

End-of-life care and physician-assisted dying

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



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

This volume is the last in a three part report on a project on end-of-life care and physician-assisted dying. The project was overseen by a steering group appointed by BMA Council, working with a staff project team from across the BMA.

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Thanks are also due to the various BMA committee members who commented on an earlier draft of this report.

Foreword from the Project and Steering Group Chair

This third volume of the BMA's report on end-of-life care and physician-assisted dying marks the culmination of this project, bringing together our response to the research and the discussions with groups of members and experts, and making recommendations which will add to existing calls from across the sector to prioritise and improve end-of-life care.

There is a clear desire amongst doctors to have better support and training to help improve the care they can offer patients at the end of their lives, whilst both doctors and the public recognise the pressures on doctors' time, and that the communication and coordination on which the best examples of practice so depend are too often constrained by conflicting demands on that time.

During our review and discussions, the challenges of delivering on people's choices, and of meeting their expectations, were recurrent themes. Paucity of information, limited discussion and societal change may combine to drive unmeetable expectations which are unhelpful for doctors, patients and their families or close circle. Being realistic in our expectations should not limit our ambitions to improve; the information we have gathered indicates that there are many improvements that might be made without seismic change or massive investment. Indeed, some high-impact developments would need relatively small change and need not wait for major, governmental intervention to make a real difference to patients, their families and those close to them. Nonetheless there is much that governments should and could do to ensure the best of end-of-life care is available and accessible to all – much of which could even have a beneficial impact on current financial, and other, challenges.

Throughout the first two volumes the difficult area of physician-assisted dying has been considered. We have not sought to provide detailed recommendations on this topic in this third volume, as our aim was to inform debate, not to define it. Nonetheless we have highlighted key areas that merit discussion and we are pleased that this project, and some of the associated activities, have begun to move debate beyond over-simplistic for/against positioning to consider some of the complex issues surrounding physician-assisted dying, its potential complexities and changing legislative and practical frameworks – conscious that the environment, assumptions and assertions are changeable and open to interpretation. That discussion continues through BMA Communities, our divisions, our regional and national councils and, ultimately at our Annual Representatives Meeting in June 2016.

Definitions are important here, and it is easy to confound debate by misunderstanding meaning. This project has taken a consistent approach and I urge that you keep the definition used (on page 66) in mind as you think about the issues in these reports.

These volumes are not a quick read – but they are a valuable read, and merit your time and detailed consideration. My sincere thanks to all of those involved in this project – the writers, researchers, steering group team, communications, conferences and design teams. Their enthusiasm both for this project and for developing different ways for the BMA to work with members, has been well worth their skills and commitment.

Dr Ian Wilson
Project and steering group chair
BMA Representative Body Chair

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Introduction

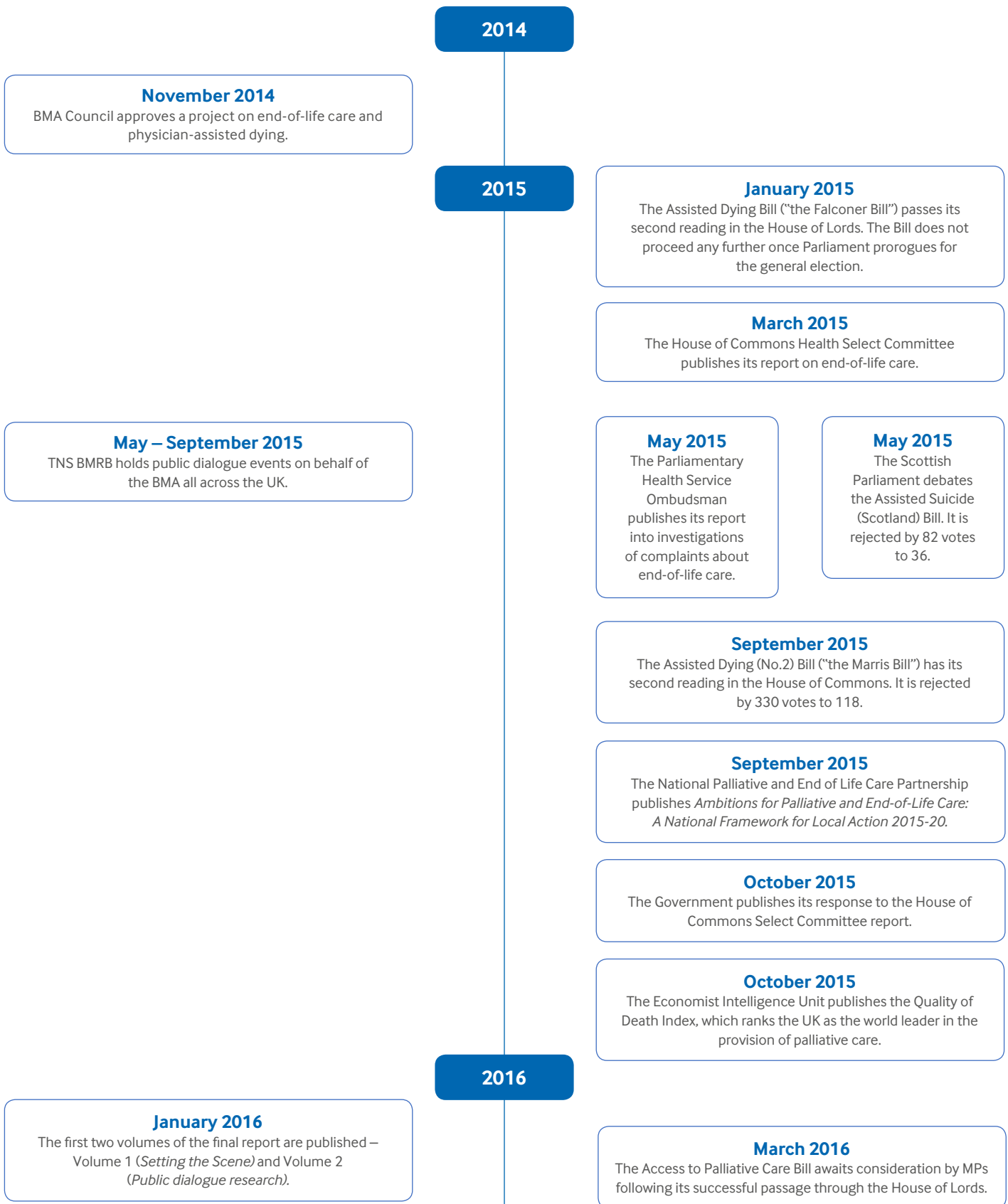
This is the final part of a three volume report of our project covering both end-of-life care and physician-assisted dying. The purpose of this volume is to reflect on some of the points emerging from the public dialogue research we commissioned with doctors and the public (reported, in detail, in [volume 2](#) of this report) and to see what lessons can be learnt and what changes are needed to ensure that our members are able to provide high quality end-of-life care for all of their patients. It does not seek to address all aspects of end-of-life care or to repeat the work undertaken so comprehensively by other organisations. Rather, it presents our reflections and recommendations on the public dialogue research we commissioned, and sets the agenda for our future work and policy development in this area. For information, existing BMA policy relevant to the project can be found in appendix one.

In relation to end-of-life care, the findings from the dialogue events held as part of the research were not radically different to other reviews, surveys and research that have gone before. In some ways this is reassuring; it helps to build up a coherent picture of what needs to be done. In other ways, however, it is disappointing. Disappointing in the sense that for some time it has been recognised that improvements in care are needed, and those changes have been identified by multiple reviews, but change has not happened quickly enough, so that in some ways we, as a society, are still failing on this account. Despite the good intentions of all concerned, and the wise words and promises of governments, end-of-life care has not been given the priority it deserves by the NHS. All of us will face death at some point and the way that death is managed will have a lasting impact on those left behind. There are pockets of excellence around the UK but we need to get care right for everyone, all of the time.

Achieving this is no simple task and will require significant investment, both financial and workforce, as well as genuine collaboration and joint working. In this report we have set out what we see as the main challenges identified in our research, and the ways we can see to address them. We are keen to work with others to seek, and contribute towards, the changes that are needed. We recognise that further research is needed in a number of areas, and we encourage our members to take opportunities to participate in this and play a role in actively advancing knowledge in this area.

Attendees at the public events were asked what they believed a good end-of-life care approach would look like. They identified eight factors, with the central theme of being treated as a person which encompasses notions of respect, choice and dignity. Other important factors fell into the themes of medical services; location; information; communication; planning and coordination; emotional support; and financial and legal issues. Our reflections and recommendations cover all of these broad themes with three additional, overarching themes: the need to ensure fair and timely access to high-quality services based on individual need, across the UK; the need for better training and support for those professionals caring for patients at the end of life; and the role of families and those close to patients in end-of-life care. Our evidence review (found in [volume 1](#)) and the events ([volume 2](#)) also addressed some aspects of physician-assisted dying, specifically exploring views on the impact on the doctor-patient relationship if physician-assisted dying were to be legalised in the UK. This is an issue on which there has been very little research but it is an issue that is frequently raised in debates on the subject at our annual representative meetings. The knowledge and insights we have gained will be made available to inform our future thinking as and when the BMA discusses this issue. Some initial reflections on the findings are made at the end of this volume.

A timeline of the project



Part one

Overarching findings and key messages

Part one: Overarching findings and key messages

The dialogue events we commissioned generated a lot of information which is set out in [volume 2](#). This third and final volume reflects on the discussions that took place, highlights some of the key challenges raised by our members and the public and makes a number of recommendations for change. There are some findings – our ‘take-home messages’ – that stand out as being particularly striking and important. These are overarching issues that are reflected in, but go beyond, the key themes discussed in part 2 of this report.

- We heard many examples of excellent practice and initiatives around the UK but it was clear that there is considerable variation in the quality of care provided to patients across the country and even within geographical areas, as well as between different conditions. High quality care is not being delivered consistently and the infrastructure within which care is delivered needs to be improved in order to address this.
- Doctors need more training and support in order to improve the quality of end-of-life care they are able to provide.
- The wellbeing of families was one of the most important considerations for the public when thinking about end-of-life care but the doctors at the events were less likely to identify this as a key concern for the public.

1. Ensuring consistently high quality services

‘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

During the events with doctors some excellent initiatives were discussed and many doctors expressed surprise, admiration and in some cases envy at the comprehensive and coherent systems in place, particularly in hospices and in some communities. Unfortunately, we also heard of many cases where patients had been unable to get the support and care they needed or where problems with communication and coordination had led to confusion and missed opportunities. Some families, in particular, spoke of long delays in getting appropriate pain medication out of hours where relatives were being cared for at home.

Overall, there was a feeling amongst doctors that things were improving and the current political momentum to improve end-of-life care was welcomed. We also welcome the increased recognition of end-of-life care as an area requiring improvement, and the examples of good practice we came across. We note, however, that some significant changes, including investment in funding and workforce, will be needed to develop the infrastructure within which care is provided so as to ensure that high quality care is accessible to all patients, across the UK, irrespective of their age, capacity and medical condition. It is clear that, in order to provide consistently high-quality services, staff who are providing care to patients facing the end of life need to be supported in this role.

Figure 1: Areas of concern for doctors about the current provision of end-of-life care in the UK

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



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In seeking to improve the quality and consistency of care provided, we need to be ambitious but also realistic about what is achievable in the short to medium term to ensure that the expectations raised are manageable. The current emphasis on patient "choice" in government strategies is meaningless without an infrastructure within which choices can realistically be met, and can add to the pressure on doctors, patients and families. Unfortunately, at the present time, it is unrealistic for the BMA to expect that hospice beds should be available for everyone who wants and needs one or, for example, that everyone who wants to die at home will be able to do so, because the facilities and support are simply not available to allow this to happen.

There are, however, a number of areas for improvement that are both important and achievable without the need for massive (and unrealistic) investment. Much change can be brought about by better use of existing resources and ensuring social care support is in place, as well as embracing new technologies to monitor patients and improve communications. Section 5 addresses a number of issues related to medical services where improvements could be made, including: recognising when patients may be dying, particularly frail elderly patients with multiple comorbidities; adequately addressing mental capacity issues for decision-making and treating comorbid mental disorders; avoiding inappropriate and unnecessary hospital admissions; improving inefficient and slow discharge processes to transfer people out of hospital once they have been admitted; and the need for an approach to the care of people dying from conditions other than cancer, such as COPD (chronic obstructive pulmonary disease) and heart failure, which recognises the overall pattern of an illness, differentiating reversible conditions from the underlying irreversible disorders. The need for improved provision of, and access to, services also features strongly in the discussion in section 10 on emotional support, as well as the importance of the provision of information and the coordination of care – discussed in sections 7 and 8; these are all relatively easy to resolve. Training and support for those providing end-of-life care services is also a central issue where improvements are needed and can be achieved (see below). There is a clear role here for all those involved in commissioning, planning, organising, staffing and managing services but many of the problems are overarching structural and systemic issues beyond the control of individual doctors, managers or commissioners and a coordinated national approach is required. Services will not be identical throughout the UK, nor should they be – different challenges will face those in rural and urban locations for example – but the same overall quality of service should be available to meet the specific needs of individuals within the local population.

Within the range of services available, all patients should have timely and fair access to the services they need. All patients with complex needs should be able to access specialist palliative care, whether in hospital, a hospice or in the community. Those who are not experts in palliative care and are providing care to patients who are nearing the end of life, should be able to get advice and support from experts in palliative care whenever they need it. In order to achieve this, systems should be put in place to ensure that specialist palliative care is available as part of emergency services so that a rapid response can be provided in an urgent situation.

‘I think you’re a person that’s dying anyway and it’s very low on priorities...’

Public

For all of this to happen, end-of-life care needs to be prioritised by all governments across the UK, both in terms of funding and planning. It requires having a clear and consistent approach to ensure that the right services, at the right level, are available at the right time for everyone. The question is how to move forward from where we are now to where we want to be. Many excellent reports have been written, many recommendations made and many organisations are contributing to the debate. Now is the time to bring all of this together and to come up with a clear, funded plan of action to make change happen. We hope national governments will accept the challenge to make end-of-life care a top priority and to work together with other organisations to make these much needed changes; we offer our help and support to achieve this.

Key points:

- There are examples of excellent end-of-life care being provided throughout the UK but there is considerable variation between and within geographical areas and between medical conditions.
- Significant changes, and investment in funding and workforce, will be needed to develop the infrastructure within which care is provided in order to address this inconsistency.
- Our aspirations should be ambitious but also realistic about what can be achieved within the short to medium term so that unrealistic expectations are not raised amongst the public – the language of “choice” is important but only as far as it represents genuine and realistic options.
- In order to make the significant number of achievable changes that will lead to the fairer provision of services, national governments need to make end-of-life care a top priority and work with other organisations to develop a clear, funded, plan of action.
- The BMA would welcome the opportunity to work with governments and others to achieve this goal.

2. The need for education, training and support

“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

Doctors and other health professionals play a critical role in caring for patients at the end of life, and are very often fundamental to how good a death is perceived to be by surviving family members, friends, and carers. At the dialogue events we heard from a number of people with recent experience of bereavement, and in the overwhelming majority of cases where they felt their loved ones had received good end-of-life care, highly-skilled, knowledgeable and compassionate doctors featured prominently. Participants who had no direct experience of end-of-life care also highlighted as important the provision of high-quality care by highly skilled individuals.

Education and training

The UK has led the way in developing and providing high-quality specialist end-of-life care, and there are significant numbers of palliative care specialists, whose training will have equipped them with the particular knowledge and skills to deliver this. Such individuals, however, make up a small percentage of the total number of health and care staff working in the UK. The overwhelming majority of the medical workforce – doctors and other health professionals working in the community, in hospitals, in care homes – will all be involved in providing care at some level for patients approaching the end of life, without it being the main component of their work. Despite this, there was a tendency amongst the doctors attending the events to feel that end-of-life care was primarily a concern for only certain groups of doctors (e.g., palliative care physicians or oncologists). It is crucial that awareness of end-of-life issues is generated in the medical profession, and that it is made clear that it is not the sole preserve of a few specially trained doctors. All those involved in clinical care – including those working in out-of-hours services - must have a basic understanding of end-of-life issues, and understand when and how to involve other specialties or disciplines. Multi-disciplinary team (MDT) training can play a particular role here and help with team working and collaboration.

