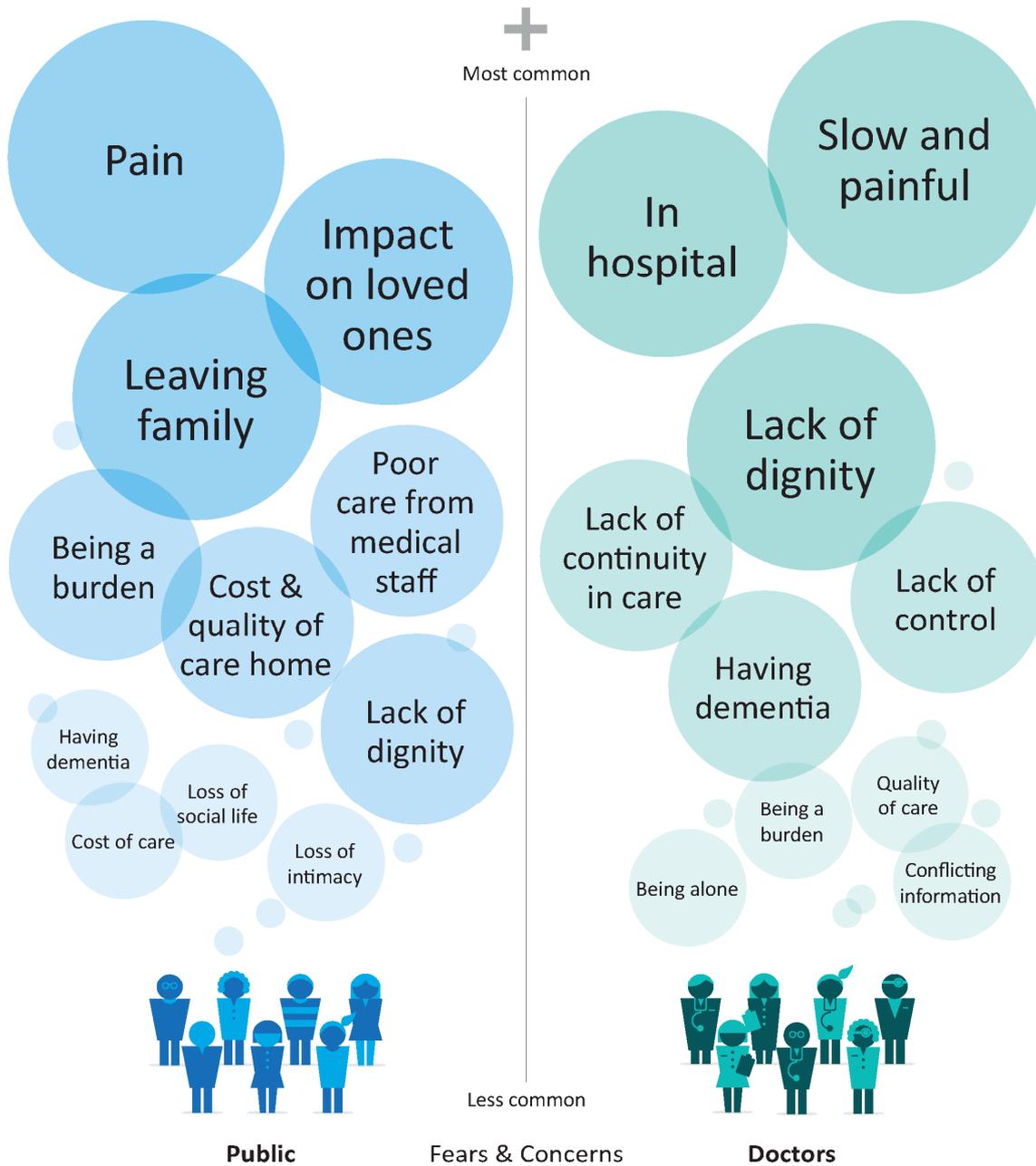
Participants from **table 4** (those recently bereaved) were often **less fearful** and had a clearer picture of how end-of-life care works and what is possible and available. They were often less theoretical and more focussed on **practical concerns** such as timely access to services and resources. Their hopes and fears were sometimes shaped by the positive or negative experiences they and their loved one had had. They often raised pain management, costs, impact on family, quality of life, and being prepared and able to say goodbye as important issues. However they were also able to provide more detail about concerns such as smooth and timely provision of services and resources (e.g. pain relief and appropriate equipment). They raised good communication and coordination of care as important in this session, and the practicalities of communication with medical professionals was a particular worry. They hoped for a 'go between' for families and doctors and better communication from palliative teams.

Some **subtle differences** regarding their responses and hopes and fears emerged between different demographic groups. **Younger people** sometimes found it easier to speak about hopes and fears in relation to their parents' deaths, whereas older people were more comfortable and able to talk about their own and their spouses'. Younger people tended to focus slightly more on fears about death itself and the 'unknown' element, rather than end of life more widely. For those who were **parents**, the impact of their end of life and dying on their children was a significant concern. They were often worried about being a burden during their end-of-life care, and then about the impact of their death on children and how they would cope – particularly if children were still young. Parents of younger children were concerned about who would look after them. Parents of older children were often concerned about losing their dignity in front of them as symptoms worsened. Despite these variations, the broader picture of the public's hopes and fears was consistent across demographic groups.

Public and medical attitudes to end of life care and physician assisted dying

The public's fears and concerns about end of life and dying

Most common

Pain

Impact on loved ones

Leaving family

In hospital

Slow and painful

Poor care from medical staff

Being a burden

Cost & quality of care home

Lack of dignity

Lack of continuity in care

Lack of control

Having dementia

Having dementia

Lack of dignity

Cost of care

Loss of social life

Loss of intimacy

Being a burden

Quality of care

Being alone

Conflicting information

Less common

Public　　　Fears & Concerns　　　**Doctors**

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4.3. Doctors' views on the public's hopes, fears and concerns

The doctors were asked what they perceived the public's hopes, fears and concerns about end of life and dying to be. The issues raised by the doctors **broadly reflected those reported by the public** and many of the same hopes and concerns were discussed.

However, doctors were more likely than the public to mention **specific** symptoms and side effects experienced at end of life, which the public may not have been aware of (e.g. losing the ability to swallow and breathing difficulties). They were also more likely to discuss specific process and procedural aspects, which again the public may not have been aware of, for example NHS finances.

A more important key difference was that the doctors were **less likely to mention the impact on family and loved ones** and how they would cope during end-of-life care and after the patient's death. Leaving family and loved ones and the impact on them before and after death were key concerns for the public and discussed on the majority of their tables.

Figure 11: Doctors' perceptions of the public's hopes, fears and concerns about end of life and dying

Hopes, fears and concerns - doctors

Slow and painful * In hospital * Lack of dignity * Suffering * The unknown * Lack of care and being side-lined * Lack of continuity * Being lost in the system * Lack of control * Lack of choice * Lack of dignity / independence * Having dementia * Poor care * Quality of care * How relatives will cope * the process of dying * Being a burden / dependence on relatives * Breathing problems * Cost of care / NHS finances * Being alone / loneliness * Doctors giving up on them * Receiving conflicting information

People don't think about it * Fast / in sleep * Pain free * At home / location choice * Dignified * Having your affairs in order and family supported * Receiving the best care * Maintaining control * Not being alone * Maintaining normality * Patients are unrealistic with their expectations

During this session, headline findings from the table during the morning session with the public were fed in to the doctors' discussion by the moderator and they were given the opportunity to comment on these (with the caveat that they were findings from one table at one event in that location). Although broadly doctors recognised and concurred with the hopes and fears of the public, some expressed **surprise** at some of the hopes and fears. Some doctors worried that it might be difficult to meet some of the public's hopes to their satisfaction. Some doctors felt some of the public's hopes were **overly optimistic**. In particular, it may not be possible for GPs to coordinate with hospital care; doctors may not be aware of

patient's non-physical and more holistic needs (and even when they are, may be unable to address these); and it may not be possible for patients to choose where their end-of-life care takes place or practically to fulfil their wishes in this area. Doctors also noted that patients may not be aware of or recognise the reality and likelihood of unpleasant physical symptoms during end of life, particularly those not related to pain.

Doctors raised two other particular **concerns** and surprises. Some felt that a **conflict** arose from emphasis on not being a **burden to family members**, given doctors' experiences of family members often being very keen to be involved in their loved ones' end-of-life care. Meanwhile some doctors expressed concern that the public's only **source of information** about end-of-life care and dying was often media representations which may be potentially unrealistic or exaggerated and sensationalised. They were concerned that the public was not accessing more balanced and practical information.

4.4.   What a 'good death' looks like

The public and doctors explored what a 'good death' looks like and is constituted by. As with the hopes and fears, the elements reported by the public were **broadly similar across all of the tables** and locations. The key aspects were raised on the majority of tables with a handful of other concerns and priorities being raised at many tables across the events. The issues raised were similar across demographic groups with little variation demonstrated.

Infographic 2 illustrates the key elements of a good death for the public. For the vast majority of people, a 'good death' would be **quick and in their sleep and painless**. These three aspects were frequently the first things quickly raised on the tables when this topic was posed and concurred with by all respondents. Once respondents had discussed the issue further, some other elements were frequently raised at most tables: that desired **family** members and loved ones would be there (although some respondents caveated this by saying that they would like to choose when family members and loved ones were and were not present – often relating to wanting to avoid them being there in undignified moments or due to a desire to want to avoid distressing loved ones further), they would not be **alone**, death would occur in a chosen **location** (usually at home or in a hospice), **finances** would be sorted, and the end-of-life care received will have been **personalised** to the individual.

> *"I think bringing in family members as well is just opening a can of worms up, they might not agree..."* (Public, Table 1)
>
> *"It would have to be the most beautiful place ever, in a really nice location, I'd want my room to have a really nice view, you might as well have it as nice as you can."* (Public, Table1)
>
> *"I didn't want him to be treated as a number because he was a person."* (Public, Table 2)

Other aspects raised frequently were that the death would be **dignified** (usually referring to family and loved ones not witnessing what were perceived to be undignified symptoms and side effects) and the individual in **control**. Some respondents were also concerned that they would be able to **communicate** (sometimes with reference to dementia), be **prepared** and able to have said **goodbye** and achieve any **final wishes**.

> "Having the expenses covered. That's the key part of planning." (Public, Table 2)

The doctors' views on what the public hopes for and thinks constitutes a 'good death' **broadly reflected the public's views**. Many of the key elements raised by the public were raised on the majority of the

doctors' tables: death being quick and in your sleep, painless, in a location of choice, not being alone and being in control. However many doctors also discussed issues around receiving an accurate prognosis which was just as important to patients. The doctors also often reported a good death to be dignified and where affairs are in order and finances sorted. Some mentioned not being abandoned by medical staff and being comfortable and able to maintain as much normality as possible – which links to a concern from the public for care being personalised. Some doctors also referred to meeting any religious wishes.
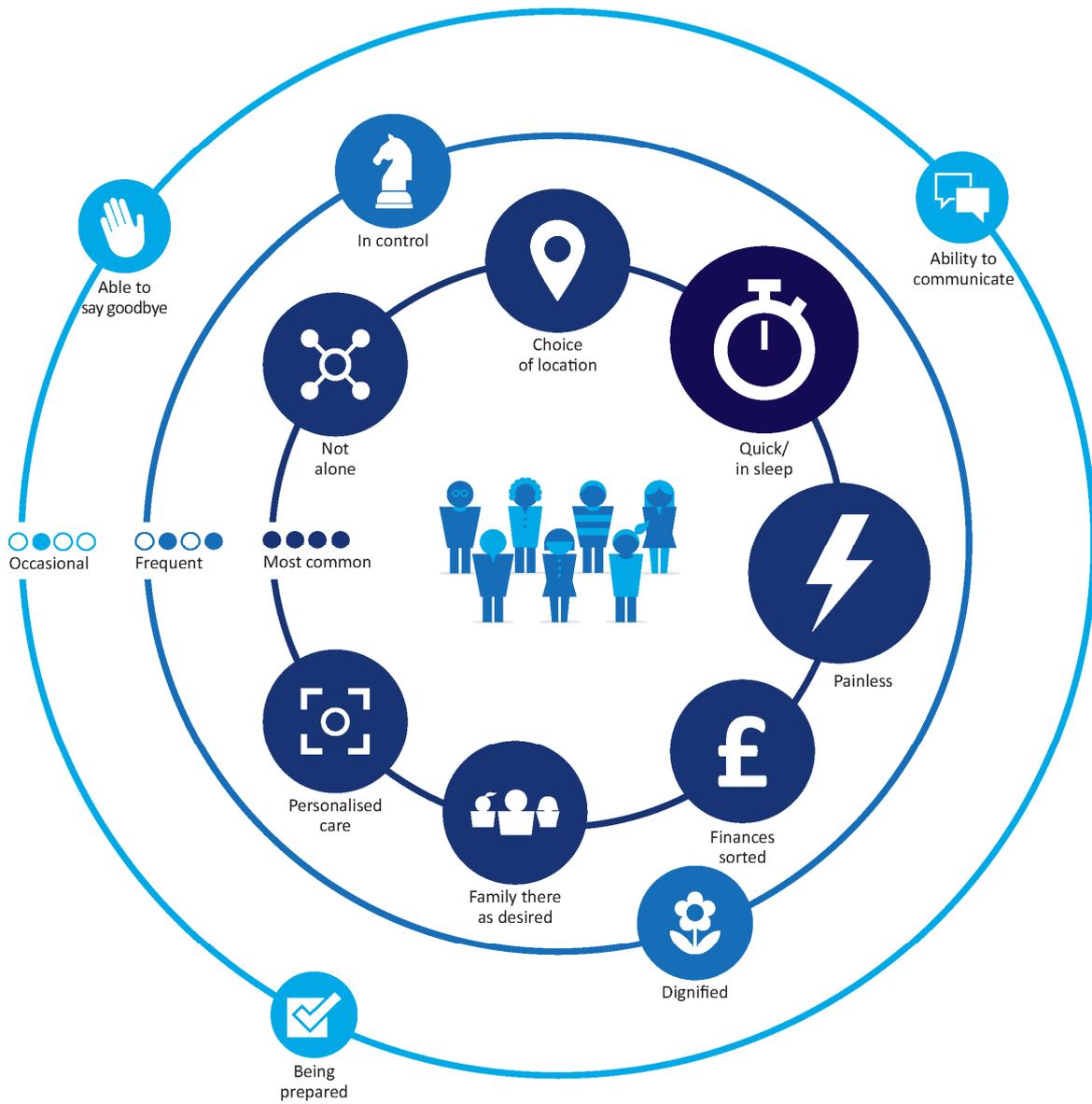
Figure 12: Public and medical views about what the public thinks a 'good death' looks like

Public	Doctors
Most common • Quick / in sleep • Painless • Family there • Choice of location • Not alone • Finances sorted • Personalised care	**Most common** • Quick / in sleep • Painless • Choice of location • Not alone • In control • Accurate prognosis
Frequent • Dignified • In control	**Frequent** • Dignified • Affairs in order • Finances sorted
Occasional • Ability to communicate • Being prepared • Able to say goodbye • Able to achieve final wishes	**Occasional** • Not being abandoned • Normality

Public and medical attitudes to end of life care and physician assisted dying

What a good death looks like for the public

In control

Able to
say goodbye

Ability to
communicate

Choice
of location

Not
alone

Quick/
in sleep

Occasional Frequent Most common

Painless

Personalised
care

Family there
as desired

Finances
sorted

Dignified

Being
prepared

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5. Public perceptions and experiences of end-of-life care in the UK

The second workshop session focussed on end-of-life care. As the discussions with the public and doctors focussed on slightly different issues they are reported in separate chapters. This chapter focusses on the public's knowledge, perceptions and views about and experiences of end-of-life care.

Participants at tables 1-3 were initially asked what they knew about end-of-life care: what it includes, what it excludes and where their information came from. They were then asked to work in pairs and think about what 'good' end-of-life care should look like in terms of the needs that should be addressed, how end-of-life care might be provided in practice and how this might change through the course of a terminal illness. The group was then brought back together and the elements of what needs end-of-life care should address and how it might work in practice were collected and discussed. These were then compared with a set of best practice principles provided as stimulus[4].

Initially, Table 4 participants were asked to begin by talking about their experiences of end-of-life care for their bereaved relative and then followed the same set of topics as Tables 1-3. However, it became clear that with so many experiences to recount there was insufficient opportunity to cover the remaining issues in the detail they deserved. Consequently, for the remaining sessions, Table 4 participants were asked to spend 5-10 minutes writing down their experiences, with key topics and experiences then being discussed as a group with a focus on what worked well and less well. The written narratives provided by the participants were collected and used in the analysis of end-of-life care provision.

Stimulus materials were used during the session: a definition of end-of-life care was provided[5] to ensure that all the participants were discussing the same concept; and the set of best practice principles referenced in footnote 4 below. The materials can also be found in the appendix.

5.1. Public knowledge of end-of-life care

Overall, the public without recent experience of bereavement (Tables 1-3) knew little about what end-of-life care is, what it comprises, how it would be accessed, or about its availability. As participants themselves commented, this is perhaps not surprising as people tend to work on a 'need to know' basis and find out about services when they are required.

> *"Haven't a clue. Reading between the lines, (end-of-life care) is the basic minimum to keep you ticking over until you fall off the great life conveyor belt, and you pop your clogs…And what also*

---

[4] Taken from: The Choice in End-of-life care Programme Board (February 2015) *What's important to me. A review of choice in end-of-life care, Executive Summary.*

[5] End-of-life care: refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for days, weeks, months or even longer. It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

comes through [from the definition] is that they try to reduce the amount of suffering, to what you can live with." (Public, Table 2)

As outlined in the previous chapter, **end of life and dying are not general topics of conversation** or something people want to think about or feel comfortable discussing. However, many members of the public had fairly **low expectations of NHS-provided end-of-life care**, views that were often driven by media coverage of over-stretched health services and regional services being in deficit.

"Short staffed services so you're not going to get the care you need." (Public, Table 2)

"I think you're a person that's dying anyway and it's very low on priorities..." (Public, Table 2)

Some people also mentioned 'horror stories' that appeared in the media about care homes and treatment of elderly patients in hospitals.

"If I had to put my mum into a care home I'd want a CCTV on it, I would..." (Public, Table 3)

"If every care home was like this [best practice diagram] you'd feel relaxed but every care home ain't like this. They're businesses at the end of the day and they're out to make profit...." (Public, Table 2)

By contrast, the public also commented on how TV soap operas tended to portray end-of-life care in a highly sanitised way, a perception that they thought was unlikely to reflect reality (e.g. Holby City).

There were some exceptions to these low expectations, namely of the **services provided by hospices and Macmillan Cancer Support and Marie Curie nurses who were all highly regarded**. While Tables 1-3 often had no direct experience of these, their general perception was that they provided very high quality end-of-life services. This was borne out by participants who had experienced recent bereavement and had used hospices and Macmillan Cancer Support services.

"I think the care you get at home, from home help, Macmillan nurses – my perception… is that that's probably better care than you get at hospital. All the people who come into your home are there to care for you, no one else, so you get that personal care." (Public, Table 4)

"There's lots of services out there. There's carers who come in, supplied by government, there's hospices…" (Public, Table 3)

However, Table 4 participants were very mixed in the views they gave about the end-of-life care services that had been provided to their loved ones more generally. **Experiences of end-of-life care clearly varied both across the UK** and within geographical areas as well as between rural and urban locations.

"My concern would be to see it implemented across the UK regardless of where you live and not become like a lot of other treatments, a postcode lottery..." (Public, Table 4).

5.2.   What good end-of-life care looks like for the public

The participants were asked to describe what a good end-of-life care approach would look like for a family member or loved one of theirs. The analysis drew together the views given across all the tables with and without recent experience of bereavement. The participants identified **eight key needs or areas that they thought needed to be considered and addressed to provide good end-of-life care** to an individual:

- Being treated as a person
- The timely provision of medical services
- The location of where end-of-life care services are delivered (hospital, hospice or community)
- The provision of information (diagnosis, prognosis, treatment options, progression, and other services which are available)
- Good communication between all the parties involved with end-of-life care (the patient and their family and GPs, specialists, nurses, counsellors etc.)
- Coordinated care that is well planned - but flexible and reflects the prognosis and patient's wishes
- Emotional support in the form of counselling and spiritual care for the patient and their family as desired by them
- Financial and legal advice to ensure that their estate is properly managed and their family are adequately cared for financially.

As the diagram below illustrates, **being treated as a person is central to and at the heart of the provision of good end-of-life care**. The timely provision of high quality medical services, the location of where care is provided and the provision of adequate medical information at the level desired by the individual were also frequently mentioned and emphatically emphasised by many people.

Figure 13: What good end-of-life care looks like for the public

5.2.1. Being treated as a person

Being treated as a person, rather than as a number or condition or being de-humanised in other ways, is central to the provision of high quality end-of-life care. People wanted to be **treated as an individual and cared for as a person in a way which enabled them to make choices**, be involved and be recognised as more than a patient and their condition. As one man said; "*You should be treated like you're not dying...you should be treated like any other person*" (Public, Table 2).

> *"I think you worry that because the medical people see it every day, a thousand times a week or whatever you become a number rather than a person, even at the end."* (Public, Table 1)
>
> *"That the doctor is thinking of you, you're not number 15, to think of you as a person."* (Public, Table 2)
>
> *"You hope you get a good compassionate one. Somebody who doesn't just treat you as a number or a piece of meat and actually connects..."* (Public, Table 3)

The theme of being treated like a person emerged from many of the tables across many of the locations. Whilst some respondents raised and discussed this explicitly, this idea also formed the foundation of some of the other key issues other respondents raised.

> *"To be respected in life and death by the professional that are handling you...if you die in hospital they need to treat you with dignity."* (Public, Table 2)

Being treated as a person is woven throughout the other seven key areas. When discussed explicitly it was also found to mean and cover a wide range of issues for people, for example:

- Having choice over whether or not to have treatment
- Being able to choose your type of treatment from the options available
- Being actively engaged in and able to choose and influence your treatment and care plan
- Being able to choose the location of your end-of-life care and death – and for this to change as your condition progresses according to evolving needs (particularly between a hospital, hospice and home)
- Being encouraged and enabled to live as normal a life as possible, within the constraints of the diagnosis
- Privacy - when required
- Access to loved ones - when desired and required.

> *"You're the patient, it's about what you want."* (Public, Table 4)
>
> *"I want to be as involved as I want in decisions about my care."* (Public, Table 1)
>
> *"Not a generic plan, what works for a cancer patient but this is what you need, what YOU need..."* (Public, Table 2)

5.2.2. Medical services

Of all the end-of-life care needs identified, **the timely provision of high quality medical services was paramount**, although there were concerns about whether the NHS could universally provide this.

> *"You want to access the right services when you need them. Well, with all the cuts, are there actually going to be these services? It's a scary prospect."* (Public, Table 2)

The public wanted medical care that was the best that could be provided – and not subject to a 'postcode lottery'. Medical services should be timely and provided as and when required, flexibly as their condition progresses. This included the complete range of medical services, treatments and equipment that were required by their diagnosis, as well as the most appropriate medications. Respondents often referred to getting 'the best' and the most 'advanced' medical services available at the time.

The provision of medications and pain management were of particular concern to the public, with considerable fear being expressed about being in pain – here and in the first session of the workshop.

> *"One of the worries is to make sure the medical team would detect that you were in pain and would know from nervous reflexes and the tests that they do. Because the thought of being in pain and unable to voice it gives you the horrors."* (Public, Table 3)

Table 4 respondents expressed considerable concern about the provision of pain medications in the community. While some experiences had been extremely positive with the district nursing services said to be excellent, others were less positive about their experiences, especially where medications were required at the weekend. Participants were often extremely grateful for the district nursing services and were keen not to criticise a service that they knew in some areas to be severely over-stretched; in other cases there was said to be a breakdown in communication between the various medical services.

5.2.3. Location

The public often spent a lot of time discussing where end-of-life care should be provided. While there was a general recognition that hospital care is often essential, it was the least well regarded by the public, including those who had recently been bereaved.

> *"Die in the place of your choice. Sometimes it might not be your choice, because the care you need might not be in the place you want it."* (Public, Table 1)

Generally, **the public did not want to receive end-of-life care, nor did they want to die, in hospital**. Their preference was often for hospice or home care, the reasons being that both were seen as providing a more homely and personal environment with round the clock, flexible, personalised care.

> *"You'd have to have a choice, whether you want to be in a place like that (hospice) or at home."* (Public, Table 3)

There was also some fear of hospitals and the hospital environment, and horror stories they had heard in the media, for some respondents.

Hospice care was generally seen as providing the 'gold standard' for end-of-life care, although was generally perceived to be limited in availability by the public. However, it was also apparent that for the public participants from tables 1-3, there was a general lack of knowledge about when hospice care is required, what it consists of and whether it is always necessary for terminally ill patients. Few members of the public knew how long a patient was likely to receive hospice care, with estimates ranging from six months to two weeks or less.

> *"[Staff at the hospice] do what you need and the nurses are all very cheerful"* (Public, Table 4)

Community care which includes home-based services were generally thought to be the most desirable by many members of the public, including those who had been recently bereaved. Being in a familiar environment and surrounded by family and belongings were important factors in their desire for home-based and personalised services. However, the public also raised some concerns and recognised

that there would be difficulties in providing these services. Their concerns were primarily about being a burden to one's family (particularly your spouse and adult children), which would only be mitigated if there was sufficient NHS or charity-provided home care. The issue of medication availability was also raised, especially the need for pain medication out of hours and at weekends.

Woven throughout the discussion of where end-of-life care should be provided was the concern that terminally ill people should not be left alone – a fear that was frequently raised by members of the public.

> *"It's that age old fear, you don't want to be alone…You've got your care plan, you go to your physicians, your appointments, but most of the time, you're on your own. So the support would always be there. There would always be somebody there to talk to."* (Public, Table 2)

5.2.4. Information

The **provision of adequate and desired medical information** was high on the list of the public's priority needs. Overall, the public across tables 1-4 wanted to know:

- The diagnosis
- The prognosis
- Any changes to their prognosis
- The treatment options available and any side effects
- Other services available.

Considering their experiences of being treated by doctors over the years, the public indicated that diagnoses and recommended treatment options could vary according to the particular doctor seen. They were particularly keen that in end-of-life care, the information they were provided with by the medical profession was consistent and complete. The public recognised that discussing end-of-life care and dying were difficult for doctors but it was always appreciated when done well.

> *"I have to praise the honesty of the doctor who sat my sister-in- law and me down and....had the strength of character to tell us he wouldn't be with us on Monday and I so admire that doctor for the honesty and the strength that he had to tell us what we didn't want to hear."* (Public, Table 4)

> *"I think the role of the doctor there is to be quite clear to the family what happens next, what can be done, what can't be done..."* (Public, Table 3)

Whilst many respondents reported a desire for complete information, they also recognised that **not everyone wants to know their diagnosis or their prognosis or to be actively involved in making decisions** about their treatment – for example the passive patients described in the chapter on doctor-patient relationships. Respondents therefore suggested that doctors should ascertain what the patient and the family wants to know and then provide the information desired and requested.

The public also indicated that while they might want to know all the information, they may not want their family to know this, and again, doctors should ascertain the patient's wishes and provide the family only with the information that the patient is happy to be provided and that the patients' wishes should also be made clear to the family. The public recognised that there could be a tension between the patient and the family, but ultimately it was considered that the patient's wishes were paramount.

> *"Sometimes you can't be honest with your family."* (Public, Table 1)

5.2.5. Communication

The public commented on the need for a one-stop-shop for information – a *single* **communication channel** that meant that the patient and the family would not have to seek out information about a wide range of disparate services for themselves. This would help families to plan and be aware of options.

> *"Back to my one stop shop, somewhere we could go or something we could do that would link social services and maybe hospice care, Macmillan so you have one person you could go to and know and they'll contact all the others..." (Public, Table 4)*

> *"The most important thing for me would be that I had professionals that I can voice my fears to, because I know that I would be full of fear….Professionals to manage my illness, and to manage how it would progress, what to expect, how it would be dealt with. Not being forgotten or overridden. I would want to know that I had people who could answer all my fears, who would not trivialise my fears, and had extensive knowledge, about understanding and managing peoples' fear." (Public, Table 3)*

5.2.6. Coordination

Linked closely with communication was a desire for **good coordination and planning of services, in order to provide personalised care that is flexible and open to change** according to a patient's prognosis and progression of their condition, as well as their potentially changing wishes.

> *"It's probably documenting our wishes early, a pre planning document, then as end of life gets closer and you're not capable of making decisions, it's passing that responsibility over to our family, friends or loved one who may be able to take our wishes on..."* (Public, Table 3)

The public were primarily concerned with the good coordination of medical care and services, particularly when multiple services were being accessed, particularly hospital and community care. However they also thought that in line with the idea of a one-stop information shop, that there should be a central end-of-life care coordinator assigned to an individual who provided updates, ensures coordination between services and that information is shared, and considered all the patient's needs - medical, emotional, financial and legal and spiritual where desired. Some people thought that the coordination of services should happen 'in the background' and that they should be shielded from the complexities by a central coordinator.

> *"Doctors and health services, obviously each has a role to play and it's making sure they have joined up working, there's no point working individually, you're just picking up that bit of the person you're seeing. It's making sure all the services communicate with each other then they may not miss things they may do individually..."* (Public, Table 4)

> *"…consistency of seeing same nurse in hospice or Macmillan. With pregnancy you have same midwife through pregnancy, this is probably similar, you get one Macmillan nurse throughout the process…someone there to go through the whole process with you..." (Public, Table 2)*

> *"We said we don't want loads of people, like loads of professionals, we want the same doctor or the same carer, rather than having loads of different people keep coming in and checking on you..." (Public, Table 3)*

Table 4 participants often had much to say about the coordination of care, with some very positive and very negative experiences across the areas. Table 4 participants reported that it was essential that there should be coordination of information and services between the patient and the family, hospital medical staff (including A&E), GP and community care. Some of the participants had had experiences where a patient had got into difficulties at a weekend, community services were not available and they had called an ambulance and the patient had been taken to A&E. A&E was not aware of the patient's circumstances

and they had been admitted onto a ward, resulting in a very unpleasant experience for the patient. In this respect it was suggested that patient records should be stored electronically and possibly travel with the patient so that relevant authorised personnel across hospital and community services could readily access information about treatments and medical history – so services can be provided quickly and the patient and family do not have to keep repeating this information to different staff.

> *"I think communication between services – that's something that we found to be pretty disjointed in our case."* (Public, Table 4)

5.2.7. Emotional support

Many table 4 participants **commented positively on the availability of spiritual support from a hospital chaplain but expressed some concern about the lack of wider emotional support** (e.g. counselling – for the patient and family). Death and dying were recognised as being difficult subjects to discuss and respondents recognised that not all doctors are particularly adept at dealing with such issues; neither do they always have the time to spend supporting the patient and their family.

> *"I think hospital doctors who regularly deal with death get quite complacent with how raw it is for a family, and how they need to explain it to the family so they can understand what is happening to the body."* (Public, Table 4)

In this respect, palliative care specialists, geriatricians, nurses and some GPs were singled out as being particularly skilled in this area and usually having more time to spend providing emotional support than other specialists and surgeons.

Participants who had recently experienced bereavement thought that while **emotional support was often available while the patient was dying, this tended to end abruptly with the patient's death**. In this respect there was a strongly felt desire for a counselling service that met the needs of the family after their loved one's death. While some of the public were aware that such services were available, there appeared to be insufficient coordination between internal (hospital) emotional support services and the wider community services.

> *"Counselling, not just for the patient but for the family...reassurance for you as the patient knowing that they are having the support there while you pass away."* (Public, Table 3)

5.2.8. Financial and legal support

The final area of need that was felt to be important to the public but often completely ignored by current end-of-life care services were those of financial and legal information and support. Given that the public reported thinking little about death and dying it perhaps comes as little surprise that few of the participants across the public events had a will in place, even amongst the older participants. Very few had an advance decision ('living will') in place; less than a handful. While end-of-life care is perhaps rather late to be considering wills and insurance and ensuring that one's family is going to be financially secure, the outcome from the discussions was that people should be encouraged to consider the future more and put plans in place for their family once they had departed. Many suggested that it would be helpful for support to be provided for these issues as part of end-of-life care if this has not been done before.

However, perhaps of greater relevance to the end-of-life care service was the **need to be informed about the various financial benefits that are available from the state** in terms of Personal Independence Payment, Carer's Allowance and Bereavement Benefit for partners and dependent children.

There was also a concern about the potential differences there may be in end-of-life care for private and NHS patients – a sense that NHS patients may well get a poorer form of care.

"My mum and I both fought pretty hard to get her home but to do that they had to have so much support in place, MacMillan nurses coming in, private nurses coming in and she was suffering from bed sores and we were fortunate enough that we had money and she had money that we could use that would pay for those nurses. We were saying what do you do if you don't have that money? Just because someone doesn't have money to pay for those private nurses it doesn't mean that they're not entitled to have the same way to die." (Public, Table 4)

5.3. End-of-life care – recently bereaved participants' perspective and experiences

By discussing their loved one's experiences of end-of-life care, the table 4 participants were able to identify many examples of the ways in which end-of-life care is currently working well (albeit with some omissions) and the ways in which it is currently working less well. As stated above, there was not found to be any clear geographic pattern to this and positive and negative experiences were shared by respondents in all of the event locations. This section provides an overview of these collective experiences.

Where end-of-life care worked well for their loved one, table 4 participants said that it had the following features:

- The patient was treated as an individual and person and not 'as a number' or condition
- Staff treated the person with warmth and kindness
- High quality medical care was delivered 24/7
- Care was provided in a hospice; well-coordinated community setting; or a hospital room that was treated as if it was home
- Pain was well managed
- They were able to live life as normally as possible within the limits of their condition – e.g. being able to read books, listen to music, etc.
- There was open, honest and frequent communication with the patient and their family.

"The hospital staff, the nurses and the doctors, weren't invasive in those last moments. Every time you called them they were there but they weren't knocking on the door or coming in poking and prodding...they didn't intrude on your time." (Public, Table 4)

"They [the hospice staff] looked after him but they also looked after us, his family and that I think was important. It was important for my father's wellbeing, his mental stability as he went through his final days...but his family...that was quite touching." (Public, Table 3)

"I feel that the one area that does EOLC really well is Macmillan nurses, how they care for you. I love the way they treat you at such a voluble time. They sit down with you and explain the process." (Public, Table 4)

Whilst many table 4 respondents had had positive experiences, they reported that the main areas which often remained lacking were:

- A lack of somewhere for the family and loved ones to stay in the hospital / hospice setting
- A lack of emotional support for the family after their loved one's death
- A total lack of any legal or financial information, especially about state benefits.

"When my nan was in a care home, literally the minute she passed away it was almost as if another number off the list of people had just gone and therefore that was it, their role was over." (Public, Table 3)

Figure 14: What end-of-life care currently looks like when it is working well
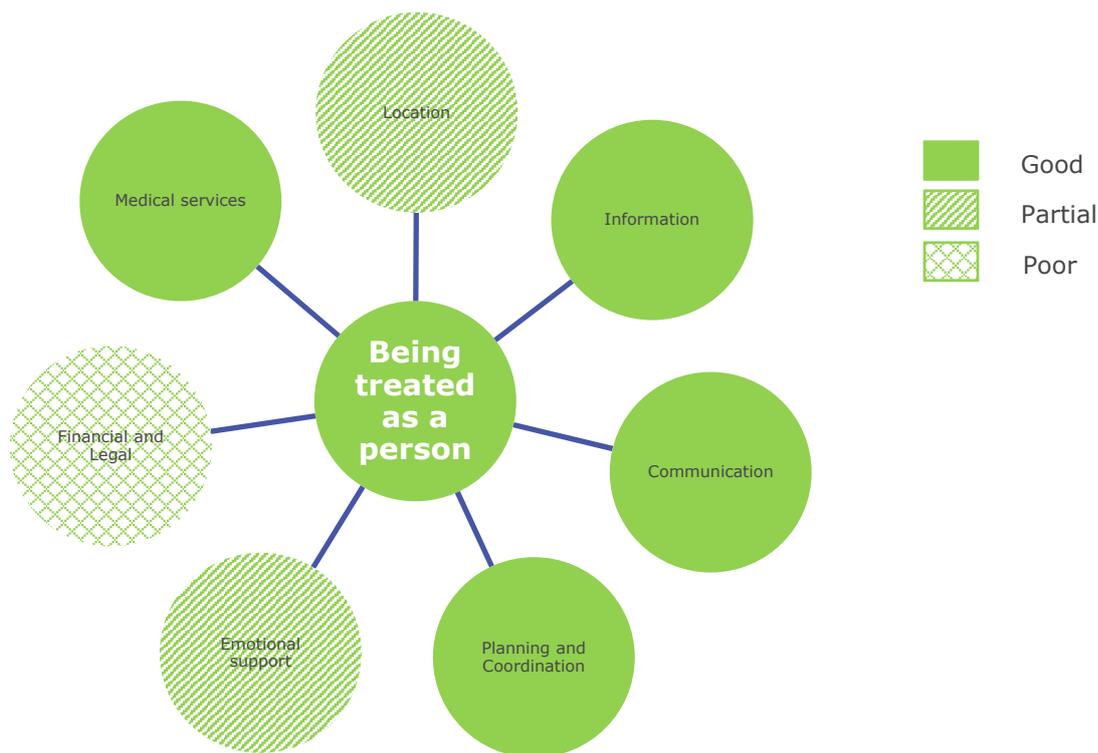
However, end-of-life care experiences were very varied across the country and within hospital authority areas. Where end-of-life care had worked less well for their loved one, Table 4 participants said that it had had the following features:

- The patient was not treated as an individual or person
- There was a lack of warmth on the part of hospital staff
- Medical services were clearly stretched, especially at weekends, with families considering that medical care was not optimum
- The patient was continually moved between wards
- The environment was considered to be bare and unfriendly
- Poor, or non-existent, coordination between the hospital and community services
- A lack of coordination between hospital services, with A&E not knowing the care plan
- A lack of choice over where end-of-life care was provided; especially a lack of hospice beds and / or community services
- Local cottage hospitals lacking 24/7 medical care
- Poor communication on the part of doctors and a perceived lack of openness and transparency about the patient's diagnosis and/or prognosis - for both the patient and the family
- No post-death family support
- No legal or financial information or support.