What was clear from speaking to doctors at the events was that not all of them felt confident in providing all aspects of end-of-life care – particularly in areas which do not involve clinical decision making. Significant numbers of medical students and junior doctors highlighted a lack of exposure in their training to patients receiving palliative care or dying, and felt they lacked confidence in discussing the end of life and dying with patients. This was a feeling shared by other doctors at more advanced stages of their careers who said they had received very little training in discussing sensitive issues with patients. There were concerns about specific issues relating to the assessment of mental capacity, in particular, dealing with language difficulties, cultural issues, diagnoses of mental illness, or dementia or other

cognitive impairments. There was a perceived lack of confidence – particularly amongst junior doctors – in the administration of pain relief, whilst doctors of all ages reported difficulties in predicting how long a patient has to live. Amongst many doctors – especially those at the beginning of their careers – there was a desire for more training to address these issues. Doctors were also concerned about the continuing support (including support for their own wellbeing) available for them as they cared for dying patients throughout their careers. These issues are all explored in more detail throughout various sections of this report.

Our findings join a number of other recommendations on the crucial role of the workforce in the provision of high-quality and compassionate end-of-life care. The importance of a skilled and well-trained workforce in delivering high-quality care, and the need for clear education and training in this area, are enshrined in all four nations' end-of-life care strategies – discussed in detail in [volume 1](#) of this report. Several other organisations and groups, including the Leadership Alliance for the Care of Dying People, the Choice in End-of-life Care Programme Board, and the House of Commons Health Committee, have noted some of the shortcomings in the level of skills and knowledge required to deliver high-quality care, and have called for appropriate training to be available for health and social care staff who provide care to people at the end of life. The General Medical Council continues to set the standards and outcomes for undergraduate medical training and, following the withdrawal of the Liverpool Care Pathway, has taken steps to try to ensure that undergraduate and postgraduate curricula equip doctors to care for dying patients. More information on this is provided in [volume 1](#).

There is a role to play here for many different bodies: professional regulators; providers of undergraduate and postgraduate education; health authorities; employers; and professional associations. There will also be a role for specialist palliative care individuals and teams in supporting the development of the wider workforce. Education in end-of-life issues should not be seen as a one-off, but part of training at all stages – including induction programmes; continuing professional development (CPD); and perhaps part of mandatory training (as is the case with CPR, infection prevention, and fire safety). There are a range of e-learning modules available to NHS staff, including the End of Life Care for All (e-ELCA) programme.¹

We recognise the current demands of training programmes for doctors. Dying, however, is the one thing that will happen at some point to every person. It is vital that doctors have the necessary confidence, knowledge and skills to identify and address end-of-life issues. The development of education and training for all doctors caring for patients at the end of life will take time; but ultimately, the development of a confident and skilled workforce will yield significant benefits for patients and their families.

Key points:

- Education and training in end of life issues is crucial for the large number of doctors for whom end-of-life care is not the sole component of their work, but who will play a significant role in caring for dying patients.
- Education and training is not a one-off event, but should be seen to be part of training at all levels.
- The development of education and training for all doctors caring for patients at the end of life will take time, but ultimately will yield significant benefits for patients and their families.

Access to ongoing support

Greater education and training in the issues around end-of-life care are a critical first step in improving the nature and quality of care provided to patients. It cannot, however, be achieved in a vacuum, and if doctors are to be adequately prepared to provide high-quality care, they must have the support of colleagues, managers, and the systems within which they work. This support must manifest itself in the following ways.

Time to dedicate to the care of dying patients

One of the biggest challenges to the provision of high-quality care identified by doctors at the events was the lack of time they had available to them: time to have difficult conversations with patients and their families; time to speak with other doctors and teams involved in patient care; and time to provide emotional support and meet some of the holistic needs of patients. Members of the public were generally sympathetic to this, and acknowledged the time pressures doctors, particularly GPs, faced.

A crucial part of the support from colleagues, managers, and employers will therefore mean giving doctors the time and space in which to provide high-quality care for patients.

Support in accessing training opportunities

In addition to ensuring that medical staff have access to appropriate training opportunities, employers must also ensure that they are able to take advantage of those opportunities, by prioritising training and releasing staff from clinical duties to attend. They also need to consider how any associated costs are handled.

It is also important for doctors, senior colleagues, and employers to recognise that not all education and training will take place in a classroom. Every encounter that a doctor has with a patient is a learning opportunity and doctors should be supported to have the time and space to reflect on these.

Clinical and practical support for doctors caring for dying patients

The expectation for the existing workforce should be that all doctors in clinical care have the core competencies required to care for dying patients. They should not be expected to be able to manage every single aspect of that care. What is expected, however, is that they should be able to identify when specialist advice is required, and to access it whenever that need arises. Information on whom doctors can contact when they have questions or need advice about providing end-of-life care should be disseminated to all those who may come into contact with patients towards the end of their life.

This is particularly important for doctors providing care out of hours. A huge number of patients' health needs will fall within out-of-hours periods – yet many of the doctors attending the events expressed concern that the quality of care provided to dying patients out of hours was sometimes poor. As discussed in [volume 1](#), existing evidence suggests that doctors working out of hours experience a lack of confidence in assessing palliative care emergencies; managing symptoms in non-cancer patients; and prescribing. Adding to these concerns is the fact that doctors working out of hours report feeling alone and being unsure of whom to call for advice – something which is compounded by the often poor communication and handover between in-hours and out-of-hours services. This emphasises the need for systems to be in place to ensure that specialist palliative care is available as part of emergency services so that a rapid response can be provided in an urgent situation. For example, in Wales, consultants in palliative medicine participate in on-call rotas to provide telephone and e-mail advice to any health care professional at any time.² Similar mechanisms are available in some other parts of the UK, although frequently the availability of this service is not widely promoted. Doctors wishing to find out about the services in their area should contact their local hospice or palliative care team.

Emotional support for doctors caring for dying patients

There should be acknowledgment from employers that, even amongst very experienced doctors, caring for patients at the end of life can exact a heavy emotional toll. Employers should ensure that appropriate emotional support is made available to doctors, or that relevant information on services available is disseminated and shared. Doctors should be supported and encouraged to access such services. This is explored in more detail in section 10 on emotional support.

Key points:

- Doctors must be backed up by support from colleagues, managers and systems, which includes ensuring that time is allowed to ensure individual patients' needs can be met.
- Provisions should be put in place to ensure that doctors can access specialist clinical and practical advice, whenever and wherever that need arises.
- Information on the emotional support available to doctors should be disseminated and shared in all places of work.

3. The central role of families and those close to patients

“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.”

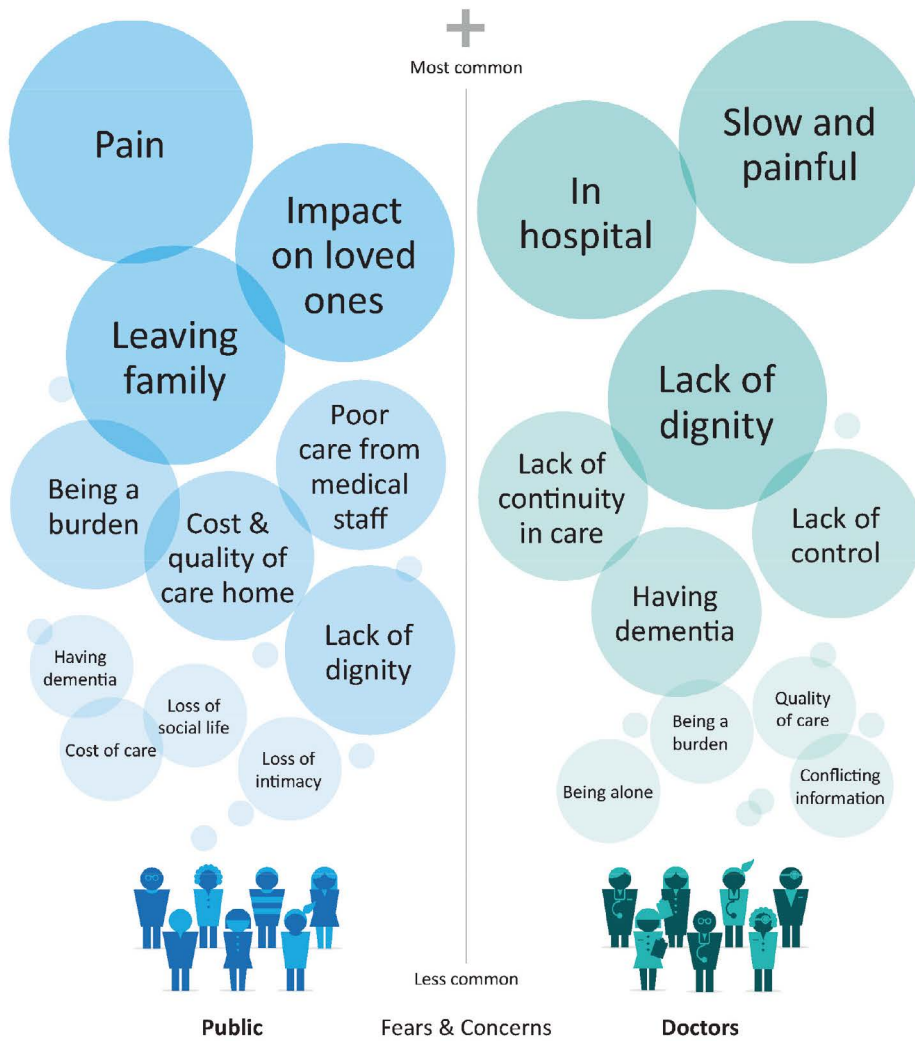
Public

In the first session of the events members of the public were asked to think about their hopes, fears and concerns about end of life and dying and, as a table, to agree their top three concerns. In the afternoon, doctors were asked what they thought the public had chosen as their top three concerns. Many of the same issues were raised and, not surprisingly, pain was cited by both groups as a major issue. The most striking feature of this exercise, however, was the prominence of the family and their welfare in the minds of the public and that the doctors at the events did not identify this as a key concern for the public. (Family is used in this context as a short-hand to refer both to those related to the individual and those who are emotionally close.) This is a significant finding which we can learn from to help to improve end-of-life care. Knowing that the impact on family members is likely to be a major concern for patients at the end of life, and taking steps to address these concerns, will not only help the families themselves in the short and long-term but may also help to reduce anxiety amongst dying patients.

Figure 2: The public's fears and concerns about end of life and dying

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



“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 terminal. I don’t want anyone having to do that for me... I would hate to put my family through that, the strain of helping me.”

Public

“Being a burden” on family members was a significant concern for the public which doctors also recognised, although some doctors commented that this conflicted with their own experience of families who were very keen to be involved in their loved one’s end-of-life care. This contradiction was also recognised in some of the discussion with the public with one person commenting that although their daughter was keen to provide care, this is “the last thing I want to happen” preferring professional care and not wanting to put family members through that strain.

As well as being important to patients, families play a key role in caring for patients at the end of life, particularly where the patient has chosen to be cared for at home. Many doctors at the events commented on the considerable workload families take on when caring for loved ones at home and that, despite the rhetoric of choice in terms of treatment location, unless the patient has a family willing and able to provide the very high level of care that may be needed (particularly for individuals with dementia), dying at home is simply not an option. Even where the family are able to provide this level of care, they need support, information, access to services and some respite. Often, although keen to keep their loved one at home, it is too much for the family and the distress that the acceptance of this can cause to patients and families must be acknowledged and addressed. Although the demands are less extreme when patients are being cared for in hospital or hospice, being there to support a dying family member or loved one is challenging and there are some simple steps that can be taken to make things easier. Flexibility in terms of visiting times, providing information about places to stay close-by, easy access to refreshments, facilities for children such as somewhere to play, free car-parking or reasonable charges and staff giving explicit consideration to the needs of the family – such as offering a cup of tea or encouraging the relative to get some rest; all of this can help.

The involvement of families features prominently in some of the discussion on the key themes below – particularly in relation to communication, information and emotional support – and so these points are not repeated here. Given the importance of this issue to patients, and the devastating impact bereavement can have on adults and children alike, however, the aim of providing family-friendly services should be a key part of the discussion around planning and delivery of end-of-life care.

It must always be kept in mind that what happens to the patient will also affect the health and wellbeing of the family and loved ones around them and that the wellbeing of family members and loved ones will, in turn, impact on the patient. As discussed in section 10 on emotional support, children who are likely to be affected by the death will have specific needs, depending on their age and development, and may require specialist support. Families may find it difficult to know how best to support a child in this situation. The possibility of children being severely affected by the death should always be thought about when providing support and information to those close to dying patients.

Whilst it is entirely appropriate, and the doctor’s professional obligation, to focus principally on the needs of the patient, it is important also to think of the duty owed to the family and loved ones of the dying patients, whose needs and wellbeing also need to be considered. Events around the death will live on in their memories and will affect their mental and physical wellbeing in bereavement. It is also important to recognise the caring role that families may have taken on and that this has its own stresses as family carers try to keep up with their own lives and manage their own feelings about the impending death of their relative. The wishes of family members cannot override the primary duty to the patient but, in most cases, the two cannot be seen in total isolation.

Confidentiality is central to the doctor-patient relationship and must be respected but this does not mean that information can never be shared. It is the responsibility of treating professionals to ascertain who the patient wants and needs to receive information about their condition and how much the patient wants family members involved in discussions about care, encouraging them to consider the practical and emotional benefit of doing so. There are, for example, occasions when family carers cannot provide their care and support adequately without timely sharing of certain information and patients need to be aware of this. Where the patient lacks capacity for the decision about sharing information with the family, it is reasonable to assume they would want information shared with those close to them, unless there are grounds to believe otherwise.

It is a requirement of the Mental Capacity Act and the Adults with Incapacity (Scotland) Act, as well as being helpful, that where a patient lacks capacity, the doctor finds out from the family about any previous discussions or other evidence in which the patient expressed wishes about their end-of-life care. Likewise family members find this approach helps to remove some of the burden of being involved in decisions around end-of-life care for their loved one. It needs to be recognised, however, that not all families are close and dealing with family disagreement and dysfunctional family relationships were highlighted by doctors as a particular challenge.

Key points:

- The welfare of family members, and the impact on them of death and dying, is a matter of significant concern to the public and those providing treatment need to be aware of this and seek to address these concerns wherever possible.
- The pressure on families of caring for dying patients at home should not be underestimated and appropriate support and services, including provision for emotional support and respite care, must form part of the care package provided.
- Those developing and delivering end-of-life care services – in hospices, hospitals and in the community – should aim to make those services as family-friendly as possible.
- Meeting the specific needs of families for information, communication and emotional support – as discussed in the relevant sections below – should form a core part of the care of dying patients.
- Health professionals should determine the extent to which patients want and need information to be given to families, and their involvement in treatment and care decisions, and should respect this.
- If a patient lacks capacity, information should be shared with those close to them unless there are grounds to believe they would not wish this to happen.

Part two

Key themes

Part two: Key themes

As part of the dialogue events we commissioned, members of the public were asked to describe “a good death” and what a good end-of-life care approach would look like for a family member or loved one of theirs. They identified eight key needs or areas that they thought needed to be considered and addressed to provide good end-of-life care.