> *"A few months ago when my mum was in hospital, there was an old lady in the bed next to her. She was obviously…well, she did pass away when mum was in there. She kept calling for help. And I kept going to the nurse and saying 'She wants someone', and they very rarely went to her."* (Public, Table 4)

"We weren't told the state she [mother] would be in once she had been put on the syringe driver, we didn't know she would become unconscious once she went on it and we wouldn't be able to say goodbye." (Public, Table 4)

"It was very very stressful and I had to fight her corner and I'm very proud I did as her main carer." (Public, Table 4)
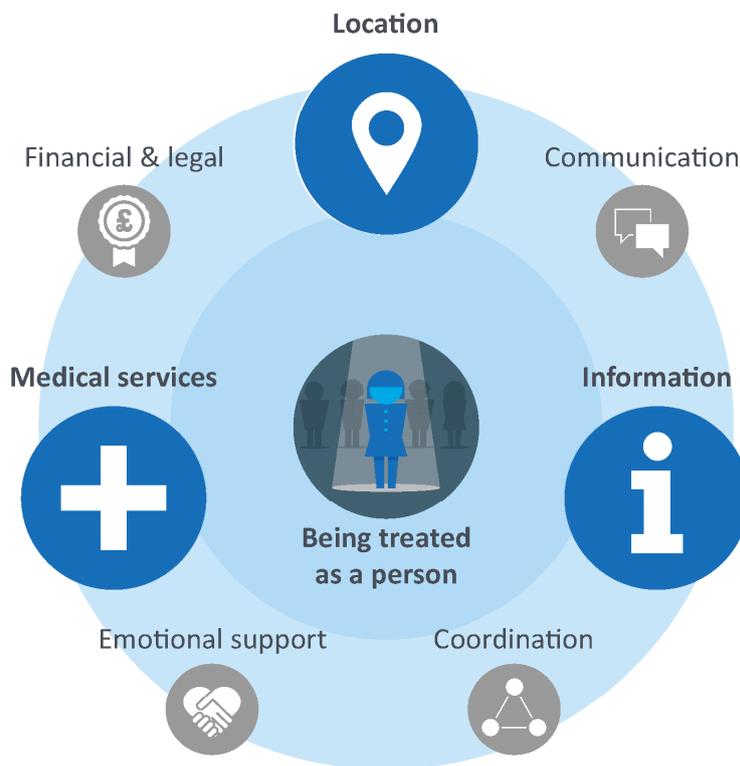
Figure 15: What end-of-life care currently looks like when it is working less well
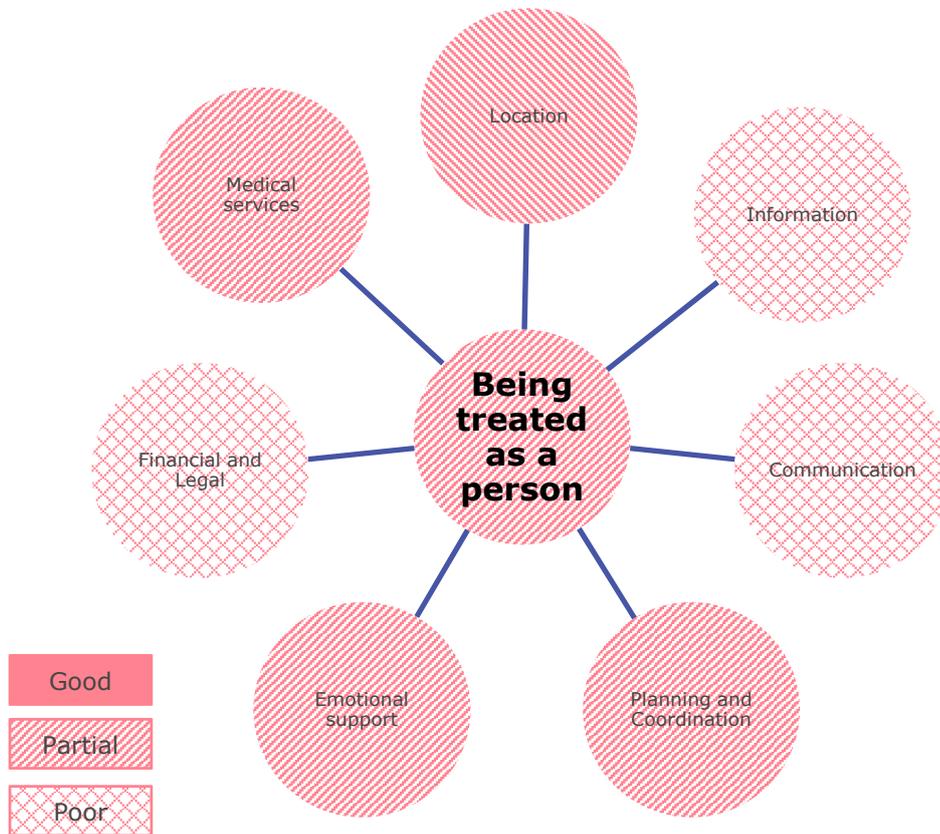
Public and medical attitudes to end of life care and physician assisted dying

What does good end of life care look like for the public?

Location

Financial & legal

Communication

Medical services

Being treated as a person

Information

Those without recent experience of bereavement know little about end of life care.

Emotional support

Coordination

Overall, the public with no experience of a family member or loved one that has received end of life care know little about what it comprises, how to access it, or its overall availability.

They generally have low expectations, except of Macmillan and hospices.

The public would like to see:

COMMUNICATION

About treatment plans, dealing with unexpected events and how treatment is co-ordinated.

This is essential between: patient, hospital medical staff, specialists, GP, community care and the family.

MEDICAL SERVICES

Timely access to: the best medical care, medical services, medications, and equipment.

Effective pain management.

Community facilities to be equivalent to hospital settings.

COORDINATION

Essential for medical care to be co-ordinated between hospital and community with communication between all parties (including GP and A&E).

Desire for electronic plans and a central co-ordinator.

LOCATION

A preference for being at home or in a hospice, rather than in hospital.

But there is a perception of limited availability and recognition being at home may be difficult.

EMOTIONAL SUPPORT

Secular / spiritual support for the patient (last rites where appropriate).

Counselling for patient and family pre-and post-death.

Recognising the emotional needs of the family.

INFORMATION

Medical information, prognosis, and diagnosis provided. But need to recognise what patient wants to know and what patient wants family to know.

Information to be consistent and not conflicting.

FINANCIAL & LEGAL

Help with financial and legal matters.

Peace of mind that family will be financially secure.

Peace of mind that wills, etc. are sorted out.

Help with benefits (when in hospital / community).

Speedy payment of benefits.

These views came from respondents who do and do not have recent experience of bereavement.

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6. Providing end-of-life care

Session 2 for the doctors began by discussing their experiences of end-of-life care and what worked well and less well. The discussion continued by considering four practical issues in relation to providing end-of-life care that were specifically raised by the moderators. These were: predicting how long a patient has to live; assessing mental capacity; confidence in identifying and treating depression; and whether they had any concerns about prescribing appropriate pain relief. Pain relief had often been raised earlier in the discussions spontaneously – and was re-introduced and further discussed here. The other three practical issues had not been raised earlier by doctors and were newly introduced into the discussions at this point. The session came to a conclusion by discussing how doctors feel about discussing end-of-life care and dying with patients.

6.1. Doctors views about what is currently working well and less well in end-of-life care provision

Throughout the discussions with doctors across the ten areas it became apparent that **the provision of end of life was a very mixed picture**. Echoing the experiences of the public that had experienced bereavement, there was no clear pattern of good or poor provision. Indeed, there appeared to be wide variation in provision within and between geographical areas irrespective of whether they were urban or rural areas. Asked why this should be so, doctors felt that this was in part a resourcing issue (both NHS and the availability of hospice care) and in part the nature and composition of the medical team providing end-of-life care.

> *"It just seems to depend on the nurses and doctors – the professionals who are there at the time."*
> (Doctor)
>
> *"I think, for End-of-life care on the whole, for patients who are recognised to be dying, it's good. But for the patients who are dying but no-one's actually worked that out yet, it's much less good."*
> (Doctor)

When discussing end-of-life care with the doctors it was clear that it is not of universal interest or relevance. End-of-life care is of particular concern to palliative specialists and oncologists; some GPs, paediatricians and other medical specialists may also have a specific interest in end-of-life care, but it was not said to be universal. Consequently, the discussion of end of life service provision tended to be discussed more fully by those who were more familiar with organising and providing end-of-life care services.

Doctors identified four key areas that in their view determined whether end-of-life care would best meet the patients' needs: the provision of medical services; the location where end-of-life care services are provided; communication between the doctor and the patient / family; and the way in which end-of-life care is planned and coordinated.

Public and medical attitudes to end of life care and physician assisted dying

Doctors raised four areas of concern about the current provision of end of life and palliative care in the UK

What is currently working less well

There is wide variation between areas, within areas and between urban and rural areas

What is currently working well

Medical services

What is currently working less well
When doctors see EOLC as a failure

Starting end of life care too late

Mental health, COPD and dementia care

What is currently working well
Early planning of end of life care

In hospital pain management

Cancer care

Location

What is currently working less well
OOH hospital care

24/7 community care

Hospice availability

Availability of district nurses

Community pain management

Direct access to hospital

What is currently working well
Hospices provide the 'gold standard' of care

24/7 hospital care (in some areas)

Macmillan nursing

Communication

What is currently working less well
When doctors are not confident in discussions

When patients do not accept their diagnosis

When family relationships are poor

What is currently working well
When doctors are confident in discussing diagnosis, prognosis and end of life care

When relationships between the patient and family and/or family and doctors are good

Coordination

What is currently working less well
When it is assumed that co-ordination is happening

When it is assumed that the palliative team will engage other specialists (e.g. secular / spiritual)

What is currently working well
Identifiable and accountable co-ordination

Hospital, GP, community health and social services co-ordination (in some areas)

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6.1.1. Medical services

There was a generally held view that patients who were dying from cancer received better medical care because of the way in which cancer services were organised in hospitals. By contrast, doctors thought that COPD patients, the elderly and frail without a specific diagnosis, and those with either dementia or where there were additional complications of mental health issues generally fared less well in terms of end-of-life care.

> *"I think if you're identified, [local EOL provider] is really good. We've got a great local hospice, a really proactive patient care team, we've got a palliative care team, you get a number, you call up you get advice, there's a team of community care nurses who come out…it's just getting identified."* (Doctor)

> *"If you've got a diagnosis of metastatic cancer, you get referred to palliative care and the chances are your care will be pretty good. But if you're elderly with a non-specific diagnosis…if you're frail with dementia, in and out of hospital…then I think your palliative care needs are much less likely to be met."* (Doctor)

In part this was said to be due to the way in which services were organised in hospitals and in part the recognition that a patient was terminal. In some instances, doctors said that **due to a lack of coordination or a single person responsible for a patient, the planning of end-of-life care could come too late to organise sufficient end-of-life services**. It was also suggested that recognising when end-of-life care was required varied by specialism and therefore tended to determine when and how care was planned. Typically, palliative specialists, oncologists and geriatricians were considered to be more likely to recognise the need for early planning of end-of-life care, whereas, surgeons less so primarily because they have less contact with the patient and tend to be focussed on treating one aspect of the patient's overall condition.

> *"…when I started my medical training and started my first job which was a care of the elderly job, the first time a patient died I thought I had failed, because they had died. No, no, no, I didn't fail because they died but because I didn't recognise they were dying!"* (Doctor)

6.1.2. Where end-of-life care services are located

Doctors were almost unanimous in their view that the best end-of-life care is provided by hospices as this is what they are designed to do – they provide a homely environment in which medical care and other support services are available around the clock. Community care was also thought to work extremely well for terminally ill patients, but only where the District Nursing services have sufficient resource and are well coordinated. Some doctors also identified specific hospitals that were notable for their ability to provide excellent quality end-of-life care; these were usually noted for their palliative care and oncology specialisms.

However, doctors felt that **the considerable variation in the quality of end-of-life care across the country was reflective of the lack of hospice beds in some areas, poorly resourced and coordinated community services** including the paucity of District Nurses and out-of-hours hospital care where the hospital has limited palliative and oncology support.

> *"If a person is alone, someone mentioned lonely people, it's our experience that they don't die at home. There isn't the care available to look after them. You don't need doctors and palliative care consultants, you need carers to be there to hold their hand and take....a mini crisis and to get the right people in in the middle of the night to provide the right care....the default method is to bounce them into hospital and tragically they end up spending the rest of their short life there."* (Doctor)

Community care was considered to be highly variable across the country. Three specific issues were raised that give rise to poor end-of-life care: the lack of communication about a patient's condition and medications between the treating hospital, the community and A&E services; an inability to directly access relevant hospital services without going via A&E; and community pain management (discussed further in section 6.4.4).

Most of the discussions concerned adult end-of-life care. However, there was some mention, especially among paediatricians of the lack of end-of-life care services for children and their families, especially for conditions that were not cancer-related.

6.1.3. Communication between doctors, the patient and their family

As discussed in the previous chapter, the public participants that had experienced bereavement were often critical of the way in which a patient's diagnosis and prognosis were discussed.

Doctors recognised that **communication between them, the patient and the family could be critical in making end of life easier to understand and accept**. However, such conversations can be very difficult because of the nature of the medical options available.

> *"Options are either very intensive or nothing, and going from treating very aggressively to deciding to stop that and palliate them instead (which means they will die very quickly) is a really difficult decision to call, and it's really difficult to have those conversations with patients because it's such a stark situation, where actually they're nearly suffocating at the moment, and the choice is, do you want me to prolong your life by sticking a mask on your face and forcing air down your lungs…it's a very short lead time to make that decision." (Doctor)*

They also recognised that **not all doctors are confident in discussing such issues with the patient, even those who have many years of medical experience**. Typically, doctors thought that palliative specialists, oncologists and GPs tended to be much better at discussing difficult issues with the patient and their family although many other specialisms could be equally as proficient, depending on their personality, training and experience of dealing with patients that are dying. In this respect the medical students attending the sessions said that there was little training in this area; their expectation was that they would learn on the job, either by watching more experienced doctors or '*being thrown in the deep end*'.

> *"We should say, 'You are coming to the end your life'. I think that is where we are failing patients. We are not preparing them. We are not even mentioning the word…So it all comes as a huge surprise…We should be far more frank."* (Doctor)

However, communication difficulties were not the sole problem of doctors. Doctors indicated that communicating about dying and end-of-life care became much more difficult when the patient does not want to know about their diagnosis or their prognosis, or where the relationship between the patient and the family is poor and the doctor finds that they are in the middle of a dysfunctional family relationship.

6.1.4. Coordination of services

The doctors in the dialogue sessions agreed that for end-of-life care to meet patient needs, it needs to be very well coordinated, irrespective of whether the patient was in hospital or living in the community; community coordination was generally much more challenging.

> *"We don't have the Liverpool Care Pathway anymore but we have this End-of-life care Plan and it makes you go through the different things needed, and it prompts you as you bring it up…it helps you to address things a little bit."* (Doctor)

Coordination was also said to be very variable across the country.

"Some patients seem to have a very good outcome. If they've got into the right sort of system – they have the right sort of cancer, the right specialist nurse that they've dealt with, the right access points then they seem to be fast tracked into the hospice and so on. Other people haven't had so much good experience, really." (Doctor)

Where coordination of services worked well it involved the hospital, GP, District Nurses and Social Services and had an identifiable and accountable coordinator. Where it **worked less well was where coordination was 'assumed'**, either that the palliative care team would coordinate services, or there was a general assumption that the hospital would coordinate services.

"It's the communication between professionals which is done really badly, particularly between primary care and secondary care. It's so difficult for doctors to speak to each other. For consultants to speak to each other in hospital is difficult enough. It's even more difficult for a GP to talk with a consultant, even if they're treating the same patient. There's not time. But it probably could be quite easily fixed, if there were communication channels." (Doctor)

6.2. Do end-of-life care services meet patients' needs?

Perhaps not surprisingly, doctors consider that their primary professional role in relation to end-of-life care is:

- Providing medical treatment
- Palliation
- Management of pain and other symptoms
- Mental health care (primarily psychiatrists)
- Coordinating end-of-life care.

Nevertheless, there was thought to have been a shift within the medical profession to recognising more of the holistic needs that a patient has at end of life.

"...It was good to see there was a kind of brain shift in medicine from treating physical symptoms the aim, to getting us thinking about what is a good death, what does a patient want? Their spiritual and emotional wellbeing is also important, as well as their pain and suffering. I think that's a good shift." (Doctor)

While they recognise that patients are likely to have a range of other needs – psycho-social, spiritual, financial, housing, etc. – these are very secondary to their role and are usually only addressed by doctors if they have the specialist knowledge, the time and an interest in doing so. However, it was also clear that some doctors go out of their way to assist patients with issues that are not medical in nature, mainly because doctors found it very difficult to find an individual or a service that could assist patients with their non-medical needs. There was a general assumption by doctors that others would assist patients with their non-medical needs – nurses (hospital and district), chaplaincy, Macmillan nurses and community resources – although they did not necessarily put the links in place for these resources to be made available to patients.

As discussed in the previous chapter, patients nearing the end of their life have a wide range of needs. Doctors do not expect to deal with these, although there was some indication that some patients can be very demanding and expect doctors to deal with the complete range of issues, medical and non-medical, that affect them. The public thought that this was quite unrealistic and not within a doctor's remit. Nevertheless, the public too recognised from their own experiences that sometimes the only person a patient has to talk to about a range of issues is the doctor – with the corresponding expectation that the doctor will address them.

Overall, while terminally ill patients have a wide range of needs, both the doctors and the public generally consider that the doctor's remit is to ensure that all aspects of the patient's health care is managed well, irrespective of whether it is hospital or community based. While some palliative specialists did say that they had good links with other organisations that would look after the non-medical aspects of care, the general conclusion was that its provision can be very hit and miss.

> *"There is a massive gap in social care across the board, funding for personal care has just crashed over the last few years. They try and prioritise patients that are palliative, but still some of them fall through the cracks." (Doctor)*

6.3. Discussing dying and end-of-life care with terminally ill patients

Without exception, **doctors did not find it easy to discuss dying and death with their patients**. It was said to be *'always distressing, but it can be rewarding and a privilege'*. This was especially so where there has been a long-standing relationship between a doctor and a patient (often a GP) and the doctor has reached a point where discussing sensitive issues and difficult diagnoses has become more frequent, less doctor–patient and more like a discussion between friends.

> *"If it's a patient I've got a reasonable rapport with, I'm quite happy to do it, and my team and colleagues, because it's something we're practiced at and we feel that it needs to be done."* (Doctor)

Very **few doctors said that they had had any training in discussing sensitive issues with patients** and that the usual way of learning was to observe and then learn on the job, with confidence growing over time. For some doctors these types of discussions were said to be a cause of major anxiety and one where training was called for.

> *"I found it very difficult to talk to patients about dying, prior to working in a hospice, because one, as a junior doctor, we're not taught very much, and two, those kinds of complex conversations we leave to the senior consultants because they have more experience."* (Doctor)

However, the doctors participating in the dialogues also felt that **not every doctor felt confident in talking about dying or had the innate skills to manage such conversations** – personality and sensitivity were key, as was the need for quality time and privacy to have such conversations.

> *"Some consultants won't tell the patient (he or she is terminally ill), partly because they're afraid what the patient's reaction will be…(the patient) will come home, they've been to outpatients or whatever, then they come to us, and say 'What exactly is wrong with me, doctor?"* (Doctor)

GP surgeries and community settings were felt to be more appropriate settings than acute hospital settings, where this was possible.

Even the most experienced doctors indicated that end of life conversations did not necessarily go to plan; they depended on how the patient and family reacted to the discussion and whether there was an expectation that the patient was going to recover or not.

6.4. Challenges in providing end-of-life care

As part of the discussion with doctors, four potential challenges in providing end-of-life care were raised and discussed. These were: predicting how long a patient has to live; the ability to assess mental capacity at end of life; identifying and treating depression; and pain management, which had often been raised spontaneously already. These are discussed in turn below.

6.4.1. Predicting how long a patient has to live

As discussed earlier, the public place considerable trust in doctors – and this extends to doctors being able to predict how long they have to live. Doctors said that **when given a terminal diagnosis patients virtually always ask how long they have to live**.

While some conditions have a *'trajectory of decline'* (such as cancer in the later stages), others such as COPD are much less predictable. Even so, doctors said that it is almost impossible to accurately predict life expectancy after a terminal diagnosis unless death is a few hours, or at most, a few days away.

However, patients want to know how long they have to live and doctors generally feel obligated to give an answer. Their approach is to provide a prognosis in blocks of time, such as *'three to six months'*, *'less than a year'*, *' a few weeks'*, etc.

> *"I generally talk in terms of days, weeks, months. Months are more difficult. Towards the end it becomes easier because patients are not eating, they're not drinking, not walking..."* (Doctor)

Even so, **doctors felt that even hazarding a guess at life expectancy could potentially undermine the trust that patients have in their doctors**:

> *"There's such a danger in giving an exact answer isn't there 'cos then you're beholden to it. If you say three months and it isn't three months then you're in trouble either way. Everyone's furious..."* (Doctor)

> *'It's not an exact science or even a science at all'.* (Doctor)

> *"Some physicians are very good at recognising that it's coming to the end of a patient's journey, and that involves alerting the team early, making them aware…Others, it's only when it's the last day or so, hours. It's more rushed. The journey is very quick, and it's not doing the patients justice."* (Doctor)

6.4.2. Assessing mental capacity

Mental capacity proved to be a topic where doctors were highly polarised in whether it was possible to assess the mental capacity of some terminally ill patients. On the one hand there were those who said that there are procedures that exist that clearly lay down how to measure mental capacity. On the other hand, some doctors said that as mental capacity can fluctuate by the day or even by the hour, or by the treatments being given, then assessing mental capacity was fraught with difficulties and open to wide interpretation but they would do so by observing the patient over a period of time.

> *"[Mental capacity] is assessed very informally. Unless we have an issue with a capacity decision, in which case we make a formal assessment, I will generally have made my decision based on my observation."* (Doctor)

> *"It's not an absolute thing. One day they might have capacity to make decisions about some things and the next day they might not have capacity to make decisions about anything."* (Doctor)

The doctors in the dialogues also indicated that the **ability to assess mental capacity was not an exact science** and that it was very dependent on knowledge, experience and confidence in making such assessments. Such skills were also likely to vary by specialism and grade depending on how much contact a doctor has with patients at the end of their lives. Social services, geriatricians and psychologists were said to be the most likely to have expertise in this area.

The whole **process of mental capacity assessment was also questioned** by some of the doctors. Some doctors seemed unaware that there needs to be different types of assessment carried out for

different decisions, when they questioned whether 'the' assessment was appropriate for a range of different decisions.

> *"Medical profession and allied professions seriously misunderstand the concept of the assessment of mental capacity and it's not done properly."* (Doctor)

> *"We're pretty good at assessing capacity on someone who says 'no' (to treatment), but we're not good at asking what they want." (Doctor)*

Language and cultural issues were also mentioned as complicating the assessment of mental capacity, as were diagnoses of mental health issues and dementia.

Despite the complications raised there was a general view that there was now better training for assessing mental capacity although this had not necessarily dealt with all the issues that doctors were raising about mental capacity assessments.

6.4.3. Identifying and treating depression

Until prompted, the issue of **depression at end of life was not well recognised** by the doctors in the dialogues. Where the subject of depression was considered it was normally considered to be the remit of psychologists, as doctors – even very experienced palliative specialists – found it difficult to identify depression.

> *"Simple depression is in some ways easy. People who are dying come with lots of complex psychological issues that happen, or from their terminal illness so patients can be very complex and it's not just about depression because of their diagnosis, it's about the other stuff that's going on in their life."* (Doctor)

However, there was also a concern that at end of life the patient is going through a whole set of new experiences, many of which were likely to make the patient feel sad. Doctors were concerned that there was a **risk of medicalising normal sadness**. This led to a discussion about the treatment of depression which can be lengthy and a further concern about the continual treatment of symptoms when palliative care may be more appropriate.

> *"What's depression and what's just appropriate sadness … there's plenty to make them sad."* *(Doctor)*

> *"You have to think 'Is it useful to make the diagnosis for the patient?', in the context that we are thinking of, which is end of life? To start thinking about depression, and treating depression, that is a long arc, in terms of seeing any benefit from that. So I don't think it's very relevant."* (Doctor)

> *"But what are you going to do? Put someone on anti-depressants at the end of their life because they're not very happy about dying?"* (Doctor)

6.4.4. Pain management

As discussed earlier the public were particularly concerned about the management of pain. From the doctor's perspective pain could be well managed although not always completely eliminated.

> *"What I've always told my patients is I can't cure your pain but I can make it better. You don't give them an expectation you can't fulfil...."* (Doctor)

Of more concern was the confidence of others in the administration of pain relief, particularly junior doctors and nurses in hospital settings and district nurses in the community setting. Their concern was

not about the ability of medical professionals to administer pain relief but worries about their practices in the light of media coverage of the Shipman case about the use of opioids to hasten death.

> *"I feel like Shipman is like a spectre that hangs over me".* (Doctor)

Some of the doctors were aware that because of these fears **patients could be given less pain relief than their condition required**.

> *"There's a problem of doses in the sense that…one of the issues I find is there's a reluctance on the part of the team looking after patients to push the doses, to palliate patients enough, because they're all frightened they'll die within an hour of the dose...I think there's a lot of pussyfooting around with dosing...."* (Doctor)

7. The potential impact of legalisation of physician-assisted dying on doctor-patient relationships

In the third and final session, the public and doctors were invited to discuss their views on the potential impact of legalisation of physician-assisted dying on doctor-patient relationships. It is important to note that participants were told that the discussions were to be focussed on the potential impact on doctor-patient relationships and not on the pro's and con's or whether or not physician-assisted dying should be legalised.

The session explored the public's and doctors' views about what, if any, impact legalisation would have on doctor-patient relationships and on society's perception of doctors more generally. Participants were also asked to consider what impact three options for deciding eligibility for physician-assisted dying could have on the relationship. The doctors were also asked to consider whether there would be any professional and/or emotional impact on doctors themselves of involvement in the process.

During this session, participants were asked to imagine a hypothetical scenario in which physician-assisted dying had been legalised for people who requested it and met certain criteria; those who have a terminal or severely life-limiting condition and who are able to make an informed choice (those who have capacity to make the decision and are acting voluntarily). Participants were asked to consider the discussion topics posed within this scenario.

Stimulus was provided to give participants background information. During the doctors' sessions, views from the public session in the morning in their location were fed in and they were given the opportunity to comment on these with the caveat that these were top-line views from one table at one event.

7.1. Reactions to the background information provided

Stimulus materials were provided to enable a more informed debate. A definition of physician-assisted dying and background information was provided and the public and doctors discussed their reactions to this. This information can be found in the appendix. The same definition of physician-assisted dying, background information and information about the role of judges in medical cases was given to the doctors and public[6].

Many of the participants, public and medical, expressed **emotional reactions** to the background information presented. Most of the public, and many of the doctors, were surprised and said that they were **not aware** of much of the information. In particular, across most of the tables, most of the public and a number of doctors reported that they were **surprised** that it is possible for complications to occur during physician-assisted dying and many were **shocked and surprised** that it can fail and by the

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[6] The doctors were additionally given information about the legislative and policy context in the UK.

length of time that it can take. Participants often focussed on the information from Oregon and were shocked that physician-assisted dying took up to 104 hours in one case.

Public participants had assumed it would be quicker, peaceful, and would not involve complications or fail. Public and medical participants were also often surprised that physician-assisted dying is legal in some states in the USA and were less aware of this than of places where it is legal in Europe.

> '"It's not black and white is it – wow – I didn't know all that at all – I just thought you got tablets or a lethal injection and you just die in the night, it all sounded nice and calm.....and you come up with this thing, 104 hours to die, some haven't died....' (Public, Table 3)

Some public and medical participants were surprised by the method and that barbiturates need to be swallowed. Some were surprised by the time physician-assisted dying has been legal for. Some tables also discussed the meaning of the term 'unbearable', what conditions would be included, how this would be employed in practice and that this term is open to interpretation.

Figure 16: Public and medical reactions to the background information provided

Public	Public & doctors	Doctors
• **Often shocked and discouraged** • **Many unaware of much of the information**	• **Surprise at complications** • **Shock at length of time** • **Surprised legal in the US**	
• Surprised method is tablets rather than injection • Surprised dementia is ruled out	• Surprised about method	• Concern around depression and non terminal conditions • Concern about capacity issues • Discuss what happens when a patient doesn't die
• Query what happens if 2 doctors disagree	• The time it has been legal for • Discussion around the term 'unbearable'	• Surprised the doctor is required to stay with the patient • Surprised there aren't more complications

7.1.1. Public reactions to the background material

The public were often discouraged by the information presented, and were less aware of the information than the doctors with many saying they were unaware of much of it. They were often surprised by the method, assuming an injection would be given. Some public participants said that they assumed physician-assisted dying would be similar to having a pet 'put to sleep' by a vet. A small number of participants were surprised that dementia would be ruled out under the criteria described and some discussed what would happen if doctors disagreed with each other about whether someone was eligible.

> "I don't think there's a lot of information about it at the moment…You get hung up on the rights, wrongs the morality of it. This is about the nuts and bolts…It's unlawful, so there's not an awful lot of information out." (Public, Table 2)

> *"I just assumed that if you went to get this done for yourself it would be quick and fast, like a lethal injection."* (Public, Table 3)

> *"It sounds a bit strange but I had my dog put to sleep, and the vet gave her the injection and she was away, and I just expected that to be the same … she just went to sleep".* (Public, Table 3)

7.1.2. Doctors' reactions to the background material

Many of the doctors were also surprised by some of the information about complications and length of time. Some of the doctors discussed concerns about identifying depression among those requesting physician-assisted dying and around non-terminal conditions. Some were also concerned about assessing capacity to make the decision to apply for assisted dying. Some also questioned what happens when a patient does not die due to complications.

A small number expressed surprise that a doctor could be required to stay with the patient (although many did not raise this concern). In one location some doctors were surprised that there are not more complications.

> *"I'm not sure if I could go into work and do what I currently do if part of it was having to sit with someone for 104 hours waiting for their barbiturates to kill them…so then if that became law does that mean that I can't do my job properly because I would find that too difficult?"* (Doctor)

7.2. The public's views on the impact on doctor-patient relationships

The public were asked to imagine what the impact would be on doctor-patient relationships. Many of the respondents **struggled to articulate** their views on this, often because it is something they had never discussed or even thought about before the workshop. Therefore the views given were **emergent** and often evolved and developed continuously during the discussions.

A small minority of respondents held a strong view but overall individuals, tables and the public events gave **a largely balanced range of potential positive and negative impacts** on the relationship. As was found in the first session, for most people trust in doctors is high and the default position is there to be lost. During these discussions, respondents often spontaneously expressed concern for doctors who would be involved in this process and for the emotional impact it could have on them.

> *"It's not opinion-based as to whether they should do it, it's purely medical…He's either doing his job by diagnosing it with the right medical information or he's not involved in it, in both cases they're just doing their job."* (Public, Table 4)

> *"Wouldn't it be hard for the doctors? They're supposed to save lives not end lives. Then they might feel awkward with the family, with the same doctor, next time you were seeing them and they were just talking with you…"* (Public, Table 3)

Whilst a largely balanced range of views was given, many tables discussed a number of **conditions** which respondents reported could affect whether and how doctor-patient relationships would be affected. Whether the impact was more positive or negative would depend on **how the process was designed, who was involved and whether there was seen to be financial motivations**.

The public had a number of concerns about the **process** which would be in place to decide eligibility and carry out physician-assisted dying and these would impact on their relationships with doctors. The impact would depend on:

- whether people were confident the decision to apply for assisted dying was the individual's

- that people were not being coerced

- that the decision was not being made by doctors. A number thought that it would be better for the relationship if the patient had to raise the topic rather than the doctor

- whether there were adequate safeguards in place, particularly for those who might see themselves as a burden to their loved ones

- whether physician-assisted dying is seen as an alternative to good end-of-life care

- whether the doctor has time to get to know you.

Often the public tended to distrust the 'system' rather than doctors themselves.

> *"It would depend on what the process was and the safeguards … it would only change my relationship if somebody else was able to make that decision against my wishes. If somebody else was trying to bump me off, basically. But if I was confident that it could only happen, on my words, then it wouldn't affect it."* (Public, Table 3)

> *"If a doctor ever gave it to me as an option, I would be extremely offended.*" (Public, Table 4)

Many respondents also discussed the impact of **who would be involved in the process**. The impact on doctor-patient relationships would be strongly affected by whether physician-assisted dying was conducted or not by specialists and a separate branch of medicine and how this would be connected and relate to the rest of the profession. The impact on doctor-patient relationships would be very different if the eligibility process and physician-assisted dying was carried out by GPs and staff in hospitals, compared with if it was done by specialists in separate centres – and respondents often mentioned Dignitas clinics in this context. Whether and how other doctors would feed into the process was also important if it was a separate branch of medicine. If GPs had no involvement in the process then these relationships would not be affected. The public often discussed how involved GPs would be, and this is important for impact because GPs are usually the first point of contact for services for most people.

A number of respondents also mentioned that their relationships with doctors would be affected depending on whether assisted dying was linked with **financial motivations** and profit-led (for those involved), or linked to resourcing and cost savings (e.g. freeing up beds). Some respondents mentioned that they trust the NHS more than commercial providers.

> *"Would a doctor become an advocate because of the practice budget, in terms of 'we're going to support this person for 6 months, 9 months of the dying process, these drugs and ongoing care, whereas if we go with this option of assisted dying then actually the cost to my practice is substantially less..."* (Public, Table 3)

It is also important to note the **range** of doctor-patient relationships which currently exist. As described, many people have a high level of trust in doctors, but a range of relationships are experienced in terms of quality and intensity. Some respondents noted that their relationship with their doctor (by which they usually meant their GP) would not be affected if they did not feel they currently have a relationship anyway, and a range of factors are important in shaping doctor-patient relationships.

> *"If you have a good relationship with your doctor you would trust them to do the right thing"* (Public, Table 4)

7.2.1. Potential positive impacts

The public suggested three key ways in which physician-assisted dying could have a positive impact on doctor-patient relationships: it could mean doctors are **more able to provide a 'good' death, choice and improve communication**.

Physician-assisted dying could mean that doctors are more able to help people and relieve pain and suffering. It could enable doctors to help people maintain control and dignity at the end of their life, particularly for those who do not want family members and loved ones to see them in what they perceive to be undignified situations. Related to these two points, many respondents referred to physician-assisted dying as being able to improve **quality of life at the end of life** and that this would positively impact the doctor-patient relationship if doctors were able to provide this. Respondents described it as being more peaceful, pain-free and humane.

> *"If I had had the choice with my husband, I would have said yes, because he was suffering for nine years, he was 15 stone and then 3.5 stone when he died, so when you see that you would pick and talk to your doctor. I would have kissed and hugged my doctor, because he helped with my husband's suffering and mine"* (Public, Table 1)

> *"You're in bits, you're so upset and you know they are going to die anyway and you just want to give them a bit of rest"* (Public, Table 1)

Some respondents also reported that assisted dying would impact positively on the relationship because doctors would be more able to provide **choice** to patients who wished to apply for it. The public saw this as being another service available to patients for them to choose; if it was legally available doctors would be better able to answer some peoples' wishes, particularly those who wish to refuse other treatment options.

> *"It's another option they're offering you, in a way. It's another bit of support that you might want to consider. I don't think that would affect the relationship with your doctor."* (Public, Table 2)

> *"It would increase trust in your doctor. It's a matter of control, and if it was legal you would know the doctor could give whatever care you want, it would be more comforting knowing that you're completely in control."* (Public, Table 4)

Some respondents discussed how legalisation could improve **communication** between doctors and patients because there would be more openness about end of life plans and wishes. Respondents in one location also said that it would remove the 'grey area' around pain medication and overdoses.

7.2.2. Potential negative impacts

The public also raised a number of potential negative impacts on the relationship; assisted dying could **increase fear of doctors and hospitals, cause conflict, damage doctors' relationships with families, and change their role**. Individual respondents often held both positive and negative views.

The most frequently mentioned concern was that physician-assisted dying could **increase fear of doctors and hospitals**. This could damage the relationship and mean that people may be too afraid to go to the doctor or hospital when they need treatment, or that they may not share as much information or alter information they give to a doctor when they do go. Respondents were concerned that people may fear hospitals and hospices in particular.

> *"If they were diagnosed with an illness, they might be a bit more wary of their doctors…they might feel negatively towards their doctors because that's not an option they want to take."* (Public, Table 1)

Respondents did not tend to spontaneously raise sub-groups of concern. However, when they were prompted to think about whether physician-assisted dying would have an impact on any particular groups then they often mentioned the **elderly, frail, disabled and vulnerable and others who might be vulnerable to coercion**. They also mentioned dementia patients, those with depression, religious groups, those who are opposed to physician-assisted dying, and those who see themselves as a burden to their family and loved ones. The public was also concerned about those without mental capacity who they feared might be persuaded to apply by doctors. This is opposed to the high level of trust the public usually reported having in doctors. Participants in one location were concerned that patients could be put on 'a conveyor belt' to physician-assisted dying.

> *"I think the elderly definitely because you tend to feel you don't have such a big say in what's going on anyway...you look at what elderly care is and the standard of elderly care is and it's frightening and after a certain age you can't get certain treatment for certain illnesses..."* (Public, Table 4)

Members of the public were also concerned that assisted dying could cause **greater conflict** between doctors and patients, in particular if a patient is refused eligibility or if a doctor opts out of being involved in the process. Respondents in one location suggested it could lead to patients 'shopping around' to find doctors who share their view on this topic. Some respondents were also concerned that legalisation could mean doctors would be less willing to build relationships with patients.