These were:

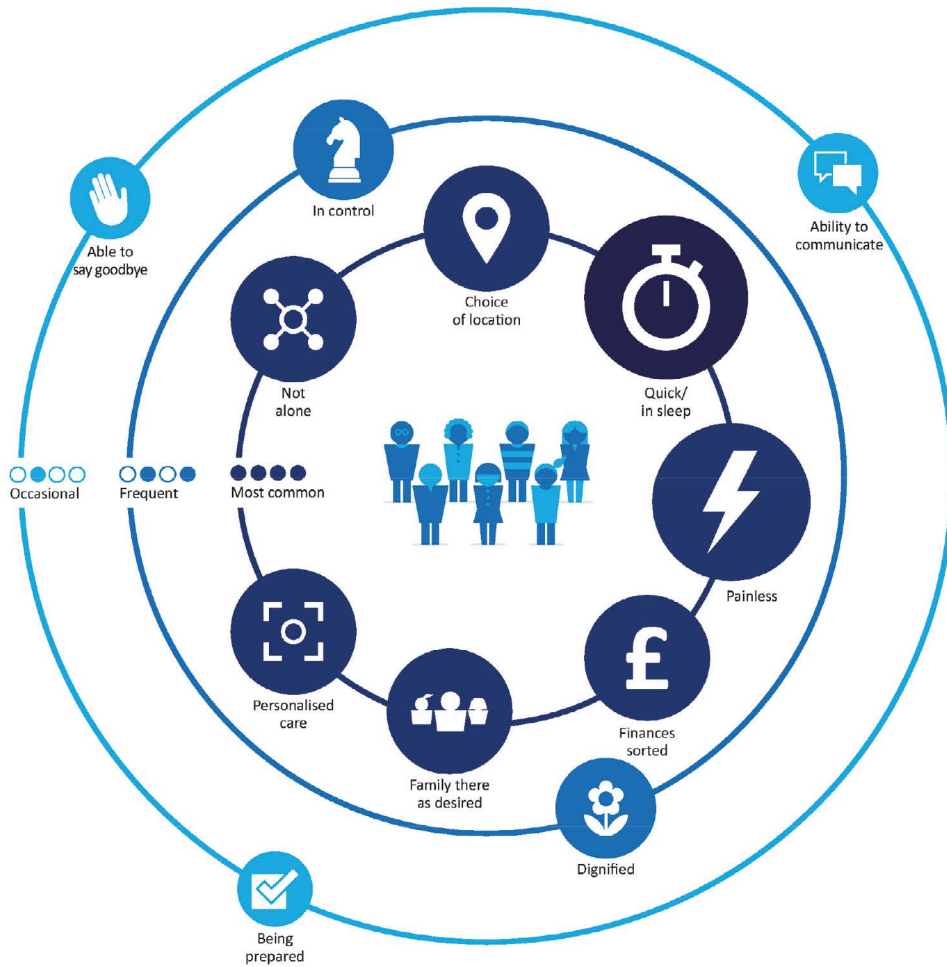
- **Being treated as a person** – which was central to and at the heart of the provision of good end-of-life care
- The timely provision of **medical services**
- The **location** of where end-of-life care services are delivered (hospital, hospice or community)
- The provision of **information** (diagnosis, prognosis, treatment options, progression and other services which are available)
- **Coordinated care** that is well planned but flexible and reflects the expected disease course and patient’s wishes
- Good **communication** between all the parties involved with end-of-life care (the patient and their family and GPs, specialists, nurses, counsellors etc.)
- **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.

These key themes, and the important components of them, are highlighted in the following infographic (figure 3) and are explored in more detail in the sections that follow.

Figure 3: What a good death looks like for the public

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

What a good death looks like for the public



Being treated as a person



4. Being treated as a person

“Not a generic plan, what works for a cancer patient, but this is what you need, what YOU need.”

Public

When participants at the events were asked to describe what good end-of-life care would look like for them, they were unanimous in their view that central to any approach would be for them to be “treated as a person”. This theme emerged both from respondents raising it explicitly, but also through more oblique discussions where it was interwoven throughout other elements of good end-of-life care. In addition to this brief section outlining the concept, therefore, other sections of this report will address more specific aspects of end-of-life care associated with “being treated as a person”.

Being treated as a person covers a wide range of ideas, but at its heart is the idea of being treated as a distinct individual, with particular needs, wishes and goals. Participants expressed concern that at the end of life people may be stripped of their identity and seen by doctors and other healthcare staff as “a number” or defined by their condition. As one participant put it “I think you worry because the medical people see it every day, a thousand times a week... you become a number rather than a person, even at the end.” Many attendees spoke of the desire for care tailored to them and their needs, as opposed to a generic plan which could be applicable to any patient with their condition.

“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

Inextricably linked to the concept of being treated as a distinct individual were ideas of “dignity”, “respect” and “compassion” – words which were commonly heard on all the tables at the events. Many attendees raised negative stories of care they had seen reported in the media (often referring to the coverage of the Liverpool Care Pathway) and expressed concern and horror that this might happen to them. Some participants were worried that

healthcare professionals could become desensitised in caring for dying patients and provide only very basic, clinical care, lacking warmth. Amongst those participants who had recent experience of bereavement it was clear that the way in which the dying person is treated by those with responsibility for their care stays with relatives long after their death. There were some mixed experiences amongst this group. One participant recalled the death of their grandmother and how “the minute she passed away it was almost as if another off the list of people had just gone.” Others spoke movingly of the warmth and compassion shown to their relatives – with many expressing their gratitude for staff who treated their relatives as normally as possible; who would laugh and joke with them; and who took the extra time to sit with them and “have a chat.” In many cases, this extended

to how staff responded after death, with hospital staff treating the body with dignity and respect. Kindness and a human, personal touch to care was valued by all attendees at the events. Although it can often seem a low priority for already overstretched staff, it is crucial

“The palliative care 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.”

Public

that doctors appreciate its importance and acknowledge that for each individual dying patient, there is only one chance to get it right.

How this concept translates into the delivery of end-of-life care can be seen in all four nations' end-of-life care strategies (discussed in [volume 1](#)), which have as their core aim the delivery of high-quality, compassionate care which treats patients with dignity and respect. A key reason for the phasing out of the Liverpool Care Pathway was the acknowledgement that a "one-size-fits-all" approach to end-of-life care was not the right method, and there was a call for an end-of-life care approach to take the form of individual plans, backed up by good condition-specific guidance. Following this, there has been a renewed focus on recognising the individuality of all patients, and forming a care plan which best meets their individual needs, circumstances, and preferences. The most recent NICE guideline on caring for dying adults has a whole section dedicated to providing individualised care.³

A crucial part of ensuring that patients' wishes and preferences are heard and incorporated into any care plan is making sure they are discussed in the first place and reviewed as people's wishes and needs change. We have already emphasised as part of our overarching themes the importance of all doctors caring for dying patients to be appropriately trained and supported. As is explored in section 9 on communication, this is particularly crucial for communication and listening skills, to enable doctors to initiate and handle difficult conversations with patients and their families. It is not enough, however, that doctors have the training to do this – they must be supported by senior staff and managers and be given the time and quiet space to have these important conversations with patients and those important to them. Linked to this is the need to overcome the general public's discomfort in talking about death and dying, and to encourage them to consider their wishes and make them known, either formally or informally.

Choice was another idea frequently elucidated from the concept of being treated like a person by those attending the events. Participants mentioned the importance of having choice over whether or not to have treatment; choice over the type of treatment from the options available; and choice over where that care is provided. As we make clear in other sections of this report, patient choice is a key element of individualised care – recognising as well, that people may change their minds. It is vital, however, that this is not just illusory: choice over location, for example, must be supported by systems and services which can make it a reality. Choice about treatment options can be elusive if patients are not supported to engage with the options available. In section 5 on medical services, we detail some of the challenges experienced by doctors in assessing mental capacity at the end of life, and maximising decision-making capabilities so that patients can participate as fully as possible. When the person does not have capacity to make a particular decision, then family involvement in best interests meetings is essential to ensure that the person's interests remain at the centre of the decision-making process.

There may be a tension between being able to treat patients as individuals and a tendency towards risk-averse practice. The most recent NICE guideline on the care of dying adults warns of the danger of placing "tradition" and "familiar policies" before the needs of individuals and families.⁴ One of the potential points at which this tension becomes evident is examined in more detail in section 5 on medical services, which highlights some of the difficulties associated with discharge planning – leading to unnecessarily long hospital stays for some patients, who may wish to be at home regardless of some of the risks that might involve. Many of these risks may be directly related to the lack of social care available and, at the point of discharge, there must be consideration of risks patients may encounter when returning to live at home, such as falls or other physical injuries which could be sustained from everyday activities, such as bathing, cooking, or moving around the home. Whilst doctors cannot, and should not, ignore those risks, there is a balance to be struck. They must ensure that compassionate and individualised care is not sacrificed as a result.

Key points:

- The importance to patients of being treated as a person should be kept at the heart of all provision of end-of-life care services.
- All individuals at the end of life should be cared for with dignity, respect, and compassion.
- Providing individualised care should be supported by training and support for doctors in communicating with and listening to patients about their wishes and preferences for end-of-life care. Patients should also be encouraged to overcome their discomfort with talking about death, and consider and express their wishes.
- There may be a tension between being able to treat patients as individuals and the tendency towards risk-averse practice. Whilst doctors should not ignore risks, they must ensure compassionate and individualised care is not compromised as a result.
- Choice must be a reality for patients in their care planning, supported by doctors who can help maximise decision making and systems which can put in place the necessary arrangements for care.

Medical services



5. Medical services

“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 non-specific diagnosis... If you’re frail with dementia, in and out of hospital...Then I think your palliative care needs are less likely to be met.”

Doctor

As we expected, in the doctors’ events there was a lot of discussion about the medical services that are available to those approaching the end of their lives and the areas where these work well and less well. A number of issues emerged from these discussions which are explored below. Many of these overlap with other sections of this report, for example where they raise points about health professionals’ need for training and support or where they relate to information and communication with patients and families.

“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

Identifying when patients may be approaching the end of their lives

A significant issue raised at most of the doctors’ events was the importance of identifying when patients may be approaching the end of their lives, so that care can be appropriately planned and inappropriate hospital admissions avoided. This was seen to be a particular problem with frail older patients with multiple comorbidities, where individual treatment episodes were seen in isolation with nobody taking an overall view of the patient’s health status. In many cases, this led to inappropriate admissions to emergency departments, and subsequently to hospital wards, where the patient remained and often died. A strong view emerged that more needed to be done to identify those patients with multiple admissions for whom this was likely to indicate that the end of life was approaching and should trigger a review of the approach to future treatment.

This finding reflects the sentiments expressed by Professor Sir Mike Richards, Chief Inspector of Hospitals at the Care Quality Commission (CQC) who, giving evidence to the House of Commons Health Committee, suggested that those dealing with acute hospital admissions should, as a matter of routine, consider the possibility that the individual may die in the next year.⁵ A lot of work has already been undertaken to encourage the identification of these patients within general practice. The Gold Standards Framework,⁶ the Supportive and Palliative Care Indicators Tool in Scotland,⁷ and the ‘Find Your 1% campaign’⁸ (one percent of a GP’s patients will die in any given year) all provide guidance to assist with this goal. Once these patients are identified, specific consideration can be given to anticipating their likely needs, so that the right care can be provided at the right time and that their

families receive enough support to be able to care for their family member or friend at home if this is desired. Inclusion on specialist palliative care registers, for example, can help to ensure that information about their needs is available to others who need to know it in order to make appropriate treatment decisions. The Choice in End-of-life Care Review (discussed in [volume 1](#)) similarly highlighted early identification of those who are thought to be in the last year(s) of life as a key feature in delivering good end-of-life care for all. The evidence from the events suggests such steps can be very effective in improving care at the end of life, but that they are not yet adopted universally.

A number of doctors highlighted the difficulty of identifying those who may be coming to the end of their lives and predicting how long individuals have to live, both in those with a clearly diagnosed terminal condition and those who have general frailty and multiple comorbidities. The evidence discussed in [volume 1](#) also indicates that this is a very imprecise science and that overall the accuracy of such diagnostic predictions is low. Nevertheless, doctors should not become too focussed on trying to predict precisely how long a patient has to live but rather that the patient may be approaching the end of life, and that this form of advance care planning might be beneficial. Whilst some uncertainty is inevitable, there was a general view at the doctors' events that more training would be helpful, particularly amongst those for whom end-of-life care is only one aspect of their work. This would enable them to have appropriate discussions about the inevitable uncertainty of such predictions as well as the patient's wishes and preferences and for care plans to be put in place. There was also a call for more communication skills training to help doctors to have those difficult conversations with patients and families, to enable them to be honest with patients both about the fact that they may be approaching the end of their life and the lack of certainty around prognosis. This is discussed in more detail in section 9 on communication.

The doctors at the events believed that residents of care homes fared particularly poorly in terms of this form of identification and advance care planning. Where there were no on-site medical staff, their experience was that care home staff would automatically call an ambulance in the event of deterioration in the patient's health. But with better recognition that the patient was likely to be approaching the end of life, and coordinated advance planning, arrangements could have been made for the patient to avoid hospital admission and be cared for in their usual place of residence. This would require some changes to the way medical services are provided to these patients and the provision of adequately trained and competent nursing and care staff to provide end-of-life care. Currently all patients in residential homes, that do not have medical services on site, are registered with a general practice, and GPs are consulted in the event of a medical episode requiring treatment. However, this is often to deal with the particular issue at hand rather than to take a more overarching and holistic view of the patient's health status and to make an advance plan for managing future episodes. In many cases, the time is simply not available for this necessary broader review of the patient's health status and care needs to take place or for discussions with patients and those important to them.

Although a lot of the discussion at the events focussed on this group of frail elderly patients, similar points were made about patients with other conditions such as COPD and heart failure. Overall, there was a view that cancer patients generally fared better, in terms of having their care needs identified and met, but that improvements were needed for many other conditions. This disparity between conditions was also highlighted in the end-of-life care strategy for Wales (discussed in [volume 1](#)) which highlighted the need to encourage GPs to use palliative care registers for those thought to have less than one year to live and "in particular, non-cancer patients".

There was also debate generally at the doctors' events about some doctors' reluctance to accept that providing or continuing treatment may not always be in their patients' best interests. Some doctors considered that their colleagues did not always look at the overall situation before deciding to provide treatment and in some of these cases a hospital admission, or aggressive treatment, may not have been appropriate. Similarly, many doctors are reluctant to decrease treatment in a managed way as a patient approaches the end of life.

As discussed above, part of this is associated with systems failing to provide the time and space to make these assessments but it also needs to be acknowledged that some doctors remain reluctant to make that call, associating a decision not to pursue further active treatment as an acceptance of failure. We have long advocated that for every medical intervention a judgement should be made about whether that intervention would be appropriate and proportionate, in the sense of providing a net benefit to the individual patient, taking account of their past and present wishes and values.⁹

There is a key role for education and training in prompting a culture shift in terms of the way in which some doctors view death. Clinical staff need to ensure that treatments provided are both appropriate and proportionate, and they should be supported to identify and accept when patients are coming to the end of their lives without viewing this as a failure. This culture change should be implemented at as early a stage as possible, ideally with medical students receiving early exposure to dying patients; this should also be reinforced throughout their careers.

It is equally important, however, that patients are not abandoned or denied treatment for reversible conditions or to relieve symptoms simply because they seem to be approaching the end of their life or have a terminal condition. In such situations the doctor can feel under pressure as both the patient and family find it very difficult to accept the inherent uncertainty of disease progression. Individual assessments should be made on the basis of each individual decision that needs to be made, so while a decision may have been made to stop chemotherapy, recognising that the patient's cancer is incurable, antibiotics for a chest infection might be appropriate. Appropriate care and treatment, including steps to relieve symptoms, must always be provided. This is about good clinical practice and person-centred care – making the individual decisions that are right for this person at this particular time.

Key points:

- More needs to be done to identify those patients, particularly but not exclusively, frail older patients with multiple comorbidities, who are likely to be approaching the end of their lives and for this to trigger a review of the goals of different medical interventions and of the patient's medications.
- Steps should be taken to ensure that doctors, including those caring for patients in care homes, are given the time and space to consider their patients' overall health status and healthcare needs, in addition to responding to particular medical episodes.
- Doctors and the public should be reminded that all treatment should be appropriate and proportionate, with the aim of providing a net benefit to the patient rather than pursuing aggressive but non-beneficial attempts to prolong life.
- There is a need for more training to help doctors to identify when patients may be approaching the end of their lives and plan accordingly, and to equip doctors with the necessary communication skills to have these difficult conversations with patients and their families.
- Acceptance of the inevitability of death, and the importance of making individual assessments about whether or not to undertake a particular investigation or treatment, needs to be emphasised early in doctors' training and throughout their careers.
- Doctors and the public should be reminded of the inherent uncertainty in the pace of disease progression and that reversible and irreversible conditions can coexist and need to be assessed in the context of the patient's wishes.
- Care should always be seen as the hallmark of the doctors' role, including when it is recognised that the patient's prognosis cannot be improved.

Reducing unnecessary and inappropriate hospital admissions

As discussed above, better identification that people are approaching the end of their life, and appropriate planning for any future medical episodes, are ways of reducing unnecessary and inappropriate hospital admissions. Another way, as discussed in section 7 on information, is to ensure that patients, and their families, have clear instructions about who to contact for help and advice where patients have expressed a desire to be cared for, and to die, at home or elsewhere in the community. Many inappropriate hospital admissions amongst this group of patients occur because the patient and/or family are concerned by a sudden deterioration in the patient's health and do not know what to do and so call an ambulance. The ambulance staff do not know the patient's medical history and therefore transfer the patient to hospital where the emergency team, similarly lacking information about decisions that have been taken about the patient's care, admit the patient to a ward. Ensuring timely discussions with patients and families and signposting who to contact in such situations will reduce the number of cases in which an ambulance is called inappropriately and make for better end-of-life care decision making. Sometimes, however, such situations cannot be avoided and the issue about the information that is available to medical staff in such circumstances is an important one which is addressed in section 8 on planning and coordination.