> *"For the patient who wants assisted dying, and the doctor says either I don't think you fit the criteria, or I cannot participate – that would have a huge impact on that relationship. Another potentially disastrous impact [is that on the] relationship with family, where someone is seeking assisted dying and you can agree, but the family has objections. Horrendous situation, who knows what the way forwards is."* (Public, Table 4)

Concerns were also raised about doctors' **relationships with family members**, which were seen to be crucial in the end-of-life care session. A doctor's relationship with the family could be affected if family members disagree with either the patient's wishes or the doctor's recommendations. The relationship could be affected during end-of-life care and the physician-assisted dying process, or after the death of the patient if the family member later perceives the wrong decision to have been made either way.

> *"I do think doctors would be penalised, especially by other family members and friends who didn't want it done. They'll just blame them, for their hurting, and how do you deal with that?"* (Public, Table 1)

The public expressed concern that the legalisation of assisted dying could change the **fundamental role** of doctors and that this could impact on relationships with them. The language the public used here was illustrative of their fears. Respondents were concerned about creating "Dr Death" and doctors "killing" patients, which is not what the public currently associate with doctors, who should work to sustain and preserve life. This could cause fear and concern among the public about the role and purpose of doctors and mean that the relationship is no longer seen as caring and compassionate.
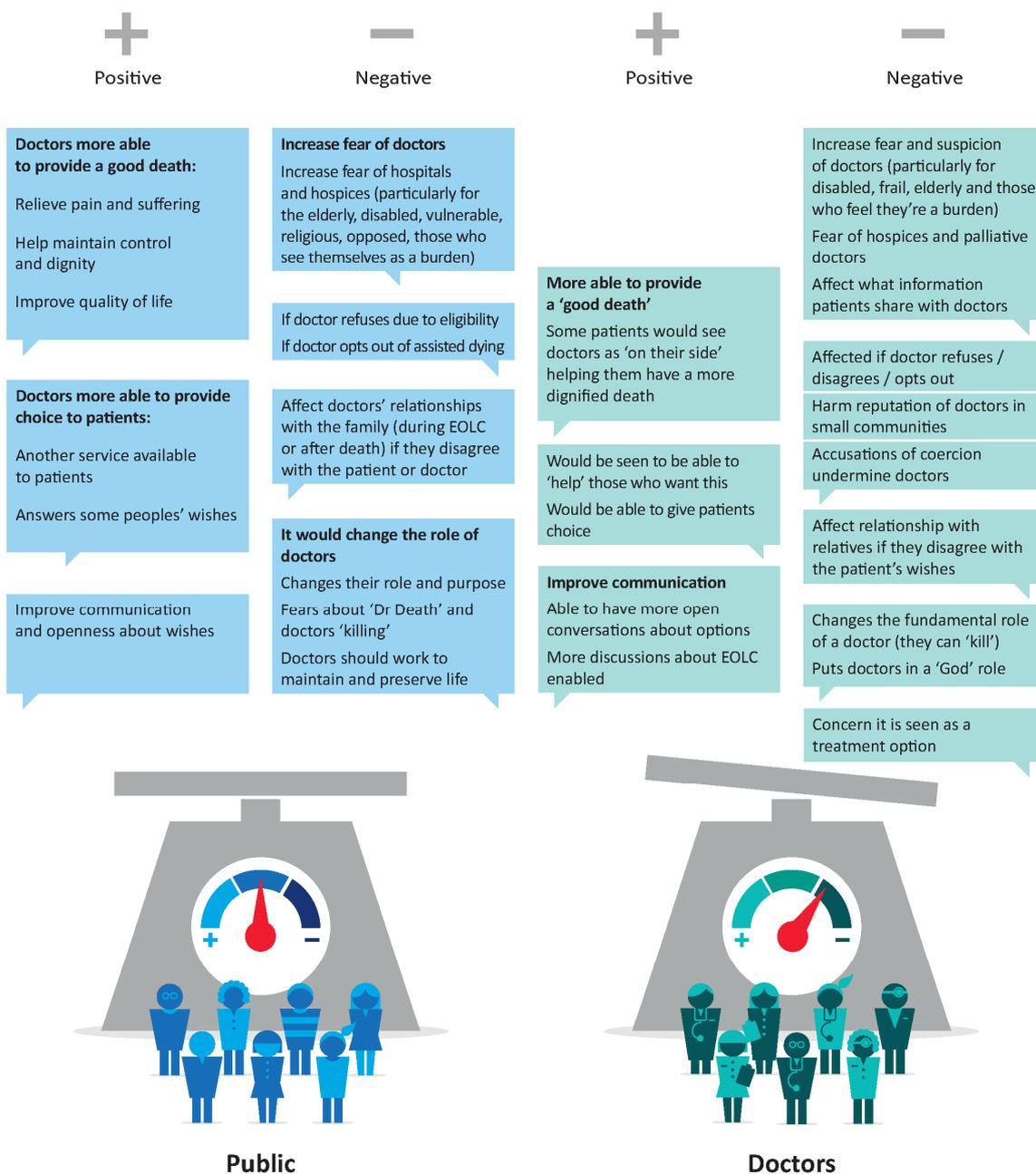
> *"If a doctor saved my daughter's life and then I was having another conversation with a doctor about ending my ill husband's life ... I really don't see how I could do that"* (Public, Table 4)

"Currently you have that barrier that it's illegal and I think it needs to stay that way cos once you lift that barrier you will be looking at your doctor in a different way cos he, she have got the power to put you down." (Public, Table 1)

Public and medical attitudes to end of life care and physician assisted dying

The impact of the legalisation of physician assisted dying on doctor-patient relationships

+ Positive	**−** Negative	**+** Positive	**−** Negative

Doctors more able to provide a good death:

Relieve pain and suffering

Help maintain control and dignity

Improve quality of life

Increase fear of doctors

Increase fear of hospitals and hospices (particularly for the elderly, disabled, vulnerable, religious, opposed, those who see themselves as a burden)

If doctor refuses due to eligibility
If doctor opts out of assisted dying

More able to provide a 'good death'

Some patients would see doctors as 'on their side' helping them have a more dignified death

Would be seen to be able to 'help' those who want this
Would be able to give patients choice

Increase fear and suspicion of doctors (particularly for disabled, frail, elderly and those who feel they're a burden)

Fear of hospices and palliative doctors

Affect what information patients share with doctors

Affected if doctor refuses / disagrees / opts out

Harm reputation of doctors in small communities

Accusations of coercion undermine doctors

Doctors more able to provide choice to patients:

Another service available to patients

Answers some peoples' wishes

Affect doctors' relationships with the family (during EOLC or after death) if they disagree with the patient or doctor

It would change the role of doctors

Changes their role and purpose
Fears about 'Dr Death' and doctors 'killing'
Doctors should work to maintain and preserve life

Improve communication

Able to have more open conversations about options
More discussions about EOLC enabled

Affect relationship with relatives if they disagree with the patient's wishes

Changes the fundamental role of a doctor (they can 'kill')
Puts doctors in a 'God' role

Improve communication and openness about wishes

Concern it is seen as a treatment option

Public

Doctors

BMA

7.3. Doctors' views on the impact on doctor-patient relationships

7.3.1. Comparison with the public's views

The doctors were asked to imagine the same scenario and within this, what they thought the impact would be on doctor-patient relationships. Doctors' responses were strongly shaped in this discussion by their wider views on physician-assisted dying and whether or not it should be legalised. Doctors often found it difficult to separate their views of the impact on doctor-patient relationships from their wider views on the subject, notably at the event at the BMA ARM in Liverpool. This meant that the views and debates on the tables were often polarised as doctors were more likely than the public to come with pre-formed opinions. However there were some tables across the events where participants held less strong views and these debates displayed a more emergent character similar to the public events.

Overall, doctors tended to be **more negative and have greater fear about the potential impact of physician-assisted dying on doctor-patient relationships than the public**. Views were mixed across all grades and types of doctors (including palliative doctors, GPs and anaesthetists) and it was not found that particular levels of seniority or particular specialisms were notably more positive or negative than others. There was a strong sense that many doctors did not see physician-assisted dying as part of their **role or remit**.

Like the public, many doctors discussed the **conditions** which they thought could affect how doctor-patient relationships would be affected. These conditions were similar to those raised by the public. Whether the impact was more positive or negative would depend on **the process in place; whether physician-assisted dying is a separate branch of medicine; whether there are financial motivations and media coverage**.

The **process** in place to decide eligibility and to carry out physician-assisted dying was also thought to be important in determining the impact on doctor-patient relationships. Doctors focussed in particular on who would make the decision for eligibility. Like the public, doctors reported that whether or not you are referred to a **specialist** to determine eligibility and whether or not physician-assisted dying is carried out by a separate branch of medicine would be key in shaping the impact on doctor-patient relationships. Whether this would be a separate branch of medicine was a key concern for many doctors. Doctors often drew comparisons here with abortion and physician-assisted dying clinics in Europe, notably Switzerland. Like the public, some doctors also reported that the impact would depend on whether there were **financial motivations** for assisted dying, whether this be profit making or achieving cost savings.

Doctors also thought that the impact on relationships themselves would be highly dependent on the media's coverage of the issue, particularly the tabloids.

7.3.2. Potential positive and negative impacts

The potential positive impacts suggested by the doctors reflect the same three categories reported by the public: physician-assisted dying would mean doctors are **more able to provide a 'good' death, choice and improve communication**.

For some doctors, physician-assisted dying could mean that some patients would be more likely to see doctors as 'on their side' and helping them to have a more peaceful and dignified death. Doctors would be more able to provide choice to patients at end of life and 'help' those who want assisted dying. Like the public, some doctors thought physician-assisted dying would improve communication because doctors and patients could have more open conversations about options. Some doctors also thought legalisation would be a catalyst to start more discussions about end-of-life care and the options available.

"The first part of the session we talked about effectively trying to give patients a good death and this would just be another tool. It doesn't mean it's prescriptive, it doesn't mean you have to give it to them, it's just another tool that's there as patient choice..." (Doctor)

"It may potentially give you a more honest relationship because at the moment you say 'I'm sorry but I can't discuss that it's not legal', but it may open up more conversations." (Doctor)

The potential negative impacts raised by the doctors again reflect the same categories reported by the public: physician-assisted dying could **increase fear, cause conflict, damage doctors' relationships with families, and change the doctors' role**.

Doctors were concerned that physician-assisted dying would increase **fear** of doctors and hospitals. Even if not expressed, this may be in the back of peoples' minds. Doctors were also concerned that it would increase **suspicion** of doctors and the medical profession. They were particularly concerned that fear and suspicion of hospices and palliative doctors would be increased. Doctors also reported concerns that patients may feel less able to share information with doctors. They were particularly concerned for the elderly, frail, disabled and those who may feel they are a burden, when this issue was raised with them by the moderators.

"If they've been diagnosed with a terminal illness they may be too scared to approach us about other things because they'd think 'Oh gosh they're just going to provoke this'...would they start to not talk to you about the symptoms they're getting from their terminal illness because they're thinking 'oh actually they might think I'm better off not being here.'' (Doctor)

Doctors were also concerned that assisted dying would cause **conflict**. Like the public, this may be caused if the doctor refuses to be involved in the process or refuses eligibility. Doctors also raised the issue that the reputation of doctors involved in the process or practice could be harmed in small communities and that this may make it difficult for them to practise. This was a particular concern for GPs. As well as increased suspicion, doctors were concerned about doctors being accused of coercion and that this could undermine individuals and the profession. They were concerned about conflict between colleagues, given the strong views which exist in the profession, and about 'fragmentation' of the profession.

"If you were really against it, you would dread a patient bringing it up, it would become more difficult. I have been treating you until now, but I cannot treat you in this way, so you have to refer them on." (Doctor)

"I cannot see a doctor in my village could be one of these two...I think it would have to be two doctors entirely separate from me, from the patient cohort because the feedback or comeback could be potentially unimaginable. I can see two stranger docs in a place in London or somewhere, I can see that working in the sense that my community is not exposed to the decision process, it becomes an event somewhere else." (Doctor)

*D*octors were also fearful about the damage physician-assisted dying could do to their relationships with **family members** if they disagree with the doctor's decision on eligibility either way, or if family members change their mind after the death of a relative about their view on their loved one's decision.

"A whole family may be registered with a GP and there's a possibility that a patient may see this as a fantastic thing and the family may be grateful or devastated then that relationship is destroyed. I don't think you can predict which way it would go." (Doctor)

Doctors also thought that physician-assisted dying would change their **fundamental role**, and used similar language to the public to express their fears and concerns that doctors would be able to 'kill'. Some doctors in two locations were also concerned that this would put them in a *'God-like'* role with which they were not comfortable. A doctor in one location said it would be a *'quantum shift'* in their role. Doctors were concerned that assisted dying may mean people no longer see them as having the patient's best interests at heart.

> *"… where do we stand if this is now an option – are we then compelled as doctors to say well actually we've got this law if you're feeling awful…do I then have to say well I've got this colleague down the road who can do this for you, I think it completely changes if we've got this other option on the table, I think we'd be failing patients if we were saying it's another medical treatment; killing someone doesn't feel to me like a medical treatment."* (Doctor)

Some doctors also expressed concern that physician-assisted dying could be seen by patients as another treatment option alongside others and end-of-life care. They were concerned and saw these as fundamentally different. However, this contradicts views given by other doctors and members of the public that a positive impact would be that it could give people more choice and options, from respondents who did understand physician-assisted dying in these terms.

7.4. The impact on the view of doctors in society

Respondents were asked to consider the potential impact of physician-assisted dying on the view of doctors in society. There was **a mix of views** on what the impact might be among doctors and the public, but overall participants **tended to respond more negatively than when they were asked about the impact on the doctor-patient relationship itself**. The doctors in particular were more negative about the potential impact here than on the relationships themselves, and again were more often more negative than the public. Doctors were again often strongly polarised during these discussions and again their suggestions often reflected their wider views on physician-assisted dying.

The potential positive and negative impacts raised by the public and medical respondents were similar to each other. They strongly reflected the kinds of issues raised in the previous discussions on the doctor-patient relationship - and these discussions often blurred.

7.4.1. The role of the media

During these discussions, the term 'society' was spontaneously and commonly associated with and understood as 'the media'. The public and doctors reported that the impact of assisted dying on the view of doctors in society would **strongly depend on the nature of the media's coverage** of the issue, and particularly tabloid coverage. This was raised on numerous tables across the events.

> *"Tabloid press scares people ... over-sensationalising, can be fear-mongering."* (Doctor)
>
> *"More kind of current issues are the irrational fears that I think people develop from reading the papers, so some patients are afraid of being in a particular hospital because of a bad report and that they might kill them off or something like that."* (Doctor)

The doctors in particular were fearful of tabloid coverage of the issue. Doctors said that **'one negative story'** about a mistake, complications or a family's reaction after the death of a loved one could have a significant impact on the way the public viewed physician-assisted dying, doctors working in this field and the profession more generally.

As when discussing the doctor-patient relationship itself, the public also thought the view of doctors in society would depend on the **process** in place and the method used, and particularly whether adequate **safeguards** were in place to protect the vulnerable. Again the extent of doctors' involvement and whether physician-assisted dying was carried out by a separate branch and **specialism** of medicine would shape the media's coverage and the view of doctors in society.

Meanwhile the doctors often drew comparison again here with abortion and the way that this is presented in the media. Many doctors thought that the view in society would be likely to evolve over time with the practice becoming gradually more accepted over time. This comparison and the way doctors are perceived was particularly drawn at one event.

7.4.2. Potential positive and negative impacts on the view of doctors in society

The potential positive and negative impacts suggested by the public and doctors were similar and were also similar to the kinds of issues raised in the previous discussions on the relationship itself.

The potential **positive impacts** on the view of doctors in society reported also referred to doctors being more able to **provide a 'good' death and choice to patients, and improving communication**.

The **public** suggested that doctors would be seen by society to be more able to relieve pain and suffering; more able to offer choice and options to people at the end of their life and more able to answer peoples' wishes.

Meanwhile **doctors** suggested that they would be seen in society to be meeting a real need; more able to give patients choice and what they want; more able to fulfil their duties to patients; and would be seen to be more able to have open conversations about end of life and dying. Doctors also suggested that it might mean that there would be more discussion about end of life and dying in our society, which was found to not be part of our culture in the first session.

The public and doctors focussed more on potential negative impacts than positive ones. The **negative impacts** on the view of doctors in society reported also referred to **increased fear, conflict, worse relations with relatives and changes to the doctor's fundamental role**.

The **public** suggested that there would be concern in society for vulnerable groups such as the elderly, frail, disabled and mental health patients who might fear doctors and going to hospital. However these suggestions were only made after prompting from moderators. The public suggested that there could be personal campaigns against doctors involved in physician-assisted dying. Legalisation could also increase the divide between faith and science in society. The view of doctors could be affected by stories from families during and after physician-assisted dying who disagree with their loved one and the doctors making the decision for eligibility. Again the view of doctors in society could be affected if they are associated with 'doctor death' and doctors 'playing God', as doctors would be seen to be less caring and compassionate. However some people did not think physician-assisted dying would change perceptions of the role of doctors, as one of the quotes below illustrates.

Meanwhile **doctors** also suggested that there may be greater fear of doctors in society. Doctors in one location referred to the way in which patients 'shied away' from doctors after Shipman. They were particularly concerned about the elderly and frail and other patients who may have concerns about coercion and abuse of physician-assisted dying and that this may become a concern in society. Doctors were concerned that physician-assisted dying would cause conflict in society, particularly in small communities and also that it could polarise the public about the medical profession. Doctors were also concerned about changes to the perception of a doctor's fundamental role in society. The public may become confused about what a doctor's role is, where it is clear at the moment that it is to preserve and maintain life and act in the patient's best interest. A doctor in one location said doctors are *'savers of life, not administrators of death'*. Doctors in two other locations expressed concern that physician-assisted dying may be seen as another 'tool' for doctors. Doctors were concerned that physician-assisted dying may increase the transactional nature of the relationship between a doctor and patient.

Public and medical respondents also again raised concerns about commercialisation and the view that physician-assisted dying could be linked with cost savings, particularly in a society with an ageing population.

7.5. The impact of three options for deciding eligibility on doctor-patient relationships

The public and medical respondents were asked to consider the impact of three different options for deciding eligibility for physician-assisted dying on doctor-patient relationships. They were asked to continue to imagine the hypothetical scenario posed and to consider the impact of the decision for eligibility being made by:

- the individual's treating doctor
- a doctor who has no clinical relationship with the individual or
- a judge, on the basis of information provided by doctors.

There was **a lack of consensus** about the impact of the three options among the public and doctors. However a difference emerged concerning **the role of judges**: the public often responded negatively to this option whereas the doctors were more positive. The public were more positive about the idea of the treating doctor making the decision than the doctors, who more often responded negatively to this option.

7.5.1. Public responses to the three options

The public often again found this topic hard to think about and discuss, within the layers of the hypothetical scenario, and because it was something alien to them and which most had never considered before. Again it was often difficult for respondents to articulate their views and views were emergent and often evolved during the discussions.

Overall there was **a lack of consensus** about the impact of each of the three options on doctor-patient relationships. No option stood out and there was also a lack of consensus in terms of which option the public preferred, with many tables not coming to a consensus and no consensus overall across the events.

However, many tables of respondents expressed more negative than positive views about the idea of judges making the decision for eligibility. The public were concerned this would be bureaucratic, a burden and upsetting for patients and their families and were concerned about how long it would take and whether there would be financial costs involved. The public associated courts and judges with crime, punishment and wrong-doing which was thought to be inappropriate for this decision. However some

members of the public appreciated that this approach could help to protect doctors and doctor-patient relationships.

> *"Not a judge, that's going to put in another layer of bureaucracy which is going to slow it down."* (Public, Table 4)
>
> *"I would feel that it's like passing it on (to someone who knows nothing about health). It's taking it away from the person who ultimately should have the power to make the decision based on what's been wrong with you, what the treatment's been."* (Public, Table 1)
>
> *"It would allow a degree of separation and allow people to maintain whatever trust they have in doctors, it would allow for that to continue."* (Public, Table 4)

The public were more positive than the doctors about the idea of the treating doctor making the decision because this would be more personal and they are likely to know you and your history better. This was particularly important if there was a need to make a decision about mental capacity.

> *"It would need to be combination of someone who knew my medical condition and would have built up some kind of relationship where he knew me as a person and not just an illness. … he would know when I'm not [name] anymore, when I can't function as I want to function, mentally as well as physically."* (Public, Table 2)
>
> *"You would hope that he (the GP) did have that relationship with them, that he would know if they were in their right mind to decide. From knowing them for years and years…from seeing them in the last year. Whereas if it was a doctor that didn't know them, they wouldn't be able to tell that."* (Public, Table 3)

A number of key themes emerged from the discussions among the public across the three options:

- **Balancing subjectivity and objectivity** – your own doctor being involved would mean the process would be more personal and emotional, but the public simultaneously valued objectivity and impartiality in the decision making process
- **A patient's experience of the process** would be important – and it should not be too time consuming, costly, a burden on the patient, or strain on family members
- **Medical knowledge** – from doctors was valued and the public assumed judges would not have this, even when told they would be given advice from doctors
- **Specialist knowledge –** of the patient's condition and the physician-assisted dying process itself was valued and thought to be important
- **Knowledge of the patient's family** – and loved ones and their medical history was valued and thought to be important
- **Coercion** – and who would be best placed to detect this was considered by some respondents, but often only after prompting rather than spontaneously
- It was also important to the public to consider the pressure put on doctors and protecting them from the burden of responsibility, blame and threat of litigation.

The potential positive and negative impacts on doctor-patient relationships of the three options raised by the public are summarised in the table below.

Figure 17: Potential positive and negative impacts on doctor-patient relationships of three options for deciding eligibility for physician-assisted dying from the public

+		-
• More personal and emotional – know you and your medical history and perhaps also the family • Have medical knowledge, unlike judges • Better able to assess coercion from family members • Would be involved anyway		• A lot of responsibility and emotional for the doctor • Refusal or opt out could ruin the relationship • Concerns about reactions of and relations with the family – during and after
• Balances subjectivity and objectivity • Patients must raise the issue • Less pressure on family doctor • Have medical knowledge • Could be a condition specialist • Could be a separate branch / specialist		• Less personal - don't know the patient and their history • Don't know the family • No time to get to know you • People may seek another doctor if one disagrees
• Protect doctors from litigation and families and their reactions • Protects the doctor-patient relationship • Impartial, objective, detached, legalistic • Able to assess evidence and manage disputes • Able to assess coercion		• Bureaucratic / a burden / upsetting • Loss of time – prolongs pain & process • Cost - who pays? • Strain on family • Impersonal • Fear of courts / associated with crime and punishment • Lack of medical knowledge
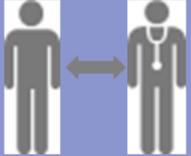
7.5.2. Doctors' responses to the three options

The doctors' views were similar and they raised many of the same hopes and concerns. No option stood out as the doctors also lacked consensus about the impact of each of the options on doctor-patient relationships and about which option they preferred.

However doctors were more positive about the idea of judges making the decision for eligibility than the public, and more negative about a patient's own doctor making the decision. The doctors more often discussed the impact of these three options on the detail of the process and how it would be carried out than the public. They also discussed the importance of the balance between objectivity and subjectivity.

> *"When heavily involved in someone's care there can be a feeling that you have to support them, you can get sucked into it if you don't stand back. You need someone involved who knows the patient, but you can lose your objectivity because you over empathise."* (Doctor)
>
> *"In terms of maintaining the therapeutic relationship that is there, that is about supporting that person, there is something that frees the doctor to continue in that supporting role if that decision is taken out of medical hands."* (Doctor)
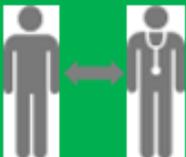
The following key themes emerged from the discussions among the doctors across the three options:

■ **Protecting doctors from blame from families and litigation** – and the burden of responsibility that would be put on them was a key area of discussion for doctors
■ **Balancing subjectivity and objectivity** – the doctors also weighed up the value of the doctor knowing the patient, their history and family against a more impartial and objective view (for doctors and patients as there would be an impact on both)

- **Separating the decision and administration** - of the process was thought to be valuable for doctors and patients
- **Involving specialists** – in the patient's condition, depression and capacity, and physician-assisted dying was valued
- **Minimising the burden** - of the process on patients and their families was thought to be important.

The potential positive and negative impacts on doctor-patient relationships of the three options raised by the doctors are summarised in the figure below.

Figure 18: Potential positive and negative impacts on doctor-patient relationships of three options for deciding eligibility for physician-assisted dying from the doctors

+		-
· Could give some people a service / option they want, control, quality of life, relieve suffering · A privilege to help people make this decision (GPs and palliative doctors) · Know the patient and their history		· Difficult to estimate prognosis · Doctors may distance themselves from patients · Would be seen as 'death doctors' · Too close and emotional · Damage relationship if disagree · Damage relationship with family
· Less pressure if responsibility is shared · Separates the decision and the administration · Could involve specialists · Could involves specialists to assess depression and capacity		· May have insufficient information and lack of personal knowledge about the patient, their history, and family · If a separate specialism, they would be known as 'death doctors'
· Protects doctors from blame and litigation · Protects trust and the relationship · Creates distance · Separates the decision and the administration · Independent and objective – but still gives doctors a central role		· Time, cost, bureaucratic process burdensome · Question how it would work in practice · Impact on doctor if judge makes a different decision · Judges unqualified for this role · Patients may pressure how information is presented

7.5.3. An alternative suggestion

No clear preference emerged from the public or doctors as to which of the three options they preferred. Consequently both the public and doctors started to think about a more preferable alternative and suggested either a panel, committee or ombudsman to make the eligibility decision which would involve at least two doctors. They thought there could be a role for judges where coercion was suspected or disputes arose.

> *"A team of doctors would be better, but not too big to make it easy to shirk responsibility for the life of the patient… with one doctor who knows the patient well to make sure they're compos mentis."* (Doctor)
>
> *"If you've got 2 doctors, one checking the other one, they're both saying…this person is eligible. Where you'd want the legal position is if one doctors disagrees with another doctor, but that would be the only time [a judge is needed]."* (Public, Table 3)

This emerged from a concern among the public and doctors **for the burden of responsibility** of making this decision and a view that this burden should be shared among multiple people rather than being taken by one or two doctors. These kinds of format would protect individual doctors from blame from family members and the threat of litigation and would better protect them from campaigns against them.

This protection was compared to jury service by some members of the public. Doctors were often keen that the decision be made in this way and that then the administration of the procedure should be carried out by a new and specialist branch of medicine.

> *"The problem would be it would come down to experience. Though I'm used to dealing with the 20 or 30 drugs I use regularly, you'd have difficulties if you were thinking about phenobarbitone or what have you...you'd have to be damn sure it was going to work and perhaps for those reasons you couldn't have the GP doing it, it would have to be a specialist death doctor or some reasonable guidance."* (Doctor,)

The public and doctors' idea of a panel, committee or ombudsman was also thought to be able to reach **a better decision** as it could include the more personal view from the patient's doctor(s) who would know their history; more objective and impartial views from other doctors; and a range of specialist views on the patient's condition, physician-assisted dying and from psychologists on depression and capacity. This format would also be better able to **detect coercion** from doctors and/or family members.

Many of the public and doctors agreed that **coercion** was an important and difficult issue, but often only when prompted to consider this by the moderator rather than raising this spontaneously. Once prompted, groups often only considered coercion by family members *or* a doctor. Some doctors expressed concern about how to deal with self or cultural coercion for those who feel they are a burden to their families. Respondents often reported that the best way to assess coercion would be via a team assessing eligibility, but also suggested that judges could play a role where coercion is suspected because they are experienced in weighing up evidence. Respondents suggested that counsellors and mental health professionals, family members, GPs, nurses, or an ombudsman would be other options for assessing whether coercion had occurred.

7.6. Potential emotional and professional impacts on doctors

The doctors were asked to consider what the professional and/or emotional impacts would be on themselves if physician-assisted dying were legalised:

- Of making the decision
- Delivering the process
- Of the practicalities of being there when a patient dies.

The majority of doctors thought there would be professional and emotional impacts on doctors, and **the majority of the impacts raised by them were negative**. The discussions on this topic were often highly polarised.

Many doctors did not see being involved with physician-assisted dying as compatible with their understanding of their fundamental role and remit as a doctor. Many expressed **discomfort** at the idea of themselves, their colleagues and/or profession being involved in this practice, either in making the decision for eligibility or the procedure itself.

> *"If it was found that a patient who died two months ago could have still been alive, how am I going to forgive myself?"* (Doctor)

However, the views expressed on this topic by individuals were usually shaped by how they perceived their role as a doctor as well as their views on physician-assisted dying more widely. Therefore we note that some doctors reported that there would be positive emotional and professional impacts on

themselves and their profession. This was particularly for those who perceived relieving pain and suffering to be central to their role and physician-assisted dying as to offer patients another option.

Many doctors said that they would want, and indeed assumed, that they would be able to **opt out** of being involved in the process.

> *"That's the problem of just looking at this from the patient's perspective. You've to look at it from the doctor's perspective. Even though I could probably sit with a bit of paper and write a scenario where I could see it might be appropriate….I don't think I could be involved in it."* (Doctor)

Some doctors mentioned that they thought themselves or their profession being involved in the process would get easier over time and that they assumed they would become de-sensitised to it. Others doctors noted that the medical profession is already an emotional and sometimes upsetting job, and it was suggested that counselling should be provided for anyone involved in the process or practice.

> *"...It's a red herring whether it will make people distrust doctors or trust them more. It's people being aware it's an option they have....people will get accustomed to it and accept it is an option but the conversation needs to be initiated."* (Doctor)
>
> *"You might not know how it was going to affect you till it happens and patients do affect you in different ways and you still have to maintain your resilience and wellbeing … I think this would be very taxing."* (Doctor)

Doctors who were **positive** about the impacts of physician-assisted dying on doctors thought they would be able to help relieve pain and suffering and be involved in patients' making this choice for themselves. They also thought they would be more able to talk about the dying process with their patients; more able to talk about this option with those who ask anyway; and more able to help families.

> *'You can also see it as a final act, that you're able to help the patient through the whole process, to take them through and that's part of your caring role.'* (Doctor)
>
> *"I'm sure [it would have an impact] but not necessarily a negative one. I think actually being part of that intimate process I would find delivering comfort to the patient and their family. So I don't think I would have difficulty with it."* (Doctor)

However doctors also raised numerous **negative** impacts on themselves and their profession:

- It would be against the fundamental principles of their role
- People may leave or not enter the profession
- It may divide doctors in the profession, practices, and communities
- There would be more suspicion of doctors, and among the profession
- Administering the procedure would be emotional
- They would have concerns about mistakes being made, the reactions of families and managing consequences
- Some were concerned about relaxation of the rules in the future
- Some doctors had religious and moral concerns themselves, and were concerned about these concerns for other doctors
- Some thought that a decision and involvement could 'haunt' you in the future
- Some doctors feared the risk of litigation assisted dying would bring.

8. Key insights

8.1. Key insights

8.1.1. Doctor-patient relationships
- The public have high levels of trust in doctors and this trust is 'there to be lost', unlike with other professionals where it first must be gained
- Doctor-patient relationships are shaped by a number of factors including access, continuity, attitude, and length and quality of time spent with the doctor
- Doctors recognise the high level of trust and high expectations the public have of them
- The relationship changes when a patient has a terminal illness and becomes more intense and the role of the family becomes more important
- The intensity of the relationship varies by medical specialism
- Patients want to feel engaged in their health care – to be treated as a person not a condition – but views differ regarding how to achieve this.

8.1.2. Hopes, fears and concerns about end of life and dying
- The public do not often think, talk about or plan for end of life and dying
- Many people had not made any practical arrangements for their end of life (e.g. wills, insurance, care plans) and people prefer to plan for life rather than death
- The public's main fears about end of life and dying concern pain, their family and loved ones, choice, dignity, being a burden and fear of the unknown
- The public hope for a quick death in their sleep which is painless, where they get to choose when their family and loved ones are there, the location (often at home or in a hospice) and that they have a good quality of life, personalised care, are not alone and have their finances sorted out
- The doctors identified many of the hopes and fears the public have, however they were less likely to mention the impact on the family which was a major concern for the public
- Some doctors thought the public were overly optimistic about their hopes for a good death (e.g. being able to choose the location).

8.1.3. Perceptions and experiences of end-of-life care
- The public without recent experience of bereavement know very little about end-of-life care, what it consists of, how to access it or its availability. Those with recent experience of bereavement were mixed in their views about its quality
- Being treated as a person, rather than a number or medical condition, is central to the provision of good end-of-life care for the public. Seven other factors were important, particularly factors one to three:

  (1) timely access to medical services (including pain management)

  (2) choice of location of care and death (and a preference for being in a hospice or the community)

  (3) access to the level of information desired by the patient (and for information to be consistent)

(4) good communication (between the patient, doctors, services and the family)

(5) good planning and coordination of services (and for this to be personalised)

(6) emotional support (secular and spiritual, and for the patient and family – during and after end-of-life care)

(7) help with financial and legal issues (particularly for older people).

- Those with recent experience of bereavement reported that end-of-life care is currently working well where patients are treated as a person, have good access to medical services, the right level of information, there is good communication and coordination of services. It is working less well where patients are not treated as a person, have poor access to services, less choice of location, coordination is poor and emotional support is lacking. They reported that in some areas the provision of information, communication and financial and legal advice are particularly poor. There was no clear pattern of quality of end-of-life care across geographic areas
- During this research we found that end of life and dying are topics that many people do not think about and find it uncomfortable to talk about, even with their loved ones and which many people have not made any plans for. Some doctors also reported finding end of life and dying difficult to talk about with patients. Many public respondents without recent experience of bereavement knew very little about end-of-life care and what is available and what options there are for them. Therefore we would recommend more work is done, for example a public awareness campaign, about these issues which directs people to more information and encourages them to discuss these issues with family members and loved ones, to enable forward planning and better communication with medical professionals.

8.1.4. Provision of end-of-life care
- Doctors reported that there is wide variation in the quality of end-of-life care provision between areas, within areas and between rural and urban locations
- Doctors reported concerns about medical services; some locations (particularly out-of-hours care, community care, and out-of-hours community care); communication; and coordination of care
- Discussing end of life and dying is never easy and can be distressing for doctors, but is often seen as part of the job – but there is a desire for more training
- For many doctors end-of-life care is primarily a concern for palliative doctors, oncologists and GPs. Patients' holistic needs are seen as secondary to treatment, palliation and pain management and dependent on whether there is time available
- Pain is a key concern for the public – doctors view this as something which can be managed but not eliminated but have concerns about administration and confidence within the profession
- A prognosis is almost always requested by the patient and/or family but doctors reported that it is almost impossible to give the level of detail desired
- Doctors were often polarised about the profession's ability to assess mental capacity – with some being confident in the procedures and others reporting them to be open to wide interpretation
- Doctors reported that it is difficult to identify and treat depression in end-of-life care settings. Some doctors lacked confidence in this area and it emerged as a key concern.

8.1.5. The potential impact of physician-assisted dying on doctor-patient relationships
- Most of the public, and many doctors, were shocked and surprised by the information provided about complications, failure and length of time it can take to die
- Overall, the public presented a balanced range of views and potential positive and negative impacts on the doctor-patient relationship. Doctors were more likely to focus on the potential negative impacts on

the relationship than the public. For the public and doctors, physician-assisted dying could mean doctors are more able to provide a 'good' death, choice to patients and improve communication about end of life and dying. However it could also increase fear of doctors and hospitals; cause conflict between doctors, patients and families; damage doctors' relationships with families where there are disputes and disagreements; and change the fundamental role of doctors. The public expressed particular concern for vulnerable groups whose fear of doctors may increase, but this was only raised after prompting rather than spontaneously. Public and medical respondents thought the impact would depend on the process in place, who was involved, and whether there were financial motivations.

- The impact on the view of doctors in society would strongly depend on the media's coverage of this issue – as well as the method, process and safeguarding procedures, and particularly the extent of doctors' involvement. There was a high degree of fear among doctors about media coverage of this topic for their profession. The positive and negative impacts raised reflected the same categories raised in the discussions about the impact on the relationship itself.

- There was a lack of consensus among the public and doctors about the potential impact of three options given for who could decide eligibility. No option stood out for either group. However the public responded more negatively to the judge option than the doctors, and the doctors responded more negatively to the idea of the treating doctor than the public. A suggestion emerged among the public and the doctor for eligibility to be decided by a panel, committee or ombudsman

- Doctors thought there would be emotional and professional impacts on themselves, their colleagues and the profession, and they more often reported negative than positive impacts.

9. Appendices

9.1. Formal feedback from doctors about the running of the events

	Excellent %	Good %	Fair %	Poor %
Please evaluate the event facilitator with regard to overall management of the event	67.4	30.6	1.6	0.4
Please evaluate your table facilitator across the sessions for aiding debate and discussion amongst delegates	65.0	32.9	1.4	0.7
Please evaluate your table facilitator across the sessions for ensuring everyone had the chance to give their opinions	67.9	30.4	1.2	0.0
How would you rate the overall quality of the event?	63.1	35.3	1.6	0.0

Notes:

Percentages may not add to 100% due to rounding.

The 'Poor' rating relates to only one of the events.