Facilitating discharge

During the events the researchers heard many experiences of patients being admitted to hospital and then remaining there for considerable periods after their need for inpatient care had ended, because the necessary care package could not be put in place within a short period of time. In many cases delays were caused by difficulties in accessing the equipment, facilities or support needed – the BMA has previously drawn attention to these issues in its resource for patients on discharge from hospital.¹⁰ For patients who are at the end of their life this could mean the difference between spending their last days and dying in hospital or being in their own home. As discussed in section 8, better communication and coordination between hospitals and local care homes, hospices and those providing care to those living in the community, as well as relevant departments in local authorities, are essential if this situation is to be improved. It is also important to consider whether we have become too risk-averse in discharge planning, and whether some patients could be discharged from hospital relatively safely without every piece of equipment or facility being in place. Delays in discharging patients from hospital are not only against the interests of the patients who unnecessarily remain in hospital, but also reduce the services available for others in need of medical care. A recent report has suggested that delayed discharge may be costing the NHS up to £900 million per year.¹¹

Steps therefore need to be taken to make discharge planning more effective, to identify the barriers to discharge and take steps to eradicate them. Where delays in putting a package of care together are unavoidable, many patients would be happy to be discharged from hospital, despite what may be a less than ideal care package being in place. Where there are risks of discharge, but these are within an acceptable level, the situation should be explained to the patient, and/or the family, and their views should be sought and, where possible, acted upon. In some areas, programmes of "discharge-to-assess" - where patients are discharged from hospital and then assessed in their homes – has removed many barriers that have previously delayed discharge, and yielded benefits for patients and their families in allowing more accurate assessment than those which would have taken place in the unfamiliar environment of an inpatient unit.¹² This could be considered as a possible solution to some of the problems associated with discharge.

Key points:

- Steps need to be taken to make discharge planning more effective, to identify the barriers to discharge and take steps to eradicate them. Programmes of “discharge-to-assess” could be considered as a possible solution.
- Some delayed discharges may occur through risk-averse decision making causing unnecessarily long hospital stays. Where there are risks in transferring a patient to home, but these are within an acceptable level, this should be explained to the patient and/or the family and their views should be sought and, where possible, acted upon.

Pain management

The appropriate management of pain was, as we expected, a big issue for the public and doctors alike. Many doctors expressed a desire for more training – both in managing physical pain and in identifying other forms of pain and distress. Identifying and managing pain in patients with cognitive impairments, including dementia, can be particularly challenging.¹³ As discussed in section 2, doctors also wanted more support to be available, to enable them to seek specialist advice and reassurance, through local networks, as and when necessary particularly, but not exclusively, for those caring for patients in the community. A number of practical issues were also raised that deserve attention.

There was a perception amongst some members of the public, which needs to be corrected, that doctors knowingly and intentionally administer drugs to end patients’ lives. Such action would be both unlawful and unethical. Doctors can, and should, administer strong analgesics and sedatives at the end of life where this is necessary to manage the patient’s pain and distress. Sometimes the patient will die very shortly afterwards, either by coincidence or, it has been suggested, because death was being delayed by the presence of pain and once the patient is comfortable and pain is well managed, natural death can occur. Many doctors are, however, fearful of how their actions may be interpreted and, at virtually all of the events – with doctors and the public – there was some mention of Harold Shipman and his crimes.

Many of the doctors present did not feel that their own prescribing was affected by this but many were convinced that some colleagues – particularly junior doctors and nurses in hospitals and district nurses in the community – were too conservative in their prescribing. This resulted in patients being denied sufficient pain relief, because of concerns that the doctor would be considered culpable in the event of the patient’s death and may face professional or criminal sanctions. This is clearly a matter of significant concern. It is crucial that these anxieties are addressed as early as possible through education and training for doctors. Doctors at all grades must be aware of the basics of pain control, and understand when they should involve senior colleagues or colleagues from different disciplines in treatment. As part of this training, it is necessary to emphasise 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

the under-treatment of pain (possibly as a result of those fears) can be just as serious as the over-treatment of pain. In addition, although there is already clear guidance from the GMC (General Medical Council) about the need to take steps to manage any pain or other symptoms, we would welcome clear statements by both the GMC and the NMC (Nursing and Midwifery Council) to address these specific concerns.

Various reports – including the recent NICE guideline on the care of dying adults in the last days of life¹⁴ – note that not all people in the last days of life will experience pain, and that there are many other symptoms (such as breathlessness, nausea, delirium, anxiety and agitation) which will also require careful management. Any education and training programme on end-of-life care should ensure these topics are also given adequate attention.

It was evident from the dialogue events that pain and symptom control are huge issues for the public. This reflects the findings from the Choices Review (see [volume 1](#)), which found that pain management and symptom control were the aspects of their overall wellbeing that mattered most to those consulted. Doctors at the events, however, expressed concern that the public had unrealistic expectations about what can be achieved in terms of pain relief at the end of life – namely, that there was an expectation that pain could be relieved completely, when it was more realistic to talk in terms of “managing” or “alleviating” pain to an acceptable level, so that patients can continue to function how and when they choose. When talking about their hopes and fears about the end of life during the public events, pain was mentioned more than any other issue; the most frequent hope was that death would be quick and “pain-free”. As a corollary, being in pain was frequently mentioned as the primary fear about dying. Amongst participants who had experienced a recent bereavement, the presence or absence of pain played a key role in their memory of the death and whether or not it was deemed to have been a “good death”. It is important that the public has a realistic understanding of what is, and is not, feasible in terms of pain relief and every opportunity should be taken to educate the public that although pain cannot always be completely eradicated, much can be done to control pain and reduce that pain to a manageable level. There is some research evidence about how far different types of pain, and distressing symptoms, can be reduced by appropriate interventions, and evidence from the VOICES survey (discussed in [volume 1](#)) indicates that the extent to which this is achieved varies depending on the location of care, but more research in this area may be helpful. The upcoming report from the BMA Board of Science on pain relief and analgesic use, due for publication in later summer/autumn 2016 will explore many of these issues in more detail.

Discussing their own experiences of providing end-of-life care, some of the doctors who cared for patients in the community described anticipatory prescribing and “just in case” boxes very positively and described excellent examples of their use. Others, however, were less positive about the way this worked in practice in their area. Access to medication in the community, particularly out of hours, was raised as a particular concern by those members of the public who had recent experience of bereavement. Many of the problems with accessing the medication that was required seemed to involve a breakdown in communication between the various medical services. Whatever the reason, pain management is a crucial issue for how end-of-life care is judged and how families, and other loved ones, remember the last few days of the patient’s life. It is essential, that pain is recognised as requiring urgent attention and that systems are in place to provide the pain management that is needed. The issue of coordination of medical services is addressed in more detail in section 8, but in terms of medical services, systems need to be in place, in all areas, to ensure the availability of specialist advice and the medication and equipment required for pain control as needed, including out of hours both in hospital and in the community. Although problems with access to pain relief were primarily raised in relation to those being cared for in the community, access to drugs can also be a problem in hospitals where electronic prescribing means there is no drug cupboard on the ward and so more forward-planning is required for their access. Care is needed to ensure that systems, such as electronic prescribing, that are intended to improve efficiency do not have unintended negative consequences.

Key points:

- Information for the public should clearly dispel the myth that doctors deliberately and intentionally give drugs to end patients' lives.
- The public should be given a realistic view of what can be achieved in relation to pain at the end of life and that whilst, in some cases, pain cannot be eradicated completely it can be controlled and made more manageable.
- Doctors of all grades should receive training in the basics of pain control, and understand when they should involve senior colleagues or colleagues from different disciplines in treatment. Training should also include the management of other symptoms at the end of life.
- Training should emphasise that the under-treatment of pain is just as serious as the over-treatment of pain.
- The GMC and the NMC should take specific steps to address anxiety amongst doctors and nurses about administering high, but appropriate, levels of strong analgesics and sedatives, to patients at the end of life.
- Further research should be undertaken into the control and management of complex pain and other distressing symptoms.
- Systems need to be in place, in all areas, to ensure appropriate and timely availability of medication and equipment, particularly for those being cared for in the community.
- Hospital prescribing systems need to ensure the appropriate and timely availability of medication, in the event of a sudden change in the patient's condition.

Patients with mental health care needs

One of the issues raised with the doctors at the events, in terms of providing end-of-life care, was the identification and treatment of depression. Interestingly, this was rarely raised as an issue until doctors were prompted to consider it. Most of the doctors believed that depression was very difficult to identify in patients who are approaching the end of their lives and they often found it hard to differentiate between sadness, as a result of their situation, and clinical depression requiring treatment. Some were concerned about medicalising low mood. A crucial aspect of training therefore is ensuring that doctors can distinguish between natural sadness at approaching death and clinical depression requiring psychiatric or psychological treatment.

Identifying depression is not, however, just a matter of distinguishing between the two. There is a continuum of mood states among terminally ill patients, ranging from denial to acceptance, at any one of which a patient's judgement and decisional competence may be affected. Patients can be affected in different ways, at different stages, and short-term psychological interventions are often needed. It is crucial that training ensures doctors can recognise those who may benefit from specific therapy, in addition to the need for ongoing support for patients as they come to terms with their changed expectations for their own lives as the result of a loss of health and loss of their envisaged future.

As discussed in [volume 1](#), there is a significant incidence of moderate to severe depression amongst those who are terminally ill which is often unrecognised. Depression, anxiety, altered mood states or concomitant mental illness can impact on patients' capacity to make or be involved with decisions about future treatment. They can also impact negatively on family relationships. Those providing end-of-life care should, therefore, be alert to signs of depression, anxiety, altered mood states secondary to treatment or medication and other mental illness amongst their patients and doctors should respond accordingly.

Those responsible for organising services should ensure that, when necessary, appropriate mental health care provisions – including primary care mental health teams - are available to patients at the end of life, with relevant specialists either becoming part of the core treating team or being available for input as and when necessary.

Key points:

- Doctors should be mindful of the potential for patients at the end of life to be vulnerable to depression and training should ensure that doctors are able to diagnose and manage depression in those patients nearing the end of life, distinguishing it from natural sadness.
- Doctors should also be aware of the continuum of mood states among terminally ill patients and how this might affect patients' judgement or decisional competence.
- Training must ensure that doctors can recognise those who may benefit from specific therapy, in addition to equipping them with the necessary skills to provide ongoing support for patients as they come to terms with their condition.
- Mental health services for people at the end of life – including primary care mental health teams – should be more readily available and those responsible for organising services should ensure that, where necessary, relevant specialists either become part of the core treating team or are available for input as and when necessary.

Treating patients who lack capacity to consent

Assessing mental capacity was one of the challenges of providing end-of-life care that was discussed with doctors at the dialogue events. Mixed views were heard. Some were very experienced, very confident and very knowledgeable about the law and guidance; others were less so. It was acknowledged that although the processes were in place for assessing mental capacity, it was not always a straightforward procedure in practice. Capacity could be observed to fluctuate depending on the time of day or the nature of treatments being given. Language and cultural issues were also frequently mentioned as complicating the assessment of mental capacity, as well as diagnoses of mental illness or dementia.

There was a general view that whilst there was now better training for assessing mental capacity than previously, it did not necessarily address all the complexities around mental capacity assessments which can affect patients at the end of life. Doctors need better training in assessing capacity in patients who may have fluctuating capacity, cognitive impairments, or language barriers, where there can currently be a tendency to assume incapacity. This training should include understanding how to maximise decision-making capabilities, so that patients can be as involved as much as possible in decisions about their care, and recognising that assessments of capacity are decision-specific.

Key points:

- Current training on mental capacity does not always address all of the complexities involved in assessing decision-specific capacity in patients.
- Training should look to emphasise specific issues associated with mental capacity which are particularly applicable to the end of life – such as fluctuating capacity, patients with cognitive impairments, and recognising that capacity must be assessed for specific decisions.
- Doctors should understand how to best maximise decision-making capabilities.

Location



6. Location

“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

Where a person is cared for at the end of life is of critical importance to their view of what good end-of-life care looks like and what they perceive to be a “good death”. It will also be instrumental in relatives’ memories of that death. As discussed in [volume 1](#), existing evidence suggests that people have strong views on where they would like to be cared for and die. Numerous surveys indicate that the vast majority of the public have a preference to be cared for and die at home, a finding which is backed up by the research we commissioned which found that a large number of attendees expressed a similar desire – home being, in their view, a homely and familiar environment where they would be able to receive personalised care, surrounded by those close to them. This wish is followed by being cared for in a hospice, with hospital being seen as the least desirable place to be cared for and die. Some, however, were adamant that they did not want to be cared for at home – mainly because they did not want to be a burden on their family – and so it is important to remember that there is no single option that is right for everybody. Furthermore, patients’ preferences can change, and so any care plan must be sufficiently flexible to allow for this.

In theory, all patients should be able to choose where to receive care and where to die – whether that be their own home, a hospital, a hospice, or a residential care home. Indeed, all four nations’ end-of-life care strategies (see [volume 1](#)) emphasise the importance of ensuring patients are cared for, and die, in a place of their choice. Yet despite the fact that the majority of the public express a wish to be cared for and die at home or in a hospice, most deaths still take place in hospital (over half of all deaths in England, Wales, and Scotland). Various factors such as family support, the changing nature of a patient’s condition, and crucially, the resources available will all impact on whether a patient’s preference can be met. If patients facing the end of life are to be given choice in this area, it must be supported by integrated systems and services which can make it a reality.

Home

As noted above, home is stated as the preferred place of care and death more than other options. The reasons behind this are clear: people wish to be cared for and die in a place that is familiar, comfortable and where they can be surrounded by their family and those important to them. There was also a perception amongst many of the members of the public who attended the events that home was the place where they were most likely to be able to receive dignified and personalised care, rather than just being seen as a “number”. This was a view shared by many members of the public who had experienced a recent bereavement

Very few participants expressed a view about being cared for at home unreservedly, however, and many acknowledged that there could be factors which limit this option – including the availability of resources; the nature of the illness; the severity and management of symptoms; and the adequacy of support available at home. The management of pain and access to essential medications, for example, were particular concerns for the public. As explored elsewhere in this report, from the point of view of doctors and those with experience of caring for relatives in the community, pain was seen to be less well managed

in community settings than in hospitals. If patients are to be properly cared for in the community, access to essential equipment and medications, whenever they are needed, must be better facilitated.

“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... the default method is to bounce them into hospital and tragically they end up spending the rest of their short life there.”

Doctor

Those who had recent experience of bereavement expressed the view that where being cared for at home worked well, it was because care had been well coordinated between services and a clear package of care was in place. The problems associated with the coordination of care are explored in detail in section 8, but the consequences of a failure to coordinate care for patients at home are illustrated starkly by the number of inappropriate admissions of patients at the end of life to hospital. The researchers heard on countless occasions, from both doctors and patients, about families struggling to cope as a result of the lack of support, and calling an ambulance at a point of crisis – resulting in the patient being admitted to hospital through A&E. In order to ensure that deciding where to be cared for at the end of life is not just an illusory choice, better coordination is needed between different health services and social services to enable the necessary support and practical arrangements to be put in place.

Many participants also expressed a concern about being a “burden” on their families if they were to be cared for at home, which can only be addressed to an extent with appropriate support from social services – whether that be the provision of home care, particular equipment, or financial assistance. This highlights the importance of guaranteeing that any coordination of care assesses the extent to which social services may need to be involved and ensures that they are contacted and involved in that patient’s care.

Participants were worried, however, that the resources to provide this support were not always available. Entitlement to and provision of social care vary across the UK: whilst in some areas it is free for those who meet certain eligibility criteria, in other areas it will be means tested, or families will be required to fund it themselves. Various reports – including the House of Commons Health Committee report on end-of-life care (see [volume 1](#)) – have called for free social care to be available to all those at the end of life. Governments must take this into consideration.