9.2. Public achieved sample

Public Events – Achieved sample	18-30	31-59	60+	Male	Female	ABC1	C2DE	Bereavement
London	8	10	9	13	14	14	13	7
Leeds	9	9	8	12	14	13	13	7
Liverpool	9	10	9	12	16	14	14	7
Taunton	10	10	8	13	15	16	12	7
Birmingham	9	10	9	13	15	14	14	7
Cambridge	8	9	10	13	14	13	14	8
Dundee	9	6	9	12	12	13	11	7
Glasgow	7	9	9	11	14	12	13	5
Belfast	9	10	10	15	14	15	14	8
Cardiff	9	8	10	10	17	14	13	7
Total per event	**87**	**91**	**91**	**124**	**145**	**138**	**131**	**70**
Overall Total								**269**

9.3. Doctors achieved sample

Total by location

Doctors' Events – Achieved sample	
London (pilot)	25
Leeds	23
Liverpool	19
Liverpool – BMA ARM	20
Taunton	20
Birmingham	19
Cambridge	22
Dundee	20
Glasgow	20
Belfast	22
Cardiff	27
TOTAL	**237**

Grade

GRADE	London	Leeds	Liverpool	ARM	Taunton	Birmingham	Cambridge	Dundee	Glasgow	Belfast	Cardiff	TOTAL
Consultant	7	4	4	6	4	3	3	5	4	6	7	**53**
Foundation trainee	2	2	2	2	1	1	1	1	1	1	2	**16**
GP non Partner salaried/locum/sessional	3	2	2		3	1	4	2	2	3	4	**26**
GP partner/principal	4	3	3	2	3	2	3	3	3	4	3	**33**
GP trainee	1	2		1	2	1		1		1		**9**
Medical student	2	3	1	2	1	3	3	2	3	3	2	**25**
Retired	2	1	2	2	1	2	2	1	2	2	2	**19**
Specialty doctor	1	3	3	1	2	2	2	2	2	2	3	**23**
Specialty trainee	3	3	2	4	3	4	4	3	3		4	**33**
Total	**25**	**23**	**19**	**20**	**20**	**19**	**22**	**20**	**20**	**22**	**27**	**237**

Gender

	Female	Male	Total
London	17	8	**25**
Leeds	11	12	**23**
Liverpool	8	11	**19**
ARM	8	12	**20**
Taunton	10	10	**20**
Birmingham	8	11	**19**
Cambridge	12	10	**22**
Dundee	10	10	**20**
Glasgow	10	10	**20**
Belfast	9	13	**22**
Cardiff	12	15	**27**
TOTAL	**115**	**122**	**237**

Specialism

SPECIALITY	London	Leeds	Liverpool	ARM	Taunton	Birmingham	Cambridge	Dundee	Glasgow	Belfast	Cardiff	TOTAL
Acute internal medicine						1				1		**2**
Anaesthetics		2	1	1	2		1	2	2	1		**12**
Endocrinology	1											**1**
Endocrinology and diabetes mellitus		1					1					**2**
Forensic Psychiatry			1									**1**
Gastroenterology								1				**1**
General internal medicine				2								**2**
General practice	7	6	5	2	8	4	7	6	5	8	9	**67**
Genitourinary medicine	1											**1**
Geriatric medicine	2	1	1		1			1	2	2	3	**13**
Haematology	1							1				**2**
Histopathology	1											**1**
Intensive care											1	**1**
Medical microbiology	1											**1**
N/A	7	7	6	6	3	6	6	4	6	6	6	**63**
Neurology				2				1			1	**4**
Oncology – clinical / medical		2			1		1	1	1			**6**
Paediatrics	1			1				2				**4**
Pain management	1					1					1	**3**
Palliative care	1	1	3	1	2	4	3		1	2	3	**21**
Psychiatry		1	2	3	3		3	1	2	1		**16**
Respiratory medicine	1					1					1	**3**
Rheumatology							1					**1**
Sexual health		1										**1**
Surgery - various		1		1					1	1	2	**6**
Trauma and orthopaedics				1				1				**2**
Total	**25**	**23**	**19**	**20**	**20**	**19**	**22**	**20**	**20**	**22**	**27**	**237**

9.4. Public topic guide

<div align="center">

British Medical Association
Workshop Topic Guide – Public (3.5 hours)

</div>

The aims of these workshops are to explore:

- Fears and concerns about the impact of serious/terminal illness and about facing death
- Perceptions of the availability, accessibility and quality of palliative care in the UK
- Views about the potential impact of legalised assisted dying on the patient-doctor relationship.

The workshop is not aiming to discuss the pros and cons of assisted dying. Nor is the session trying to influence public opinion.

Recruitment has included participants with experience of a terminal illness or palliative care e.g. family/friends.

Topic guide and how it will be used by facilitators: A topic guide is used to encourage participants to discuss their views, perceptions, attitudes and experiences in an open way without excluding issues which may be of importance to the study. However, facilitation is guided by the clear aims of the study to ensure discussion is focused on the key objectives.

The following guide does not contain pre-set questions, but rather lists the key themes and sub-themes to be explored within workshops. It does not include follow-up questions like `why', `when', `how', etc. as it is assumed that participants' views will be fully explored throughout to understand how and why these views are held.

Facilitators to be provided with information regarding approaches to address common misconceptions/or concerns. To include:

- *Liverpool Care Pathway*
- *Doesn't assisted suicide already happen?*
- *Does legalised assisted dying lead to an increase in suicides?*
- *Assisted dying and capital punishment*
- *High profile cases*

A member of staff from BMA will be present at each table to take notes of key discussion points. They will not participate in the discussion. They will provide clarification <u>only</u> if requested by the moderator.

- ## 09:00 – 09:30: Registration – 30 mins

Members of the public to register for the event, receive their incentives, and refreshments provided.

- ## 09:30 – 09:45: Introductory plenary session – 15 mins

	Timings	Stimulus materials provided	Themes covered
2.1	**15 mins**	None	- Welcome and introductions to staff - Introduction to TNS-BMRB – an independent research agency - The purpose and aims of the research - Introduction to BMA: The British Medical Association is the voice of doctors and medical students in the UK. We are an apolitical professional association and independent trade union, representing doctors and medical students from all branches of medicine across the UK and supporting them to deliver the highest standards of patient care. We have a membership of over 153,000, which continues to grow every year. - The report will be published on the BMA's website early next year. If respondents would like to receive a summary and link to the report they can give their contact details to the BMA today. - Length, format and agenda for the day - Confidentiality – of the event, discussions are private - Recording – confidentiality, anonymity (your name and the area will not be cited) and how your data will be stored and used - No preconceptions about peoples' views and conduct in the workshop, there are no right or wrong answers - Comfort breaks and toilets, - There is a room outside if you need a break and support leaflets available - How to claim their incentives - Moderator to instruct participants to join their allocated table

- ### 09:45-10:35 – Session 1: Understanding, hopes, fears and concerns about illness and dying – 50 mins

Researcher note: the aim of session is to warm participants up and to explore their views about health, illness and their relationships with doctors and health services. It will then get people thinking about death and dying and explore what is important to them personally, what they consider a 'good death' to look like and what is needed to achieve this. The session will explore their hopes, fears and concerns about dying. It will explore how much they know and discuss where they get information about this topic from.

Read out: In this session we will be exploring your views about health and illness, relationships with doctors and health services and your hopes, fears and concerns about illness and dying.

3.1	5-10 mins 09:45 – 09:55	None	**Introductions** - Their first name, if they have a job – what would they like to tell us about themselves (e.g. family and hobbies)

3.2	20 mins
	
	 09:55 – 10:15
		None	We want you to think about your past and current relationships with doctors, practitioners and health services
			
			 - How would you describe your relationship with your GP?
			  - is it a family doctor
			  - length of relationship
			  - continuity of seeing the same person
			
			 - Is there anything special about the doctor-patient relationship?
			 - If you've accessed more specialist services
			  - how did this compare with relationships with GPs
			 - If you think about professionals in general, who are the most trustworthy and where do doctors sit?
			
			 We now want to discuss how involved you are in decisions about your health:
			
			 - How engaged are you with your own health care?
			 - When you see your GP or other health professionals how involved do you feel in your health care?
			 - How involved would like to be in any treatment plans?
			 - How actively do you feel you're able to make decisions and discuss options about your health?
			 - Whether you/family members have any acute or long term health conditions – what interaction they had with doctors?

3.3	5mins
	
	10:15 –
	10:20
		None	• Do you ever think about your end of life and dying?
			  - What do you think about?
			  - Have you discussed this with anyone?
			  - Have you made a will?
			  - Have you made any advanced plans for your death and dying?
			  - How far do you feel able to prepare?
			
			• Where do you find out/get your information about end of life and dying? **SPONTANEOUS THEN PROBE:**
			  - media
			  - personal experience
			  - family stories
			  - work
			  - films
			  - novels
			  - other

3.4	10 mins
	
	10:20 –
	10:30
			• What are your concerns/fears about having a long-term illness and the prospect of dying?
			  - What are your hopes about having a long-term illness and the prospect of dying?
			
			SPONTANEOUS - DO NOT PROMPT BUT PROBE IF RAISED:
			1 Pain and other symptoms (e.g. nausea and vomiting, incontinence and constipation, breathlessness, mouth care, sleep, mobility)
			2 Dignity (e.g. fear of being dependent on others for personal care)
			3 Choice, and control about treatment options
			  - Confidence and trust that you will be listened to and your wishes respected
			4 Location
			5 Beliefs – social, cultural, spiritual
			6 Relationships (e.g. partner, family, friends, sex)
			7 Regrets and unfinished business
			8 Other – e.g. legal, financial
			
			• What are the three **most** important concerns/fears for you? (Note: table to come to agreement on their top 3)

3.5	5 mins		• When thinking about dying, what do you think is important in order for you to achieve a 'good death'?

	10:30 – 10:35			-	What needs to be in place for you to achieve this?
				-	What are the challenges to achieving a good death?
				-	Is the location of where you receive care/support important or not? (**PROBE** hospice, hospital, home)

| **10:35-10:45 – BREAK – 10mins** |

- ## 10:45-11:35 – Session 2: End-of-life care – 50 mins

Read out: This session is about the end of life services that are available and your understanding of them and perceptions of them. It will explore what you want to be in place and believe to be good EOLC, and then how well you think the current system is able to provide what they need in order to have a good death.

Please note there is a room outside if you need a break or quiet moment.

Researcher note: Anecdotal evidence suggests that the way in which end-of-life care is provided does not always align with the formal end-of-life care strategies and the services that, in theory, should be available. We want to gather more evidence on how far end-of-life care in practice matches up with theory, and how far end-of-life care meets the needs of the public in relation to what they identify as being most important to them at the end of their lives.

Tables 1-3: Participants with <u>no</u> experience of terminal illness/palliative care for relatives – ONLY

| 4.1 | 10 mins

10:45 – 10:55 | **STIMULUS A**
Aim: to provide a definition of end-of-life care
• Provide definition of end-of-life care | **** Facilitators to be provided information on how to respond to common misconceptions about end-of-life care.*

Facilitator to show STIMULUS A

• What do you know about end-of-life care and what it includes and what does it not

   - Where did you find out/get your information (**PROBE:** media, personal experience, family stories, work, films, novels and other?)
   - Any differences by location (hospital, hospice, home) or type of illness?
   - Whether differences between services geographically
   - Any concerns regarding end-of-life care? |

			• Whether anyone in the group has had family/loved one experience of end-of-life care? (if not already discussed)

4.2	20 mins
	
	10:55 – 11:15
		Activity 1: Materials provided:
		
		Participants provided with flip chart paper to map out a good end of life approach to dying
			• What should 'good' end-of-life care look like for you?
			  - What are their expectations
			
			ACTIVITY IN PAIRS: Ask participants to design a "good" end-of-life care approach for a family member or loved one:
			
			Probes:
			  - What needs should be addressed?
			  - Who should be involved?
			  - How it might work in practice?
			  - Would this change through the course of the illness?
			  - What would the challenges be?
			  - What is the role of doctors and health services in this?
			  - Level of individual involvement in decisions? (include concerns about consent)

4.3	5 mins 11:15 – 11:20		GROUP DISCUSSION: *Bring the group back together and write up key elements on a flip chart* • What were their key fears, hopes and challenges? **PROBE** discussion of location - hospitals, hospices and home • What are the challenges of achieving this?
4.4	15 mins 11:20 – 11:35	**STIMULUS B** Aim: to show best practice principles of a good end of life strategy	*Facilitator to show STIMULUS B – best practice principles* • How these align, or not, with their hopes, desires, values • Do any of the principles stand out for them – which are the most and least important; is anything missing? • How this compares with either personal experience or perceptions of what currently happens? • What are the challenges of providing the best practice principles? • Whether they raise any concerns • How does this make you feel about your own / family members' deaths?

		11:35-11:45 – BREAK – 10mins	

Table 4: Participants <u>with</u> experience of terminal illness/palliative care for relatives – ONLY

Read out: This session is about the end of life services that are available and your understanding of them and perceptions of them. It will explore what you want to be in place and believe to be good EOLC, and then how well you think the current system is able to provide what they need in order to have a good death.

Please note there is a room outside if you need a break or quiet moment.

| 4.4 | 20 mins

10:45 –
11:05 | **STIMULUS A**
Aim: to provide definitions of palliative and end-of-life care
• Provide definition of end-of-life care | **** Facilitators to be provided information on how to respond to common misconceptions about end-of-life care.*

Facilitator to ask respondents at the start of the session to take 5 minutes to write down on paper some details about the family member or loved one who recently died, and inform them we will discuss this in the session. Facilitator to collect this information at the end. To include:
- *Name, age, relationship to me*
- *Condition*
- *Where they died (home, hospice, hospital)*
- *Services they used in their end-of-life care*
- *Any treatment received*

• Explore experiences of end-of-life care and palliative care in the group (where respondents are comfortable to discuss this)
- **PROBE** (where appropriate) who the relative was, their age, their condition, what treatment they received, their end-of-life care pathway, which services they used, where they died
- How involved were you in your relative's care plans
• The extent to which the relatives needs were met?
• What worked well and what worked less well
• Perceptions of the staff involved
• Explore differences between services geographically |

			• Extent to which the services met their perceptions and expectations? • Extent to which their experience reflects public perceptions / stories in the media?

4.5	20 mins
	
	11:05 – 11:25
		Activity 1: Materials provided:
		
		Participants provided with flip chart paper to map out a good end of life approach to dying
			FLIP CHART ACTIVITY AS A GROUP:
			• What should a 'good' approach to end of life look like for you?
			
			  - What needs should be addressed?
			  - Who should be involved?
			  - How it might work in practice?
			  - What support do people need and what is needed for carers
			  - Would this change through the course of the illness?
			  - What would the challenges be?
			  - What is the role of doctors and health services in this?
			  - Level of individual involvement in decisions? (include concerns about consent)
			
			PROBE: discussion of location - hospitals, hospices and home
			
			• How does this compare with how it worked in practice?

4.6	10 mins 11:25 – 11:35	**STIMULUS B** Aim: to show best practice principles of a good end of end to life strategy	*Facilitator to show STIMULUS B – best practice principles* • How this aligns and compares with your own / family members' experience or wider perceptions of what currently happens? • Do any of the principles stand out for them – which are the most and least important; is anything missing? • Whether they raise any concerns • What are the challenges of providing the best practice principles? •
		11:35-11:45 – BREAK – 10mins	

Read out: we are interested in exploring the public's views about what, if any, impact legalising doctor assisted dying would have on the doctor/patient relationship and on society's perception of doctors more generally. We are not looking at views on whether doctor assisted dying is right or wrong – more about knowledge and if introduced, impact on the doctor and patient relationship.

Researcher note: In many of the countries where assisted dying is lawful – and in the Bill recently debated in the House of Lords - assistance is limited to individuals who are terminally ill and who are expected to die within six months.

5.1	15 mins
	
	 11:45 – 12:00
		STIMULUS C
		
		 - Definition of *Physician-assisted dying*
		
		 STIMULUS D
		 - Present factual information about how assisted dying is carried out in countries where it is legal.
			Facilitator to provide stimulus C and D together and allow respondents time to read through them.
			
			 - Does this information match their expectations?
			   - Is any of this new information?
			   - Are there any surprises?
			
			 DO NOT PROMPT BUT PROBE IF RAISED SPONTANEOUSLY:
			 - Doctors' ability to accurately diagnose terminal illness, assess capacity, predict prognosis, and diagnose depression at the end of life.

5.2	20 mins 12:00 – 12:20	None	We want you now to think hypothetically, about the situation if doctor assisted dying were to be legalised for those who meet certain criteria e.g. those who have a terminal or severely life-limiting condition and who are able to make an informed choice. You and your doctor: - How, if at all, do you think this would change the relationship between you and your doctor/s? (note: positive or negative change?)

			- Would this differ according to the type of doctor? (e.g. GPs, specialists, other health services)
			
			Doctors and society:
			
			• How, if at all, do you think this would change the relationship between patients and doctors more generally? (positive or negative change?)
			  - **PROBE** changes for particular groups e.g. religious/cultural, disabled, elderly, particular conditions
			
			• How, if at all, might it change the way doctors are perceived by society more generally? (positive or negative change?)
			  - would trust and/or confidence be affected either positively or negatively
			  - variation by type of doctor particular types of doctors (GPs, specialists, other health services)

5.3	**20mins** **12:20 – 12:40**	**STIMULUS E** Aim to provide information on: • the current role of judges	Continuing to think about the hypothetical situation proposed: We want you to think about the doctor-patient relationship, and how that would be impacted if the decision **that an individual was eligible** for assisted dying (after the individual had made the request) was made by: ❖ the individual's treating doctor ❖ a doctor who has no clinical relationship with the individual or ❖ a judge, on the basis of information provided by doctors • For each, what would be the impact on the relationship between you and your doctor (e.g. treating doctor/GP)? • Whether who makes the decision affects your relationship with the doctor? • How would like you like it to operate? • Who do you think would be best placed to detect whether there has been any pressure or coercion?

5.4	5 mins 12:40 – 12:45		• Do you have any further thoughts about the experience of dying and the kind of support you think you will need?

• 12:45 – 13:00 – Closing plenary sessions – 15 mins

- Bring the participants together to thank them for their time and participation
- Provide feedback and share final thoughts from discussion about the experience of dying and kind of support they need
- Ask if they have any final thoughts to share about any of the topics

Thanks and close

Researcher note: please ensure all charts and stimulus material are collected at the end of the session

British Medical Association

Workshop Topic Guide – Doctors (3 hours, 45 mins)

The aims of the workshops are to explore:

- Patients' fears and concerns about the impact of serious/terminal illness and about facing death
- Perceptions of the availability, accessibility and quality of end-of-life care and palliative care in the UK
- Views about the potential impact of legalised assisted dying on the doctor-patient relationship
- The professional and emotional impact of involvement in assisted dying upon doctors

The workshop is not aiming to discuss the pros and cons of assisted dying. Nor is the session trying to influence doctor opinion.

Topic guide and how it will be used by facilitators: A topic guide is used to encourage participants to discuss their views, perceptions, attitudes and experiences in an open way without excluding issues which may be of importance to the study. However, facilitation is guided by the clear aims of the study to ensure discussion is focused on the key objectives.

The following guide does not contain pre-set questions, but rather lists the key themes and sub-themes to be explored within workshops. It does not include follow-up questions like `why', `when', `how', etc. as it is assumed that participants' views will be fully explored throughout to understand how and why these views are held.

Facilitators to be provided with information regarding approaches to address common misconceptions/or concerns. To include:

- *Liverpool Care Pathway*
- *Doesn't assisted suicide already happen?*
- *Does legalised assisted dying lead to an increase in suicides?*
- *Assisted dying and capital punishment*
- *High profile cases*

A member of staff from BMA will be present at each table to take notes of key discussion points. They will not participate in the discussion. They will provide clarification <u>only</u> if requested by the moderator.

- 13:15 – 13:45: Registration – 30 mins

Doctors to register for the event, lunch provided.

- ## 13:45 – 14:00: Introductory plenary session – 15 mins

	Timings	Stimulus materials provided	Themes covered
2.1	**15 mins**	N/A	- Welcome and introductions to staff - Introduction to TNS-BMRB – an independent research agency - The purpose and aims of the research, including why the BMA is carrying out this research, and why we have chosen to engage with grassroots members. - The report will be published online and the BMA will send respondents a summary and link to the report - Length, format and agenda for the day - We will not be discussing the arguments for and against the legalisation of physician-assisted dying and instead will focus on the impact hypothetical legalisation would have on the doctor-patient relationship - Confidentiality – of the event, discussions are private - Recording – confidentiality, (your name and the area will not be cited) anonymity and how your data will be stored and used - No preconceptions about peoples' views and conduct in the workshop, there are no right or wrong answers - Comfort breaks and toilets, - There is a room outside if you need a break and support leaflets available - Moderator to instruct participants to join their allocated table

- ## 14:00-14:45 – Session 1: Relationships with patients – 45mins

Read out: the aim of this introductory session is to explore your experiences and views about doctor-patient relationships and the challenges and facilitators of having relationships with patients. We will also be discussing whether the doctor-patient relationship changes when a patient has a terminal illness, and what you think the public's fears and concerns are about having a long term illness and the prospect of dying.

As stated, we will not be discussing the arguments for and against physician-assisted dying in this session or the rest of the event.

3.1	5 mins 14:00 – 14:05	N/A	**Introductions** • Their first name, job, role, specialism, previous experience and length of time in the medical profession

3.2	10 mins 14:05 – 14:15		We would first like to discuss your views about doctor-patient relationships :
			
			• How would you describe the relationship you have with your patients?
			
			  - Is there anything special about the doctor-patient relationship?
			  - Do patients expect a relationship?
			  - What challenges/barriers are there to making a relationship?
			  - How does the relationship vary across specialism/services?
			  PROBE palliative care/end-of-life care
			
			• What do patients expect from the doctor-patient relationship
			– if/how this has changed over time
			• How they think patients perceive the doctor-patient relationship?
			  - Variations by specialism, or individual needs/demographics

3.3	5 mins 14:15 – 14:20		• Do you think the doctor-patient relationship changes when a patient has a terminal or disabling illness?
			  - How does it change?
			  - Explore variation across specialism/ services

3.4	20 mins 14:20 – 14:40		• What concerns/fears do you think the public has about having a long-term illness and prospect of dying?
			  - What hopes do you think the public has about having a long-term illness and prospect of dying?
			
			SPONTANEOUS - DO NOT PROMPT BUT PROBE IF RAISED:
			  1) Pain and other symptoms (e.g. nausea and vomiting, incontinence and constipation, breathlessness, mouth care, sleep, mobility
			  2) Dignity (e.g. fear of becoming dependent on someone for personal care),
			  3) Choice and control about treatment options

			- **Confidence and trust that you will be listened to and respected** 4) **Location** 5) **Beliefs – social, cultural, spiritual** 6) **Relationships (e.g. partner, family, friends, sex)** 7) **Regrets and unfinished business** **Other – e.g. legal, financial** • From your experience, what do you think the public's top 3 fears/concerns about having a long term illness and dying are? *Feed in views of the public from the morning session – their top 3 concerns/fears* • Are any of these surprising? • What are the challenges/facilitators in meeting these needs?
3.5	**5 mins** **14:40 – 14:45**		• How informed do you think the public are about end-of-life care? • What are public perceptions of end-of-life care? - Where do these come from? • Notify doctors that we will be discussing end-of-life care after the break.
			•
		14:45-15:00 – BREAK – 15mins	

• ## 15:00-16:00 – Session 2: End-of-life care – 1 hr

Read out: In this session we will be discussing end-of-life care. We want to explore your experiences of the provision of end-of-life care and how they match up with what is theoretically available and how far end-of-life care meets patients' needs. We will also be discussing how you feel about providing various aspects of end-of-life care.

Researcher note: When patients are told they have a terminal illness, a key question they want answered is how long they have left to live. We want to explore how confident doctors feel in estimating how long patients have to live. Doctors are required to assess capacity in relation to a range of treatments at the end of life, including when patients refuse life-prolonging treatment. We want to get a better understanding of how confident doctors feel in assessing capacity. As a sub-set of this, we would be interested to know how confident doctors feel about identifying depression amongst patients at the end of life.

4.1	25 mins 15:00 – 15:25	N/A	In this session we want to discuss, based on your own professional experience, how end-of-life care works in practice. If you have not had experience (in a professional capacity), we would like to discuss your perceptions about how things work in practice. • In your local area, how accessible is end-of-life care for patients? • What works well and less well? • How well do you think doctors are able to relieve pain and suffering at the end of life? • How well does end-of-life care currently meet patients' needs? - How well does it meet patients' holistic needs (e.g. emotional, spiritual, psychological, financial etc.) • Are we providing patients with the best end of life and palliative care possible? (Explore why or why not) - Do you have any concerns about the provision of end-of-life care? - Any variation by location of where end-of-life care is provided – Hospital, Hospice, Home? -
4.2	10 mins 15:25 – 15:35	N/A	We now want to move on to think about some of the practical elements of providing end-of-life care in more detail. First we want to discuss any issues around assessing how long patients have to live in end-of-life care: • What role do **you** have at the moment in predicting how long a patient has to live? • Do you have any concerns around **doctors** being able to predict how long a patient has to live? • What enables that/what are the challenges?
4.3	5 mins 15:35 – 15:40		• How well is mental capacity assessed in end-of-life care? • Do you have any concerns about **doctors** assessing mental capacity to refuse life-prolonging treatment in end-of-life care? - What enables that/what are the challenges?
4.4	5 mins 15:40 – 15:45		• How confident are you about **doctors** identifying and treating depression in end-of-life care? - What enables that/what are the challenges

| 4.5 | 15 mins 15:45 – 16:00 | | • How do you feel about discussing end-of-life care with patients?
 • How do you feel about discussing dying with patients?
 • Do **you** have any concerns about prescribing appropriate pain relief towards the end of life?
   - Do you have any concerns about **doctors** more generally prescribing pain relief at end of life?
 • How comfortable would you say you feel about discussing and meeting patients' holistic needs in end-of-life care?
   - (E.g. emotional, spiritual, psychological etc.)
 • How confident do you feel about bringing in other professionals?

 • Of the practical aspects of providing end-of-life care we have discussed in this session, would you say any concern you the most or more than others? |
| | | **16:00-16:15 – BREAK – 15mins** | |

- ## 16:15-17:15 – Session 3: Doctor assisted dying and doctor- patient relationships – 1hr

Read out: In this session, we will be exploring doctors' views about what, if any, impact legalising assisted dying would have on the doctor/patient relationship and on society's perception of doctors more generally. We also want to explore how doctors themselves might feel about assisting patients to die, and how this might impact on them professionally and emotionally and on some of the practical aspects we discussed in the last session We will not be discussing the arguments for and against the legalisation of physician-assisted dying and instead will focus on the impact hypothetical legalisation would have on the doctor-patient relationship.

Researcher note: In many of the countries where assisted dying is lawful – and in the Falconer Bill recently debated in the House of Lords - assistance is limited to individuals who are terminally ill and who are expected to die within six months.

| 5.1 | 5 mins 16:15 – 16:20 | **Dr's STIMULUS A** Aim to provide information on | *Moderator introduction: We are now going to discuss physician-assisted dying. We recognise that doctors will have different levels of knowledge about how this is practised in countries where it is legal. (Note: it is not currently legal in the UK).* |

		Definition of *Physician-assisted dying* and brief description of how it is practised in other countries:	*Facilitator to show stimulus A as background* • Is this what you expected? - Is any of this new information? - Is any of this information surprising? -
5.2	15 mins 16:20 – 16:35	• Dr's STIMULUS B: Explanation of the Falconer bill - assistance is limited to individuals who are terminally ill and who are expected to die within six months, and Assisted Suicide (Scotland) Bill	*Facilitator to show stimulus B as background* We want you now to think **hypothetically** about the situation if physician-assisted dying were to be legalised in the UK for those who meet certain criteria e.g. those who have a terminal or severely life-limiting condition, who have capacity to make the decision and are acting voluntarily. • How, if at all, do you think this would change the relationship between doctors and individual patients (change positively or negatively?) - explore variations for any different groups/individuals - How, if at all, do you think this would change the relationship between you and your patients? • How, if at all, do you think this would change the way doctors are perceived by society more generally? (Note: change positively or negatively?)
5.3	15mins 16:35 – 16:50	**Dr's STIMULUS C** Aim to provide information on: the current role of judges	Continuing to think about this hypothetical situation, in order to be eligible for assisted dying, a decision would be needed that the individual: ❖ Meets the medical criteria (e.g. diagnosis and prognosis); ❖ Has the capacity to make the decision (e.g. the choice is not undermined by a psychiatric disorder such as clinical depression; ❖ Is acting voluntarily and free from coercion Who should making this decision fall to? ❖ the individual's treating doctor ❖ a doctor who has no clinical relationship with the individual or ❖ a judge, on the basis of information provided by doctors • Do you have confidence or concerns in relation to any of these issues?

5.4	**10 mins** **16:50 – 17:00**		• For each of these three options, what would be the impact on the doctor-patient relationship? PROMPT: what if the court appointed an independent doctor to provide the lethal drugs?

5.5	**10 mins**
	
	17:00 – 17:10
		N/A	Continuing to think about this hypothetical situation:
			
			• What might be the professional and/or emotional impact on doctors themselves?
			  - In making the decision
			  - In delivering the process
			  - In the practicalities of being there when a patient dies

5.6	**5 mins** **17:10 – 17:15**		Feed in views of the public from the morning session. (Note that these are views from one event only) • What is their response – what they would have expected/ are they surprised/ any concerns?

• 17:15-17:30 – Closing plenary sessions – 15 mins

- Bring the participants together to thank them for their time and participation
- Provide feedback from the four tables
- Ask if they have any final thoughts and/or issues that the discussion has raised in terms of meeting patient needs or in relation to the doctor/patient relationship.

Thanks and close

Researcher note: please ensure all charts and stimulus material are collected at the end of the session

9.6. Public stimulus

Stimulus A

ELCPAD Workshop Topic Guide – Public   **BMA**

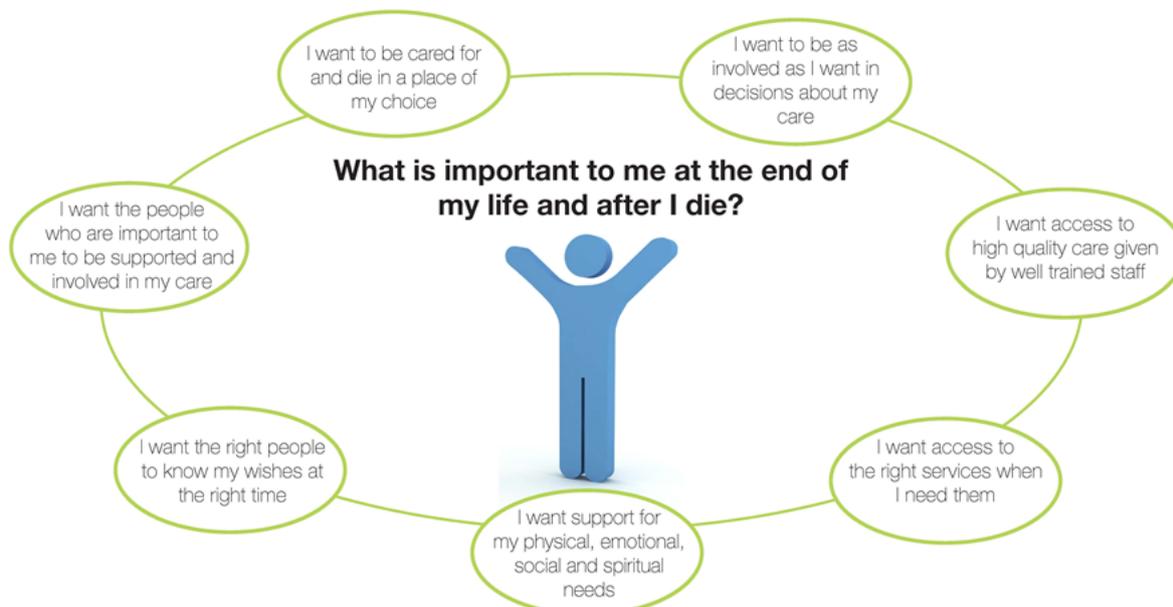**STIMULUS A – WHAT DO WE MEAN BY END OF LIFE CARE?**

End of life care: refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end of life care phase may last for days, weeks, months or even longer.

It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die.

It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Stimulus B

STIMULUS B – WHAT SHOULD GOOD END OF LIFE CARE INCLUDE?

I want to be cared for and die in a place of my choice

I want to be as involved as I want in decisions about my care

I want the people who are important to me to be supported and involved in my care

What is important to me at the end of my life and after I die?

I want access to high quality care given by well trained staff

I want the right people to know my wishes at the right time

I want access to the right services when I need them

I want support for my physical, emotional, social and spiritual needs

Taken from: The Choice in End of Life Care Programme Board (February 2015) *What's important to me. A review of choice in end of life care, Executive Summary.*

Stimulus C

<table>
<tr><td colspan="2">STIMULUS C – WHAT DO WE MEAN BY …..?</td></tr>
<tr><td>Physician-assisted dying</td><td>An overarching term to describe physician involvement in measures intentionally designed to terminate a person's life.
This may include knowingly and intentionally providing a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. Administration of the drug may be by the individual him or herself (physician-assisted suicide) or by the physician or another person (euthanasia.)</td></tr>
<tr><td colspan="2" align="center">PHYSICIAN ASSISTED DYING IS UNLAWFUL IN THE UK</td></tr>
</table>

Stimulus D

STIMULUS D – HOW IS ASSISTED DYING CARRIED OUT IN THE COUNTRIES WHERE IT IS LEGAL?

- Assisted dying is legal in certain US states (Oregon, Vermont and Washington) for those with a terminal illness, and in the Netherlands, Belgium, Switzerland and Luxembourg for those with an unbearable and incurable illness.

- In all these countries, individuals must have the capacity to make an informed decision, must be acting voluntarily, and must have the agreement of two doctors.

- The most common method of assisted suicide used in countries where it is legal is by swallowing a large dose of barbiturates mixed in a large glass of water.

- The most common method of euthanasia used in countries where it is legal is by an injection of a coma-inducing substance followed by an injection of a paralysing agent/muscle relaxant.

- There have been 859 deaths from physician assisted dying in Oregon since the law was passed in 1998.
  - Information on complications is available in 530 of these 859 cases;
    - 23/530 experienced complications (known complications in physician assisted dying include nausea and vomiting, seizure or muscle spasms).
    - In addition, in a further 6 cases the drugs failed to work and did not result in death.
  - Information on time from taking medication to death is available in 512 of these 859 cases:
    - Half died within 25 minutes (shortest 1 minute) and half took longer than 25 minutes (longest 104hrs)

Stimulus E

STIMULUS E – THE ROLE OF JUDGES IN MEDICAL CASES

Judges in the civil (non-criminal) courts have a lot of experience of considering and ruling on medical cases. These are often cases where there is uncertainty or disagreement about the patient's ability to make a decision or about whether treatment should be provided. Some types of decision are considered so important that a decision must always be made by the court.

The judge is provided with information from the patient (if possible), family members and doctors and then weighs up the arguments, applies the relevant law and makes a decision about what should happen.

It has been suggested that if assisted dying were to be legalized in the UK, it should be a judge, using these procedures, that makes the decision about whether the individual is eligible for assistance to die.

9.7. Doctors' stimulus

Stimulus A

ELCPAD Workshop Topic Guide – Doctors
STIMULUS A: WHAT DO WE MEAN BY …?

Physician-assisted dying	An overarching term to describe physician involvement in measures intentionally designed to terminate a person's life. This may include knowingly and intentionally providing a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. Administration of the drug may be by the individual him or herself (physician-assisted suicide) or by the physician or another person (euthanasia.)
PHYSICIAN ASSISTED DYING IS UNLAWFUL IN THE UK	

HOW IS ASSISTED DYING CARRIED OUT IN THE COUNTRIES WHERE IT IS LEGAL?

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  . Information on time from taking medication to death is available in 512 of these 859 cases:
      ○ Half died within 25 minutes (shortest 1 minute) and half took longer than 25 minutes (longest 104hrs)

Stimulus B

This version of the doctors' stimulus was used in the English events. It was amended slightly for the Scotland events to reflect regional variations in the legislative proposals.

STIMULUS B – LEGISLATIVE AND POLICY CONTEXT IN THE UK

Legislative and policy context

Assisted Dying Bill

- The Assisted Dying Bill (sometimes referred to as the Falconer Bill) was introduced as a Private Member's Bill into the House of Lords by Lord Falconer in June 2014.
- Under the Bill, a person requesting assisted dying in England and Wales would have to be at least 18-years-old; terminally ill and expected to die within six months; and have the capacity to make such a decision.
- Two doctors would have to agree that the individual met the eligibility requirements of the Bill. A doctor would be required to provide the medication; prepare it for self-administration; and stay with the person until the time of death.
- The Bill fell when Parliament prorogued for the General Election on Monday 30 March.

Assisted Suicide (Scotland) Bill

- The Assisted Suicide (Scotland) Bill was introduced into the Scottish Parliament on 13 November 2013 by SNP MSP Margo McDonald. Following her death in April 2014, the Bill was being taken forward by Green MSP Patrick Harvie.
- The Bill had its stage one debate on 27th May 2015 in the Scottish Parliament and was rejected. MSPs voted against the Bill 82 votes to 36, and the Bill will not progress any further in this session.
- Under the Bill, a person requesting assisted dying would have to be at least 16-years-old; have an illness that is terminal or life-shortening; or a condition that is progressive and either terminal or life-shortening and see no prospect of improvement in their quality of life; and have the capacity to make such a decision.
- Two doctors would have to agree that the person making the request met the eligibility requirements of the Bill, and agree that the patient's conclusion about their quality of life was not inconsistent with the facts known to them.
- The Bill would have created the new role of a "licensed facilitator" who would provide and prepare the medication, and be with the person at the time of death.

- There are no proposals for legislation in Northern Ireland.

Stimulus C

STIMULUS C – THE ROLE OF JUDGES IN MEDICAL CASES

Judges in the civil (non-criminal) courts have a lot of experience of considering and ruling on medical cases. These are often cases where there is uncertainty or disagreement about the patient's ability to make a decision or about whether treatment should be provided. Some types of decision are considered so important that a decision must always be made by the court.

The judge is provided with information from the patient (if possible), family members and doctors and then weighs up the arguments, applies the relevant law and makes a decision about what should happen.

It has been suggested that if assisted dying were to be legalized in the UK, it should be a judge, using these procedures, that makes the decision about whether the individual is eligible for assistance to die.