Even where resources are provided, the availability of trained carers can be problematic. A key part of resourcing care at home will be the provision of nursing and other care staff to support carers, and those responsible for providing services in the community must make this a cornerstone of any end-of-life care planning. Whilst doctors and members of the public alike expressed gratitude for the high level of care nurses provided, there were concerns about the paucity of district nurses; we recognise also the current shortage of care workers in the care sector.¹⁵ Macmillan and Marie Curie nurses were particularly highly regarded by members of the public. Some funding for this is provided by the NHS, but both are charitable organisations and there are clear issues of resources and access. Another option to complement medical and nursing care for patients staying at home is “compassionate communities”, an initiative designed to encourage communities to support people who are dying and their families.¹⁶ The way in which this is actually implemented can vary, but it usually involves volunteers in the community working with medical teams to provide care for patients in their own home (without taking responsibility for medical care). Tasks done by volunteers may include doing shopping, provision of meals, fetching a prescription, or sitting with the patient while the carer has a break – which is particularly important if the patient cannot be left alone.

Doctors at the events noted that very often families could be insistent that they would care for the patient at home, without always recognising the difficulties this involved. Very often, for example, it will not be feasible for family members to care for their relative without having to stop working – which has very obvious financial implications for the family. Without diminishing the need to ensure systems are in place to support families caring for relatives at home, information about what caring for a dying patient actually entails and the support that is, and is not, provided should be more readily available. This will help make sure that family members are able to make an informed decision about whether that patient will be best cared for at home.

Various other reasons were provided for why home may not always be the best place to be cared for at the end of life. A number of participants expressed a wish to die somewhere other than home, so as not to taint the memory of that place for the family members who will continue to live there. There was also an appreciation that being cared for at home at the end of life may not be possible depending on the level of deterioration, and that as the disease progresses, it may be more appropriate to be cared for in a different setting. This supports the earlier findings of research described in [volume 1](#) that preferences on place of care and death can be complex, and change over time depending on circumstances. It is important for any care plan to recognise that preferences may change or fluctuate, and take this into account in remaining flexible to enable moves between locations and services.

Key points:

- In order to ensure that deciding where to be cared for at the end of life is not just an illusory choice, there must be better coordination between different health services and social services to enable the necessary support and practical arrangements to be put in place.
- This includes ensuring access to essential equipment and medications, whenever they are needed.
- Coordination of care must also involve an assessment of the extent to which social services may need to be involved and should ensure that they are contacted and involved in that patient's care.
- A key part of resourcing care at home will be the provision of nursing and trained care assistant staff to support carers. Those responsible for providing services in the community must make this a cornerstone of their local palliative and end-of-life care service plans.
- Information about what caring for a dying patient actually entails and the support that is, and is not, available should be more readily accessible to help patients and their families make an informed decision about whether they will be best cared for at home.
- Preferences on place of care and death can change, depending on circumstances. It is important for any care plan to take this into account and remain flexible and updated to enable moves between locations and services.

Hospice

Hospice care also features prominently in the general public's preference for place of end-of-life care and death. Participants at the events generally viewed hospice care as "the gold standard" for end-of-life care. As with the desire to be cared for at home, hospice care was ranked highly due to the perception that it could provide a homely environment, with flexible and personalised care. Doctors too were near unanimous in their view that the best end-of-life care is provided by hospices, noting that it addressed all aspects of the physical, psychological, social, emotional and spiritual needs of patients and their families – which, as is explored elsewhere in section 10 on emotional support, doctors providing care in other settings sometimes find difficult to do.

The UK is a leading figure worldwide in the development of the hospice movement, and hospices are recognised as centres of excellence in all four nations' strategies for end-of-life care (see [volume 1](#)). Yet there remains a huge amount of variability in hospice provision across the country. At the events, both the public and doctors expressed concern about the limited resources and availability of hospice care. Many attendees shared personal stories about the excellent care provided in local hospices, but nearly all highlighted the small number of beds available. There was also an acknowledgement amongst doctors that whilst hospice care was excellent for patients with cancer, it could sometimes be more difficult for patients with other conditions to access it.

A large part of the discrepancy between areas is due to the fact that the vast majority of hospice funding is charitable, and whilst there is some state funding, it does not normally cover the full running costs. When facing financial constraints, there is a danger that those organising or commissioning services will not view this as a priority. Governments should consider how to ensure that services which are currently available – whether that is in specific hospice buildings, or through the provision of care in the community or hospitals – are available on an equitable basis.

Hospices also have an important role in education and training, and there is much the NHS and social care services can learn from the hospice movement. Those working in hospices can help inform and support their colleagues working in other care settings to provide this standard of care to all those approaching the end of life.

Key points:

- There is a huge amount of variability in hospice provision across the UK. Governments should consider how to make the hospice provision that is available – whether in specific hospice buildings, or through the provision of care in the community or hospitals – available on an equitable basis.
- Hospices can play an important role in education and training. Those working in hospices can help inform and support their colleagues working in other care settings to provide this standard of care to all those approaching the end of life.

Hospital

Being cared for and dying in a hospital was the least well regarded option by the public – largely due to a perception of the hospital environment being clinical or institutional, and horror stories they had heard in the media (often linked to the reporting of the inappropriate use of the Liverpool Care Pathway). Some participants with recent experience of bereavement were critical of the way their relatives had been cared for in hospital – although many of these problems arose as the result of an inappropriate admission to hospital following a failure to coordinate care adequately (an issue explored in more detail in section 8 of this report). Doctors were similarly critical of inappropriate admissions to hospital, which they felt could be avoided with proper coordination of care.

At the same time, however, there was acknowledgment that, for some, hospital might be the best place to be – especially with regard to pain, which both doctors and members of the public with experience recognised as potentially being better managed in hospital settings.

Much work has been carried out recently to help improve the provision of end-of-life care in hospitals and various organisations (including the NHS England and NICE) have issued guidance on caring for patients at the end of life in these settings.^{17,18} NHS Improving Quality has also recently launched a programme on transforming end-of-life care in acute hospitals.¹⁹ Many participants also highlighted examples of good end-of-life care in hospitals, mainly where patients were treated with warmth and kindness by all staff, and were able to live as normal a life as possible within the confines of their condition.

Many highlighted that hospital care worked well when their relatives had been cared for in a hospital room that was “treated as if it were home.” It therefore may be useful to explore what it is exactly that people value about being cared for at home or in a hospice over a

hospital, and whether there are aspects which could be incorporated into care, regardless of actual physical location. As noted above, for many participants the appeal of dying at home was about comfort, familiarity, dignity, privacy, and being able to maintain as normal a life as possible. Crucially, they valued being able to have their families and loved ones around them. Provisions and flexibility to allow families to be with their relatives towards the end of life (even on a very practical level, such as information about accommodation near the hospital, refreshments, or car parking) will be an important step in ensuring this. Those responsible for the running of a hospital should consider, therefore, how best to incorporate these elements in order to improve the experience of dying in hospital.

Key points:

- Dying in hospital should not necessarily be seen as a failure. Steps should be taken to improve the experience of dying in hospital along the lines of the hospice model.
- Information, advice, support and flexibility should enable families to be with their relatives in hospital towards the end of their relative's life.

Care homes

A significant number of deaths take place each year in care homes. Participants at the events tended to not discuss care homes in the context of a location to be cared for and perhaps die, but some did mention “horror stories” appearing in the media about the treatment of elderly patients in care homes.

Many care homes provide an excellent standard of care and enhance the quality of life of their residents. There are, however, several different factors which can contribute to suboptimal end-of-life care being provided in this setting. Many of these mirror the problems in ensuring people can be cared for in their own homes – mainly, a failure to coordinate care appropriately. There can be inadequate access to NHS services, for example, including district nursing care, primary care, and out-of-hours medical care. Inadequate training in end-of-life issues for staff employed in residential care homes can also mean they are ill-equipped to deal with crises, resulting in many patients being admitted to acute hospitals in their last days or weeks of life, when this is not their wish, nor even in their best interests. We heard a large number of anecdotal stories from doctors about elderly patients being admitted to hospital inappropriately – an issue explored in more detail in section 5 on medical services. In order to ensure that those being looked after in care homes at the end of life have the same access to high-quality end-of-life care, medical support must be made available to care homes to ensure the wishes and needs of those living there can be met. Support and training must be provided to all staff working in care homes – with a particular emphasis on advance care planning – to help avoid inappropriate admissions to hospital. There are various examples of good practice in training and accreditation of end-of-life care in care homes^{20,21,22} (including “train the trainer” programmes aimed at nursing homes²³), but these all need wider dissemination.

It is not just staff working in care homes who should be trained and supported in this area. Linking in with the various recommendations made regarding education, training and support in the overarching themes part of this report, it will be crucial to ensure that all doctors with responsibility for patients in care homes have access to specialist palliative care support, at whatever time of the day or night. This will ensure that issues can be managed in the patient's normal place of residence and avoid unnecessary and inappropriate hospital admission.

It also needs to be recognised that those living in residential homes can be sad and distressed by the death of another resident, and their bereavement needs should be acknowledged and met. Those working in such establishments should be able to provide support and, where appropriate, information about local bereavement services they may be able to access.

Key points:

- Support and training must be provided to all staff working in care homes – with a particular emphasis on advance care planning – to help avoid inappropriate admissions to hospital. Existing training and good practice accreditation of end-of-life care in care homes should be rolled out more widely.
- All doctors with responsibility for patients in care homes should have access to specialist palliative care support whenever that need arises. This will ensure that issues can be managed in the patient's normal place of residence and avoid unnecessary and inappropriate hospital admission.

Information



7. Information

“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

Information about death and dying for the general public

A key finding from our research was that most people did not think or talk about death and dying. At the dialogue events, many people reported finding such discussions uncomfortable and relatively taboo. Very few had thought about what they wanted at the end of life, and fewer still had shared those views with family members. Some who wanted to discuss and plan for their own end-of-life care found other family members were unwilling to have the conversation with them. Those with recent experience of family bereavement were more likely to have given thought to the implications for their own future care when reflecting on the care received by their loved one. This general reluctance, and lack of comfort, in discussing death and dying reflects some of the previous research findings discussed in [volume 1](#) of this report.

This tendency in the UK to avoid discussing death and dying can present difficulties for health professionals who are required to take account of their patients' past and present wishes, beliefs and values when making best interests decisions for those who lack the capacity to make decisions for themselves. When individuals have given advance thought to the issues and made their wishes known, through formal or informal means, the best interests process is far more straightforward and less burdensome for all concerned. Unless people discuss what is important to them with those close to them, and what they would and would not want, the extent to which their views can influence decisions will be severely limited. This lack of information can also be difficult for families who want to ensure that “the right thing” is done for their loved one but lack knowledge about what “the right thing” is and may cause conflict as often family members have different views about what the individual would want.

It was evident from the events that the public lacks information both about the practicalities of end-of-life care and what it entails and about the options available to them for anticipatory planning. Many participants were unaware of the palliative care services that are available in their area and the nature of the supportive care that continues when attempts to stop or slow disease progress are no longer deemed appropriate. It is important that doctors recognise that patients, and those close to them, may not be aware of the type of care that is available at the end of life and that this might be a concern that can easily be assuaged by reassurance and the provision of practical information. Patients need to know that they will not be abandoned and will continue to receive supportive care or treatment no matter how ill they are and irrespective of the decisions they make about starting or continuing curative treatment.

In terms of advance planning, whilst most had heard of wills (although very few had made one), only a small minority had heard of the option to make advance decisions about treatment or, in some parts of the UK, the ability to appoint someone to make decisions

on their behalf once capacity is lost. Despite publicity around the passage of legislation in Scotland (in 2001) and England and Wales (in 2005) extending the choices available to people in terms of anticipatory planning, this information does not appear to have entered public consciousness. There is clearly a need for this information to be more widely promoted so that the public is aware of the options available to them should they wish to refuse some of the treatments that might be available. Whilst capacity legislation itself is complex, the concepts themselves are not. Those portraying the information should avoid being too caught up with terminology and should focus instead on ensuring that the basic ideas – of an advance refusal, stating their wishes or appointing someone to make health and welfare decisions in the event that they are unable to do so for themselves – are understood, with signposts to more detailed information for those wishing to consider the options.

When asked, most of the public stated that the majority of the information they have about end-of-life care is obtained from the media, both fictional and news. Participants were often sceptical, however, of how accurate the information was, particularly in medical dramas where the primary purpose was entertainment rather than education and it was recognised that end-of-life care was presented in a “highly sanitised” and often unrealistic way. News reports of over-stretched NHS services and “horror stories” about care homes or poor quality care in hospitals had, with some exceptions, led to relatively low expectations of how well their end-of-life care would be managed within the NHS. This is despite the UK ranking first amongst 80 countries for the quality of its end-of-life care.²⁴ Given the centrality of the media in conveying information to the public, it is important that, as far as possible the information is accurate and gives a balanced portrayal of the issues. The BMA, doctors and other professionals have a role to play in helping those working in the media to achieve this.

There is a clear need for more, balanced, accurate information about end-of-life care to be made available and for the public to be encouraged to think about, and listen to others who wish to discuss, their wishes regarding care at the end of life. A number of organisations including the Dying Matters Coalition in England (Bwy Nawr in Wales) led by the National Council for Palliative Care, Marie Curie, Good Life, Good Death, Good Grief (in Scotland), the All Ireland Institute of Hospice and Palliative Care, Compassion in Dying and Age UK provide specific information and seek to encourage more public debate and discussion within families. Such a change will not happen overnight but providing resources, advice and encouragement is an essential part of making that change happen. End-of-life care strategies across the UK have highlighted the need for more public information and for a change in attitudes towards discussing death and dying with some, but limited, success. The Department of Health committed itself in 2008 to working with the National Council for Palliative Care to raise the profile of end-of-life care and to change attitudes to death and dying in society.²⁵ This led to the formation of the Dying Matters Coalition, which has around 33,000 members and holds an annual awareness week, but there is still much to be done. The Scottish Government has also committed itself to this goal very recently: in its 2015 strategic framework for action it announced that it will commission work to facilitate greater public and personal discussion of bereavement, death, dying and care at the end of life.²⁶ Information must be provided in a range of formats and be accessible by all, including those who have learning disabilities, difficulties with reading, or for whom English is not their first language. The fact that attitudes are entrenched and hard to change does not mean that change cannot be achieved, but it will not be easy and will involve a significant public health campaign to overcome the taboo that was mentioned at the dialogue events. Given the focus, across all national governments, on individualised care, and respecting choices at the end of life, a high-profile, publicly-funded information campaign throughout the UK, to encourage people of all ages to talk about death and dying and the importance of making others aware of their wishes, would represent a positive step forward.

Key points:

- National governments should initiate and fund a high-profile public information campaign encouraging people to think about, and make known, their wishes regarding end-of-life care, such as Dying Matters, Bwy Nawr, and Good Life, Good Death, Good Grief.
- The public campaign should include informing people, in simple language, about the options available to them to make advance decisions or to appoint someone to make decisions on their behalf.
- Given the centrality of the media in conveying information about the end of life to the public, doctors and other professionals and groups have a role to play in helping the media to present information about the end of life accurately and in a balanced way.

Information for patients and families once a terminal condition has been diagnosed

The information gap identified at the events concerned not only general information about death and dying. There was also a general perception amongst the public and doctors that patients and their families find it difficult to access the information they need once a terminal condition has been diagnosed. Both the public and doctors recounted examples of where information about the diagnosis, prognosis and treatment options had been explained well and where it had been provided less well. Some GPs reported patients being discharged from hospital without clearly understanding that their condition could not be treated and that the focus had shifted from curative treatment to end-of-life care. There was recognition, however, that this information is incredibly difficult for patients to absorb (particularly for those with some form of cognitive impairment, such as learning disabilities or dementia) and that information may have been provided but not understood or not processed. The limitations of time were also frequently raised by doctors who commented on the challenge of having such difficult and sensitive conversations with patients and their families when time and appropriate facilities were often lacking. Techniques such as reflection and paraphrasing are helpful to ensure that what is said is understood and understood correctly, but are skills that need to be learnt. As discussed in section 9 on communication, many doctors reported a lack of training and confidence in having such conversations and this is an issue where improvements should be made. It is also important, however, that hospital managers and those organising care and staffing, recognise that time needs to be made available for such information to be conveyed properly and sensitively; for doctors to ensure patients have understood the information; and to listen to the patients' concerns or questions. It is essential to ensure that time is made available for this.

“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

The report of the dialogue events ([volume 2](#)) identifies the range of ways that patients engage with healthcare generally – with people adopting either a proactive, collaborative or passive role in their care and treatment – and this variation extends through to end-of-life care. Some patients want very detailed information about their diagnosis, prognosis and treatment options and actively seek out more information, whilst others prefer to receive only a minimal amount. Some want to be given the list of options and make their own decisions about which treatment option is best for them, whereas others want to be advised about what should happen. It is important, therefore, for doctors to listen to individual patients to determine the level of information and involvement they want, and to be responsive to that. Involving patients and their families (see below) in treatment decisions to the extent that the dying person wants is a key part of providing good quality end-of-life care and is one of the five priorities for care identified by the Leadership Alliance for the Care of Dying People.²⁷

Whilst the aim should be to encourage people to receive information about their condition and treatment options, this may need to be over a period of time at a pace that suits the individual, with more information given as and when the patient is ready to receive it. This takes considerable skill – both in listening to what the patient is saying and in looking out for non-verbal clues – to support the patient through this period of transition and, again, there may be a need for more focussed training and support for doctors to hone these skills.

As discussed in the overarching themes section of this report, the wellbeing and involvement of families were ranked very highly by the public at the events. Health professionals need to be aware of this and ensure that they determine the extent to which the patient wishes information to be shared with particular family members and how much they should be involved in discussions about treatment and care options. Recognising that this can present difficulties for doctors where patients do not want information shared with family members, there is a clear legal, ethical and professional obligation to respect the wishes of the patient and this was accepted, even by those who were most vociferous about the need to involve families.

In addition to understanding the treatment options available, patients also need to know about the options for where to receive care. This issue is discussed in more detail in section 6 but in terms of information, patients should be made aware of the options that are open to them in the locality. This should include information about local hospices, community services and voluntary sector services that might be able to provide suitable care for them and a realistic understanding of the support and services that are available for those who wish to receive their end-of-life care at home. Many of the doctors at the events believed that neither patients nor families had a realistic view of the challenges of caring for a dying patient at home; caring for a patient with dementia approaching the end of life can be particularly challenging. Doctors reported that very often patients who initially expressed a desire to die at home changed their minds once the pressure on the family, and their struggle to cope, became apparent.

Another issue that came up in the events was the benefit of patients and their families having clear instructions about who to call if they needed help or advice. Some very good examples of end-of-life care in the community were presented at the doctors' events, where the patient was given a single number to call should they have any concerns or need medical attention or additional medication, with a rapid response from experienced staff, including out of hours. Such provision was, however, the exception rather than the rule. Initiatives such as this clearly play a part in reducing inappropriate and unnecessary admissions to hospital, which often occur when families have concerns but do not know who to approach and so call an ambulance. Whilst this type of set-up may not be feasible in all locations, the principle of patients being given clear information about who to contact for help or advice, including out of hours, is something that should be put into practice universally.

“We weren't told the state she [mother] would be in once she had been 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

Patients and families also need clear information about what is happening, what to expect and what to do if something unexpected happens, particularly where families are caring for patients at home. Many people have never been close to someone who is dying before and the fear and uncertainty about what will happen can make the situation even more difficult. It can also have a big impact on the family's experience and recollection of the death and poor communication can lead to lost opportunities. At least one person at the events was very critical that when the syringe driver was started nobody had advised the family that their relative was deteriorating and soon would no longer be able to communicate, which deprived the family of an opportunity to say goodbye. Similar reports are referred to by the Leadership Alliance for the Care of the Dying Patient (discussed in [volume 1](#)) which now makes clear in its statement of duties that patients and family members should be informed of the possible side-effects of specific interventions.

Key points:

- Conveying information about terminal illness in an appropriate and sensitive way, and ensuring it is understood, takes time. Hospital managers and those organising care and staffing should ensure that this time is made available.
- Health professionals should encourage patients to receive information and to be involved in healthcare decisions to the extent that they want to be.
- Health professionals should, as far as possible, establish the extent to which the patient wants family and loved ones to be involved in discussions about their care and should respect those wishes.
- Patients approaching the end of life should be given information about the options open to them including alternatives to hospital care, such as local hospices, and realistic information about the support and services available to those who wish to be cared for at home.
- Patients receiving end-of-life care at home or elsewhere in the community should be given clear information about whom to contact for advice, support or medical attention, including out of hours.
- With due regard to confidentiality, families should be provided with clear and accurate information about the patient's condition and know what to expect as death approaches.

Feedback from families about care received at the end of life

Over recent years considerable efforts have been made to learn from experience. As discussed in [volume 1](#) of this report, in England, national data are collected annually through the National Survey of Bereaved People (VOICES). Data are collected by means of a questionnaire which is sent by post to the person who informed the registrar of the death, who is usually a relative or friend of the deceased. The questionnaire, sent to a sample of approximately 49,000 people each year, seeks the views of the bereaved on a range of issues related to the quality of end-of-life care. Data are published annually on the ONS (Office for National Statistics) website. There are currently no equivalent data collection systems about end-of-life care in Scotland and Northern Ireland although the Scottish Government has recently announced its intention to support the collection, analysis, interpretation and dissemination of data, including on the outcomes of palliative and end-of-life care.²⁸ On a smaller scale, in Wales views on care received from palliative and hospice care services are collected via a questionnaire through iWantGreatCare (iWGC), although the data are not published in a systematic way.

Good and comprehensive data collection is important for driving improvements and identifying where things are working well and less well. Such data provide a more inclusive picture than individual reports of exceptionally good, or exceptionally poor, care that often feature in the media or that are the subject of formal reviews and investigations. We therefore believe that there should be formal mechanisms for collecting data on end-of-life care throughout the UK, with data published on a regular basis and with systematic review in order to identify trends and problems and to measure the improvements in end-of-life care that governments throughout the UK are seeking. This recommendation does not undermine the need for the review of individual cases and there must be robust mechanisms in place to investigate and examine all complaints. It is only by identifying and acknowledging where things go wrong that we can hope to learn from the mistakes that have been made or from systems failures.

Key points

- There should be formal mechanisms for collecting data on end-of-life care throughout the UK that are published on a regular basis and systematically reviewed. This should be in addition to robust mechanisms to investigate and examine individual complaints.

Planning and coordination



8. Planning and coordination

“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 the same 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 could probably be quite easily fixed, if there were communication channels.”

Doctor

As has been explored elsewhere in this report, doctors attending the dialogue events were resounding in their view that where end-of-life care works well, it is where individuals have given advance thought to their wishes and made them known (either formally or informally), and a care plan has been formulated to ensure those preferences are met. Where end-of-life care failed, it was principally because the planning of end-of-life care came too late to organise sufficient services and thus to implement the wishes of the patient.

The word “services” is crucial here. It is increasingly uncommon for end-of-life care to be provided in isolation by one single team in one single organisation. The provision of care at the end of life will ultimately fall to a number of different individuals, from different disciplines, from across all organisational boundaries. Patients may also need to move within and between services as their condition changes or preferences alter. In order to ensure that care is provided, as far as possible, in accordance with the patient’s wishes, services and care from multiple agencies and in different settings must be effectively coordinated.

The importance of ensuring that care is coordinated is embedded in all four nations’ end-of-life care strategies and was identified as one of the five priorities for caring for dying patients by the Leadership Alliance for the Care of Dying People in 2014 (discussed in [volume 1](#)).

There are examples of good practice across the country, and doctors at the events spoke enthusiastically of initiatives like the Gold Standards Framework or electronic systems which facilitated good coordination of care in their areas. A lack of coordination, however, can be

devastating for patients and their families. Failure to coordinate care can mean that certain services or support are not provided, leading to patients' preferences being unmet and the person possibly even dying in distressing circumstances, in a location that they did not want. Members of the public and doctors at the events expressed concern that care was not always effectively coordinated and felt that improvements needed to be made to ensure a coordinated approach to an individual's care. Coordination of care needs to be considered at several levels: coordination within an individual team; coordination between teams working within a single institution; and coordination across organisational boundaries. It is the latter two categories which were seen as most problematic by those attending the events.

Coordination of care within and between teams in a single institution

A terminally ill patient with cancer being cared for in a hospital may be cared for by an oncology team as well as a specialist palliative care team; an elderly patient with multiple comorbidities may be cared for by many more different specialties.

Where coordination worked well, it was largely due to the fact that there was an identifiable and accountable coordinator with responsibility for this. Very often amongst doctors, however, there were unclear boundaries between roles and uncertainty as to the precise responsibilities of different professionals. There was often an assumption that another team (usually the palliative care team) was responsible for coordinating care, when in actual fact, no one had taken on this responsibility.

The fact that teams in a single institution will be in the same geographical location goes a long way in overcoming many of the barriers to coordination. Hospital doctors at the events spoke positively of regular case meetings involving members of staff from every discipline involved in caring for the patient, or of IT systems which allowed for the seamless sharing of relevant information. In order to ensure this level of multi-disciplinary team working and communication within healthcare establishments, systems should ensure that time for conversations, handovers, and team meetings is valued and provided.

Similar examples of good practice in communication and delivering coordinated care were reported where the patient was cared for in the community. The dedicated use of palliative care registers within GP practices (as specified in the Gold Standards Framework), for example, ensures that the wider practice team is aware of the patient's circumstances and can prioritise and provide more appropriate care. Ongoing care is regularly reviewed at practice meetings. These examples are not common to the whole country, however, and even where these registers exist they must be kept up to date and used as a trigger to regularly review care proactively, rather than waiting for a crisis to trigger action. The Gold Standards Framework, for example, is applicable only in England and, even there uptake can be low. Improvements should be made to the way in which the care of individuals in the community is coordinated, in order to ensure some consistency and equity for patients across the UK.

Key points:

- In order to ensure strong multi-disciplinary working within healthcare establishments, systems must ensure that time and space for conversations, handovers, and team meetings is valued and provided.
- There should be greater consistency across the country in the way in which care of individuals in the community is coordinated. Any process must be subject to regular proactive review to anticipate needs, including for medication, as much as possible.

Coordination of care across services

It is increasingly rare that an individual's needs will be met by one service alone. Patients frequently need care from multiple services and they may require, or want, transfer between locations (home, hospital, hospice, care home etc.). It is in these circumstances that the provision of high-quality care can be particularly challenging.

As with the provision of coordination of care in hospitals, doctors very often assume that the coordination of care in the community is already happening, or that it is the responsibility of another individual or team (usually in palliative care). Where it works well, it is because it involves all services involved in the care of the patient – including the hospital, GP, district nurses and social services – under the auspices of an identifiable and accountable 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 in 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...”

Public

Some of the families who had cared for dying relatives at home were particularly critical of coordination of care in the community, and problems were starker where medical issues arose outside of regular working hours. As explored in section 5 on medical services, access to medication in the community (particularly out of hours) was a concern of members of the public who had recent experience of bereavement. Caring for a family member with uncontrolled symptoms can be extremely distressing for relatives, and will loom large and negatively in their memory of the death. The provision of care must therefore be coordinated to ensure the appropriate and timely availability of medication and equipment – whatever time of day or night that need arises – and that as far as possible, medication needs are anticipated.

A lack of properly coordinated care can also increase the burden on families and carers, who may find themselves unable to cope. A common story at the events was that when families found themselves unable to cope, they would very often call an ambulance, resulting in the patient being admitted to hospital through A&E where staff were not aware of the relevant information. Doctors too were very critical of what they deemed to be inappropriate admissions to hospital, which they felt could be avoided with better coordination between teams and the provision of an integrated package of care (an issue explored in more detail in section 5). At the other end of the process, if a hospital is unable to communicate with all relevant community services and ensure that the package of care required for the patient to be able to be cared for at home is in place, effective discharge from hospitals can also be complicated or even prevented.

Many doctors at the events commented that the coordination of care can be particularly good for patients with cancer, but that patients with other conditions (particularly those with uncertain disease trajectories, or who required increased multidisciplinary input) tended to fare less well. This, along with the pockets of good practice which currently exist in relation to the provision of coordinated care, indicates the importance of ensuring that those responsible for planning or commissioning healthcare should be supported with clear information about the various needs of patients at the end of life and the integrated package of care (including mental health services) which should be available to them.

Doctors attending the events were well aware that patients at the end of life have a range of other needs alongside their health and medical needs (including psychosocial, emotional, spiritual or financial needs) which will require the involvement of other services. For many patients, being cared for in their own homes will mean that their families require a great deal of support from social services – whether that be the provision of social care, particular pieces of equipment (such as a commode or bed), or financial assistance. This need for support can be particularly acute where a patient has dementia. Members of the public with recent experience of bereavement spoke of many of the difficulties in navigating the different services available and ensuring the patient’s needs were met. Any coordination of care must take into account any other needs a patient may have; assess the extent to which social services may need to be involved; and ensure that the appropriate services are contacted and involved in that patient’s care before a crisis arises.

Key points:

- Where end-of-life care works well it is usually because all services involved in the care of the patient – including the hospital, GP, district nurses, voluntary groups, and social services – are coordinated by an identifiable and accountable individual.
- Care must be coordinated to ensure appropriate and timely availability of medication and equipment – whatever time of day or night that need arises. This is particularly important for patients being cared for in the community.
- Better coordination of care between teams and services, and the provision of an integrated package of care, can reduce the number of inappropriate admissions to hospital.
- To ensure that patients' needs can be met, and that the right care is provided in the right place at the right time, those responsible for planning or commissioning healthcare should obtain and use clear information about the various needs of patients at the end of life and the integrated package of care (including mental health services) which should be available to patients.
- All coordination of care must take into account the non-medical needs of a patient and should involve other relevant services in that patient's care.

Information sharing

A major barrier to the effective coordination of care is the lack of mechanisms for communicating information. In order to provide appropriate care in line with the patient's preferences, it is crucial that every relevant health professional who has contact with the patient has all the relevant information they need – including diagnosis, prognosis, treatment plan, and the patient's wishes. Doctors at the events shared many examples of good practice for information sharing across the country, but highlighted some obvious black spots. As explored above, the provision of out-of-hours care, ambulance call-outs, and emergency admissions to hospitals were all identified as particular points where coordination of care could break down, largely because those providing care did not have the relevant information available to them. Members of the public with recent experience of bereavement expressed their frustration at having to repeat the same information to different services or staff members and felt that a set method of information sharing between professionals could prevent that duplication.

The issue of how information is shared between professionals, teams, and organisations has been considered by all four UK governments' end-of-life care strategies (see [volume 1](#)), with varying recommendations. The Northern Ireland strategy, for example, suggests the use of a "patient passport" – the patient's own document, designed to provide relevant information to be of instant help to health and social care professionals – whilst England's strategy emphasises the use of information technology, such as EPaCCS (Electronic Palliative Care Coordinating Systems) to enhance coordination. The suggestions from the participants at the events on how best to ensure coordination fell along similar lines. There was a great deal of support from the public for having patient-held notes on which all the relevant information is provided and which could travel with them to any appointment and be available in the home at a point of crisis – for example, to an out-of-hours GP or paramedic. Many participants drew comparisons between this idea and patient-held maternity notes. Other options along similar lines include a patient-held folder, in which copies of all relevant summary letters are stored.

Many doctors emphasised some of the capabilities of current IT systems in sharing sensitive information between providers. A fully integrated electronic system for sharing information would ensure that relevant information was available to any professional at any time – with a copy of the record being available to any patient who wished to hold their own. Others spoke positively of patient-held notes or "care passports" (documents designed to provide relevant information to any health or social care professional interacting with the patient).

As highlighted above, there are many examples of good practice in this area, but a clear lack of consistency across the country. Whether through patient held-notes or fully integrated IT systems, it will be vital for any future development of the healthcare system to ensure there is a mechanism for information to be shared across all relevant sectors.

Key points:

- In order to provide appropriate care in line with the patient’s preferences, it is crucial that every relevant health professional who has contact with the patient has all the relevant information they need – including diagnosis, prognosis, treatment plan, and the patient’s wishes.
- There are many examples of good practice in this area, ranging from the use of patient held notes to IT systems, but a clear lack of consistency across the country. It will be vital for any future development of the healthcare system to ensure there is a mechanism for information to be shared across all relevant sectors.

Who is responsible for coordinating care?

The coordination of care can be time-consuming (it will very often take staff away from clinical or care duties) and complex work (particularly if an individual lacks knowledge of all the services available to a patient). Where there is a lack of coordination, people can find themselves duplicating information which has already been recorded elsewhere. Patients and their families can also find the process of accessing help complicated and confusing: many members of the public with recent experience of a bereavement found that trying to access the right services and speak to the right professionals at a distressing time was very stressful.

Throughout the events, there was clear public support for the concept of a central end-of-life care coordinator assigned to an individual patient, whose responsibility it is to ensure coordination between services; for ensuring that information is shared; and for making sure that packages of care are in place in line with the patient’s needs and wishes. This way, patients and their families would always know who to approach for information, and be shielded from some of the more stressful aspects of trying to coordinate care. This concept is also in line with what many doctors told us about where end-of-life care worked well: when it had an identifiable and accountable coordinator.

This concept is not new, and many of the national strategies for end-of-life care (described in [volume 1](#)) include a similar provision: England’s strategy talks about establishing a central coordinating facility to provide a single point of access, whilst the Northern Ireland strategy suggests that each patient identified as having end-of-life care needs should have a key worker with responsibility for coordinating services and facilitating effective communication of information. Other organisations have also identified the need for such a structure. The Review of Choice in End-of-Life Care, for example, (see [volume 1](#)) advised that the option of a “care coordinator” be offered to everyone with end-of-life care needs – whether that coordinator be a health professional, family member, friend or carer – with responsibility for navigating the health and social care system, and advising on services.

Despite the provisions made in these strategies, it is clear from speaking to the public at the events that they are not being implemented in reality. Whether it is the creation of a new post, or the development of existing “main point of contact” or “named persons” systems, a clear contact point for end-of-life care coordination should be assigned to each patient to ensure coordinated care and the sharing of relevant information. We acknowledge that it will very often be impractical for a single individual to do this work, and so alternatively, the provision of an information centre or hub should be considered. This person or service should provide such practical assistance as necessary in accessing the various services available and be responsible for ensuring that care packages are in place.

Key points:

- The coordination of care can be time-consuming and complex. From the point of view of patients and their families, it can be distressing at an already stressful time, to try and coordinate the different aspects of their relative's care themselves.
- Whether it is through the creation of a new post, or the development of existing "main point of contact" or "named persons" systems, an end-of-life care coordination service should be available to each patient to ensure coordinated care and the sharing of relevant information.
- This service should also provide such practical assistance as necessary in accessing the various services available and ensuring that care packages are in place.

Communication



9. Communication

“We should say ‘you are coming to the end of 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

When the public was discussing what end-of-life care should encompass at the events, good communication between all parties was seen as an essential component. This includes communication between the patient and their family and all of the professionals involved in the patient’s care: GPs, specialists, nurses and counsellors. This is not surprising as communication, and the closely related issue of coordination (see section 8), feature prominently in most other reports on end-of-life care and form a core part of all four nations’ end-of-life care strategies. These reports and strategies are discussed in some detail in [volume 1](#) of this report.

Communication with patients and families

One table at each of the public events had individuals with recent experience of bereavement. Amongst those in this group who felt that care had worked well, a key feature was open, honest and frequent communication with the patient and family. The frequent nature of this information was particularly welcomed, with the patient and family given regular updates about any changes, or the fact that there had been no change, and what to expect next, in an open and sensitive way. Equally, amongst those who reported bad experiences, the communication was described as “poor” with specific comments about the perceived lack of openness and transparency about the patient’s diagnosis and/or prognosis. Doctors themselves also recognised the importance of good communication but were candid about the fact that this did not always happen. Many lamented the lack of training they had received and felt ill-prepared for the difficult conversations they faced.

“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 strength that he had to tell us what we didn’t want to hear.”

Public

Junior doctors and medical students in particular expressed a desire for more training in discussing the end of life and dying with patients. Many young doctors felt that they were very much “thrown in at the deep end” when starting training, with the expectation being that they learn “on the job” or by watching more experienced doctors. Whilst the importance of being able to observe more senior doctors having these conversations should not be underestimated, medical schools should consider how they can best prepare doctors for the difficult conversations they will need to have with patients and their families – possibly even from day one of their practice. Part of this should include knowing how to respond to “unanswerable questions”; how

to be confident in talking to families – including where there are difficult or dysfunctional familial relationships; and how to understand and react to different cultural patterns and sensitivities. Particularly important will be equipping doctors with the skills to initiate these conversations when they feel a patient is approaching the end of their life, without waiting for a crisis to prompt discussion – by which point it may already be too late. Where it can be arranged, placements within hospices and other establishments caring for patients at the end of life can help to boost medical students' confidence in talking about death and prepare them for their future careers. It is also important that training in communication skills is not seen as a one-off but is recognised as an ongoing need so that the skills can be honed and developed, through training and practical experience, throughout a doctor's career.

Of course, there is some information that patients want which doctors simply cannot provide, no matter how good they are at communicating with patients. Doctors described it as almost impossible to predict accurately how long a patient has to live, but acknowledged that patients virtually always ask this when given a terminal diagnosis. Doctors also recognised that patients put great weight on any predictions given and, whilst some patients are pleased to have "beaten" a doctor's estimate, others may be depressed by it – an estimate that turns out to be incorrect can undermine trust. Knowing how to address these 'unanswerable' questions and being able to communicate uncertainty in a way that is honest, helpful and supportive are key skills. Some doctors acknowledged, that as a profession we often fail patients by not being sufficiently clear about their condition and the prospects of recovery. Using euphemisms or skirting around the issue may appear more sensitive and avoid upsetting patients in the short term but may, in fact, make the situation more difficult, leaving them uncertain of their future and unable to prepare themselves and their family for their death. Many of the public expressed their admiration and gratitude to the doctors who had provided clear and honest information, albeit information that was difficult to hear, about the fact that the patient was dying.

“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

The doctors the researchers spoke to nearly always described talking to patients about dying as “difficult” and “distressing”; this was so regardless of experience and/or confidence. There was a feeling, however, that this was the way it should be: doctors should never become jaded or complacent so that they cease to recognise the impact the news they are sharing has on the patient and those important to them. At the same time, it is important for doctors to understand that these discussions will yield a positive result through open conversation and help facilitate a death that is judged to be good by the patient themselves. The fact that these difficult and intense conversations could also be positive was highlighted by a significant number of doctors who spoke about it being a “privilege” or “rewarding” to interact with patients and care for them in the final stages of their life.

“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...”

Public

Communication is, of course, two way and the importance of doctors listening to patients and their families should not be underestimated. It is vital that doctors know how to do this in a meaningful way. If doctors are to hear and understand what a patient's wishes and preferences are for their death, they must be able to listen and to understand what is important and of concern to each individual patient. Whilst this may be time-consuming, it is a critical first step in understanding what patients want in order to form care plans and should be seen as a core part of providing high-quality treatment services rather

than a luxury or “optional extra”. In addition to training, resources need to be made available to ensure that this can happen and those planning services must ensure that time is built in to allow for this aspect of communication. Doctors could, for example, be freed up from large administrative workloads to be able to devote time to listening to their patients and having open conversations. However this is achieved it is vital that doctors are allowed the time, and support from senior managers and colleagues, necessary to do this properly – as it will reap huge benefits further down the line. Clinicians must be able to understand patients’ views, beliefs, and preferences in order to formulate and facilitate care plans and treatments. Crucial to this is an understanding of the diversity of people receiving end-of-life care, the fact that there will be any number of individual, cultural, or religious preferences for the end of life, and that there will be huge variation in the level of understanding people have.

Open, honest and transparent discussions can only take place, of course, where both parties are willing for that to happen. Some of the doctors at the events noted a common barrier to open and honest communication was an unwillingness from the patient or their family to discuss the issue. Our suggestion for a public education campaign to encourage people to think about and discuss their wishes and preferences for the end of life (see section 7) will be helpful in this respect. Also, although we have focussed on the training needs and communications skills required of doctors, because this was the nature of the events, we recognise the vast number of different professionals that are involved in caring for dying patients and supporting their families; good communication skills are equally important for all of those individuals.

The public taking part in the events also identified a need for an identified single communication channel to provide information about the health and care services available, as well as related financial and legal issues, rather than leaving families to seek out information themselves about a wide range of disparate services. These issues are discussed in section 8 on planning and coordination and section 11 on financial and legal.

Key points:

- Good communication is central to good end-of-life care but is not always achieved.
- Doctors should receive more ongoing training in communication and listening skills and, in particular, in responding to “unanswerable” and difficult questions in an open, transparent and sensitive way.
- Education and training in communication skills must be supported by employers to allow the time and space for difficult conversations to take place.
- Making time to listen to patients and their families should be considered a core part of providing high-quality care and not a luxury or optional extra and, as such, resources should be made available to enable this to happen
- If communication is to be improved more work is needed to promote discussion about death and dying within the population and to encourage people to think about their wishes and preferences.

Communication between health professionals

Another aspect of communication that was raised during the events, was communication between doctors providing care to a patient. This is partly addressed in section 8 on coordination but goes beyond this to the very basic issue of individual doctors having a discussion about the patient’s needs, care and treatment. Many doctors highlighted how difficult it is for doctors to speak to each other, even for two consultants working within the same hospital; communication between doctors in primary and secondary care was perceived to be even more difficult. Time is a big issue here and it is essential that systems are in place to ensure that rotas and work patterns allow sufficient time for appropriate handovers between shifts and for team discussions. When discussing the doctor-patient relationship, the public rated continuity of care very highly. Those who had seen the same doctor repeatedly over a period of time reflected on this very positively. Whilst steps should be taken to maximise continuity of care, in practice this cannot always be achieved. Recognising this, it is essential that systems are in place to ensure that all of those who are involved in providing care to an individual patient have sufficient opportunity to share

information and discuss the patient's health and treatment on a regular basis so that a coherent and consistent approach is taken to treatment and communicated to the patient and family. The public were very critical of receiving contradictory information from different health professionals involved in their relatives' care.

The lack of communication between primary and secondary care was highlighted at the doctor events as a major problem. Other investigations and enquiries, including the Choices Review (see [volume 1](#)), have also referred specifically to the problems with communication between primary and secondary care which can impact on the quality of care provided at the end of life. Similar findings were identified in some of the cases where things went wrong which were investigated by the Parliamentary and Health Service Ombudsman.²⁹ Some of the doctors at the events attributed this problem, at least in part, to changes in referral systems. Whereby in the past GPs would know all of the local consultants and would refer patients directly to the relevant person, and so could pick up the telephone or write a letter directly to that person to discuss the patient's care, the introduction of intermediary services and generic referrals had reduced this familiarity between primary and secondary care professionals which, in turn, hampered their ability to communicate directly on a personal level. Communication between primary and secondary care may also be made more difficult by the way in which services are commissioned and thus organised, as well as time pressures in all sectors.

Further work is needed to improve communication channels between primary and secondary care and to remove the organisational barriers that exist in order to ensure a coordinated approach to patient care.

Key points:

- Systems should ensure that rotas and work patterns allow for continuity of patient care, where possible and time for appropriate handovers and team discussions, to ensure a coherent and consistent approach to treatment and communication.
- Further work is needed to improve communication channels between primary and secondary care and to facilitate doctor-to-doctor conversations

Emotional support



10. Emotional support

“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

During the dialogue events we commissioned, some doctors identified a clear shift in thinking amongst the medical profession over recent years which they welcomed. This reflected a move away from just focussing on physical symptoms and treatment to adopting a more holistic approach to treatment and care, including taking account of the patient's practical, spiritual and emotional needs. Others saw medical treatment and the physical aspects of pain and symptom relief as being their first priority, with these broader aspects of holistic care as a secondary concern and dependent on the time available. That is not to say that those doctors saw this broader role as unimportant, but that they did not necessarily see it as *their* role to assist patients with non-medical issues. Increasingly, however, it is being recognised that physical and emotional issues are closely interlinked and if we are to provide good quality end-of-life care to all patients, all members of the treating team have some role to play in ensuring that the patient's holistic, as well as purely medical, needs are addressed, whilst not necessarily dealing with all of the issues themselves. Ensuring that appropriate emotional, social and spiritual support is available to patients, and their families, during and after end-of-life care is one aspect of this holistic approach to treatment, which features prominently in each of the nations' end-of-life care strategies (discussed in [volume 1](#)). Taking account of an individual's history (including spiritual, social, and cultural factors) when assessing and treating patients is a longstanding principle of good medical practice, and is clearly stated in GMC (General Medical Council) guidance.³⁰ Another issue that came through very clearly at the events was the emotional toll that caring for patients at the end of life can have on doctors themselves and the need for this to be recognised and for appropriate and timely emotional support to be accessible to doctors, and other members of the care team, as and when necessary.

Support for patients

When the public considered what good end-of-life care should look like, emotional support both for patients and families was mentioned repeatedly. There was recognition that discussing death and dying is difficult and that doctors do not always have the time to spend supporting patients and their families – although palliative care specialists, geriatricians, nurses and GPs were singled out as being particularly skilled in this area and making more time than other specialists. There was no expectation from the public that doctors could or should meet all of a patient's emotional needs but they did believe that specialised counselling and support services should be widely available and easily accessible.

During the discussion with doctors about the emotional support available to patients and their families, it became evident that many were unaware of the services available locally, including those within their own work place. Many spoke positively about the involvement of the chaplaincy service available in hospices and many hospitals, whilst others were unfamiliar with this service or perceived it as being suitable only for those with strong and established Christian beliefs. This reflects the views expressed by chaplains themselves, in a study by the Church of England, which found that they felt “invisible” within their institution

and frustrated that staff would forget to include them in patient care.³¹ Many also felt they needed to defend themselves against the false assumption that a chaplain is going to preach at people or try to convert them while they are in a fragile state. In practice, hospital chaplains provide emotional and spiritual support to all patients and staff and have the time and expertise to listen to them and discuss whatever issues are important. There have also been very significant changes to the way hospital chaplaincy is organised over the last decade or more. Many hospitals now have a range of spiritual advisers available to support patients including Rabbis and Imams and it is a specific requirement of all hospital chaplains working within the NHS that they are able to work with patients, staff and families with “any faith or no faith”.

Although the support they provide is not restricted to religious support, it needs to be recognised that the religious associations with hospital chaplaincy may deter some patients from accessing their services and so this mechanism for support will not be suitable for everybody. Nonetheless, it is important that all patients should be aware of the support that is available to them. Healthcare providers should make information about supportive services available to health professionals – particularly but not only those treating patients at the end of life. This will ensure that doctors are aware of the full range of services available within the healthcare establishment and locally, including hospital chaplaincy, counselling services and support networks, have an accurate understanding of what they are able to provide, and can signpost patients to them. These services have an important role to play throughout end-of-life care, including when patients are coming to terms with their diagnosis and prognosis, and should not be considered an option only towards the very end of life.

In some ways providing emotional support for patients and families is easier where patients are being cared for in a hospital or hospice but the increasing efforts to allow people who wish it to be cared for and die in their own homes, means that community provision of support and counselling may need to be developed and increased. Specialist palliative care teams and organisations like Macmillan and Marie Curie provide both practical and emotional support to those within their care, but this is not available to all those being cared for at home. Some patients and families will seek help and support from their own spiritual advisors but, for those who do not, one option for increasing services might be to consider whether chaplaincy has a role beyond the hospital or hospice setting. Other forms of community based spiritual support should also be explored.

Key points:

- Health professionals should be provided with information about the range of support services that are available, and what they provide, so that they can signpost patients to them. This includes chaplaincy, counselling services and support networks.
- Information about support and counselling services should not be considered only towards the very end of life and recognition is needed of the role these services can play in helping patients at all stages, including helping them to come to terms with their diagnosis and prognosis.
- As more people are supported to be cared for and die at home, support and counselling services in the community may need to be developed and increased.

Support for families, including children

When discussing their fears and concerns about end of life and dying, the impact on families was a huge issue for the public, far more so than the doctors expected. A significant part of this was how family members would cope with their death and what support would be available for them. For those who were parents, the impact of their death on their children – particularly young children – was a major concern. Providing good bereavement support not only benefits those who use it, but the knowledge that support is available can relieve some of the anxiety of those approaching the end of their lives. In practice, however, such services are in short supply and often difficult to access.

Sadly, when recounting their own experiences of bereavement, some members of the public recalled feeling that they had been “dropped” as soon as the patient died. They reported that although emotional support was provided to the family while the patient was dying, this ended abruptly after death. Whilst some of the public were aware that counselling and bereavement services existed, they often did not know how to access them and had not been provided with that information. Many spoke very positively about the support from hospital chaplains but expressed some concerns about the lack of wider emotional support and the lack of formal links between the services available within the hospital and in the wider community. In section 11, we discuss the general need for more and better information to be provided to patients and families; information about the counselling and bereavement services that are available locally, and how to access those services, should form a core part of that. Health professionals also have a role in providing information about such services to families, and should ensure they are familiar with the services available locally.

“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

When death is thought to be approaching the family’s need for support may intensify and this is recognised in the fourth priority identified by the Leadership Alliance for the Care of Dying People (discussed in [volume 1](#)) which states that in the patient’s last few days or hours the needs of the family, and others who are important to the patient, should be actively explored, respected and met as far as possible.

Support for children

It is important that doctors always consider whether there is a child likely to be severely affected by the death and engage in open discussion with the family about the need to keep the child informed of what is happening before, and during bereavement and that others, such as the child’s school, are aware to allow them to provide support to the child. How information is given will depend on the developmental age of the child, but the evidence points to the importance of preparing children, even the very young, for their impending loss, whether the patient is their parent or someone else, such as a grandparent, to whom the child feels particularly close. When a parent is dying the future care of children needs to be discussed openly and others, such as a social worker, may need to be involved, to enable all necessary provision to be made for the children after death. In addition, a dying parent may wish to prepare a memory box of objects, letters etc., as a legacy for the child to have in later life.

The impact of bereavement on children can be particularly damaging and they often need specialist help to process the information and to deal with the grief and other emotions they may be feeling. Where the patient has young children, or where there are children who are very close to the dying person and likely to be affected by the death, information about local bereavement services to meet their specific needs should be provided to the adults responsible for their care. As with support and counselling for patients (see above) services may be useful to families throughout end-of-life care and not solely at the very end of life. Information therefore needs to be made available at an early stage so that it can be accessed as and when necessary.

Availability

Sometimes, however, the problem is not lack of information about the services available but the ability of local services to meet the demand, resulting in long delays, or restrictions, in access. Various organisations (including Macmillan and the Association for Palliative Medicine of Great Britain and Ireland in their evidence to the House of Commons Health Committee)³² have highlighted that across the UK bereavement support is fragmented, inconsistently provided and rarely seen as a priority for service providers. If end-of-life care is to be improved, this must include funding to ensure that sufficient, high quality bereavement services – including specific services for children – are available and accessible consistently throughout the UK.

Key points:

- Information about the counselling and support services available for families within the health care establishment and locally, and how to access them, should form part of the package of information provided to patients and families, as discussed in section 11.
- Health professionals should be familiar with the range of counselling and support services including those specific to young children and signpost them as appropriate to patients and their families.
- Where the patient has young children, or there are other children likely to be affected by the patient's death, information about the specialist services for children that are available locally, and how to access them, should be provided to the adults responsible for their care.
- Where such services are not readily available, doctors should encourage those with responsibility for the child or children to prepare them for their impending loss and that it is often wise to inform others, such as school, about what is happening.
- Funding should be provided to ensure that sufficient, high quality bereavement services – including specific services for children – are available and accessible consistently throughout the UK.

Support for doctors and other members of the care team

Although most of the reports and strategies on end-of-life care refer to the emotional needs of the patients and their families, very little attention is given to the emotional needs of doctors, yet this is something that came through very clearly from the events. Although professionally trained to deal with death, the emotional toll it can have on doctors should not

be underestimated. Many doctors spoke movingly about their "first death". Their vivid recollection of events and their feelings at the time, often many years later, speaks volumes about the impact it had on them. One doctor, reflecting with the benefit of many years' experience said, that whilst at the time she felt she had failed because the patient had died, she now recognised that this had not been the case, but that her failure had been in not recognising that the patient was dying, and thereby not allowing the patient and family time to prepare.

Reports of the emotional impact deaths can have on doctors came from those who specialise in end-of-life care and so have daily contact with dying patients, as well as those for whom such encounters are rare; from those who were relatively new to practice and those who were coming towards the end of their careers. Other members of

“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

the care team can be similarly affected, particularly when they have cared for a patient on a daily basis, and perhaps become close to them and their family (for example, in a care home or on an inpatient ward). Some doctors spoke of particular factors within individual cases that affected them, whilst others referred to the cumulative effect of supporting patients and their families through their grief and suffering that took its toll. It is important that those who are caring for others in these difficult circumstances are also cared for themselves. Those organising healthcare services should ensure that formal and informal mechanisms are available for doctors and other members of the care team to access emotional support and counselling as and when they need it, whether that is an experienced colleague with whom to talk through difficult or challenging cases, support from occupational health services, or more formal counselling and support services. They should also ensure that all doctors are aware of other services that are available such as those from the BMA's Doctors for Doctors unit.³³ We would like to see the use of such services expanded and normalised amongst those who are undertaking what is acknowledged to be a very difficult but

important role, so that individuals access such services at an early stage and before their health is adversely affected.

It should also be remembered that almost all doctors will, at some time in their medical lives, have to face personal family bereavement. This is a time when doctors may find that their coping skills are more fragile than normal and their sensitivities enhanced to patients and to their relatives, and they may find it difficult to provide effective patient care. Although they may be helped at this time by the support of their colleagues and team, it is important to recognise when they may need additional space and time and be encouraged to seek support from occupational health services or from counselling services outside their immediate organisations. It is important that such resources are available and well publicised. The BMA's Doctors for Doctors unit can also provide support to doctors in these situations.

Key points:

- Despite their professional training, dealing with death and dying can have a significant emotional impact on doctors and other members of the care team and this needs to be recognised.
- Those organising services should ensure that mechanisms are in place to ensure that doctors and other members of the team who are caring for patients at the end of life have access to formal and informal support as and when they need it and are aware of the range of services available to them.
- We would like to see the use of such support services expanded and normalised so that individuals are encouraged and supported to access them at an early stage before their health is adversely affected.

Financial and legal



11. Financial and Legal

“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

In section 7, we discussed the information needs of patients and those close to them in relation to their illness, treatment and care. The perceived need for information discussed by members of the public at the dialogue events, however, extended way beyond this. It included practical information about the type of care, support, state benefits and services available to those with terminal illnesses; information about, and practical assistance with, making wills; and signposts to bereavement and support services available for families after death (discussed in section 10). When the public were asked about their hopes and fears about dying, having their affairs in order and their finances sorted came out very highly. It is important that those providing and organising care to patients at the end of life recognise that these factors are very important to patients and that helping to address some of these concerns may reduce levels of anxiety and improve the overall wellbeing of patients. Some hospitals may already provide some of this information through social work departments or other support services but it needs to be a coordinated approach that is visible to patients and families at the time they need them.

The public were realistic in their expectations. They did not expect doctors to be able to provide all of this information but they did see a role for healthcare staff to clearly signpost them to existing services and to provide clear, straightforward information. Some of the public suggested a “one-stop information shop” within healthcare establishments so that families did not need to seek out a wide range of disparate services themselves. However this is organised, it is important for those providing services to people at the end of life to consider the type of information and assistance their patients, and their families, might need and wherever possible to facilitate access to this. This might be through a library-type resource, a stock of information leaflets including material in accessible formats, or a member of patient-support staff or volunteer who is able to direct the patient to relevant information or organisations. The availability of these services should be promoted to all patients so that they are able to access them. Some patients who are dying may want to make a will and any steps that can be taken to facilitate this, such as allowing non-medical hospital staff to act as witnesses, are likely to be helpful.

Key points:

- Those establishments providing or organising end-of-life care should consider the type of information and assistance patients and their families might need – including about legal and financial issues – and facilitate easy access to this including, where appropriate, allowing non-medical hospital staff to witness wills for those who wish to make them.
- Extra attention should be given to ensuring that information is provided in formats that are accessible to people who struggle with the written word or the English language.

Part three

Physician-assisted dying

Part Three: Physician-assisted dying

12. Physician-assisted dying

“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

The BMA has a longstanding policy of opposition to the legalisation of assisted dying in all its forms and recognises both the range of views which exist within the membership, and the strength of feeling this issue can prompt. This is clear from the fact that it features regularly on the agenda at the BMA’s annual representative meeting (ARM) and has been debated at seven of those annual meetings since 2003. Current BMA policy on assisted dying can be found in appendix one.

Public debate has continued in a number of countries around the world and legislation has been passed in some places. Closer to home, bills to legalise physician-assisted dying have failed or run out of time in both Houses of the UK Parliament and in the Scottish Parliament. The issue has also been brought before the Supreme Court. Details of the various debates on physician-assisted dying are provided in [Volume 1](#) of this report.

In developing this BMA project on end-of-life care and physician-assisted dying, we recognised that all too often these debates (both internal and external to the BMA) tended to focus on the binary question of support for, or opposition to, assisted dying. Much of the public debate has also tended to focus on the issues as a matter of principle, rather than considering some of the more practical issues involved. With this project, we wanted to take the opportunity to explore some of the issues around physician-assisted dying such as the possible impact legalisation could have on the doctor-patient relationship, an issue which is frequently raised in our debates – in the hope that the discussions taking place were as comprehensive and as informed as they could be.

From the outset, we were emphatic that this project was aimed neither at changing, nor confirming current BMA policy. The aim was to gather more information about attitudes and perceptions on certain aspects of physician-assisted dying, in order to facilitate more informed debate and discussion on these issues, both within the medical profession and in society more broadly. Similarly, the project was not about assessing support for or opposition to physician-assisted dying. The researchers were not seeking participants’ views on the principle of assisted dying itself – although many of those who attended the events expressed those views as part of the table discussions.

As the main aim of this component of our project was to gather information for our own internal debate and discussion, we have not made any recommendations about the future of physician-assisted dying and what role doctors should play in this. For the BMA, this is ultimately a question for our representative body to deliberate on after informed discussion

and debate. What we have done in this section is to reflect on some of the findings from the events which we considered to be particularly noteworthy.

Information on physician-assisted dying available to the public

To limit misconceptions and ensure that discussions were as informed as possible, a single definition of physician-assisted dying was provided (see below), as well as some information about how it operates in jurisdictions where it is legal. This included information about eligibility as well as the methods and complications which could be involved in the assisted dying process.

Definition of physician-assisted dying provided at the events

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.

It was apparent that despite considerable coverage of the assisted dying debate in the media, there was a lack of knowledge of certain aspects and much of the detail. Many members of the public and doctors were unaware of some of the countries where assisted dying was permitted: although many were fairly knowledgeable about the law in Switzerland (largely due to the media coverage of UK citizens traveling to Dignitas), far fewer were aware that it was legal in the Netherlands and Belgium, and in the states of Oregon, Washington and Vermont in the USA. Others were surprised at the eligibility criteria in those jurisdictions, but for differing reasons. Some members of the public were surprised that people with dementia would be excluded by the eligibility criteria in some places, whilst some doctors expressed concern about the inclusion of depression and non-terminal conditions in some of the systems.

The actual methods used in physician-assisted dying were also a cause for surprise for participants, public and doctors alike. Many participants were surprised to learn that the main method for assisted suicide in jurisdictions where it is legal involved the patient taking the drugs orally: there seemed to be an assumption that drugs would be administered intravenously (where this is administered by a doctor or other third-party, this would be euthanasia and not physician-assisted suicide). Participants were also provided with information about the types of complications that can occur with assisted dying (for example, regurgitation of medication, vomiting, seizures and muscle spasms), as well as the actual number of cases from Oregon where complications had been reported (recognising that data on complications were available in only 530 out of a total of 859 cases, due to a change in reporting mechanisms from 2010 – as reported in [volume 1](#)). A number of members of the public were surprised to learn that complications could occur at all, or that occasionally the action could fail. Many doctors were also surprised to hear that there could be complications or failure associated with assisted dying – particularly as in some of the jurisdictions where physician-assisted dying is permitted, there is no requirement for a doctor to stay with the individual. A small number of doctors expressed surprise that there were not more complications.

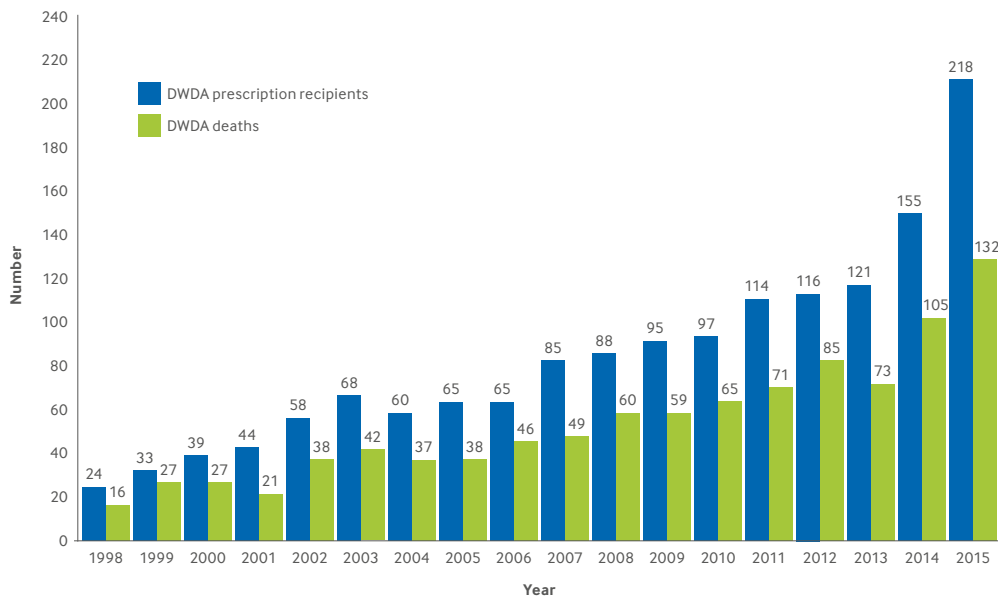
“It sounds a bit strange but I had my dog put to sleep, and the vet gave her an injection and she was away, and I just expected that to be the same...”

Public

Participants were also supplied with information from the Oregon data on time until death, which shows that half of individuals died within 25 minutes (shortest time being 1 minute) of ingestion of the lethal drugs, half took longer than 25 minutes (longest time 104 hours), and that six patients had regained consciousness. Although participants recognised that 104 hours was only one case, and an outlier, many were surprised to learn that assisted dying was anything other than instantaneous. There was a perception amongst many that death would always be immediate, with no delays or periods of unconsciousness. We heard from a number of participants that they had assumed “it was like taking a pet to the vet.”

Data from Oregon and other jurisdictions can be found in [volume 1](#). Since publication of [volume 1](#), the Oregon Health Authority has published new data on the operation of the law in 2015.³⁴ In 2015, 218 people received a prescription for lethal drugs and 132 people died as a result of ingesting drugs prescribed under the legislation. Information on the time between ingestion and unconsciousness is available in 25 out of the total 132 cases, but ranged from between 2 minutes and 15 minutes, with a median of 5 minutes (this aligns with previous years’ data, where there was a median time of 5 minutes, with a range of 1 minute to 38 minutes). Similarly, information on the time between ingestion and death was available in 25 out of the total 132 cases, and ranged from between 5 minutes and 34 hours, with a median of 25 minutes. Data on complications were unknown in 105 cases, but in the 27 cases where it was collected, there were no complications in 23 cases, 2 cases of regurgitation, and 2 cases where complications were recorded as “other”. The updated graph showing the number of prescription recipients and deaths by year in Oregon is below.

Figure 4: Death with Dignity Act prescription recipients and deaths by year, Oregon, 1998-2015



*As of January 27, 2016

There are a lot of data available around physician-assisted dying and, as the debate continues, both in the medical profession and the public, it will be helpful for this to include more of the factual reality of physician-assisted dying so that the “in principle” debate becomes a discussion of the practical issues that need to be considered. We welcome and encourage an informed debate on this topic both within the medical profession and the general public, and hope that these findings will play a role in this.

Consideration of practical issues associated with physician-assisted dying

It was clear from these events that despite the strength of feeling associated with this issue, very few participants had given detailed thought to how any such law would operate in any practical sense. When members of the public were asked to imagine the impact of legalised physician-assisted dying on the doctor-patient relationship, they often struggled because they had never thought about this issue or discussed it prior to the day. Their views were therefore more fluid than those of the doctors attending. Once these initial barriers were overcome, discussion evolved into an engaging and organic debate about some of the more nuanced and practical issues associated with physician-assisted dying – which is exactly what we were hoping would be achieved during this research, and we hope, as part of subsequent wider debate. Comprehensive consideration of all the issues covered can be found in [volume 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

The doctors who attended tended to have given more thought to this subject – largely due to the nature of the profession. They often found it more difficult to divorce their views on the doctor-patient relationship from their wider opinion on the matter, and as a result the discussions were rather more polarised than those had by the public.

Public participants acknowledged a largely balanced range of positive and negative impacts on the doctor-patient relationship associated with physician-assisted dying whereas the doctors at the events had more reservations. The range of reasons given are discussed in some detail in [volume 2](#) and are summarised in the infographic below (figure 5).

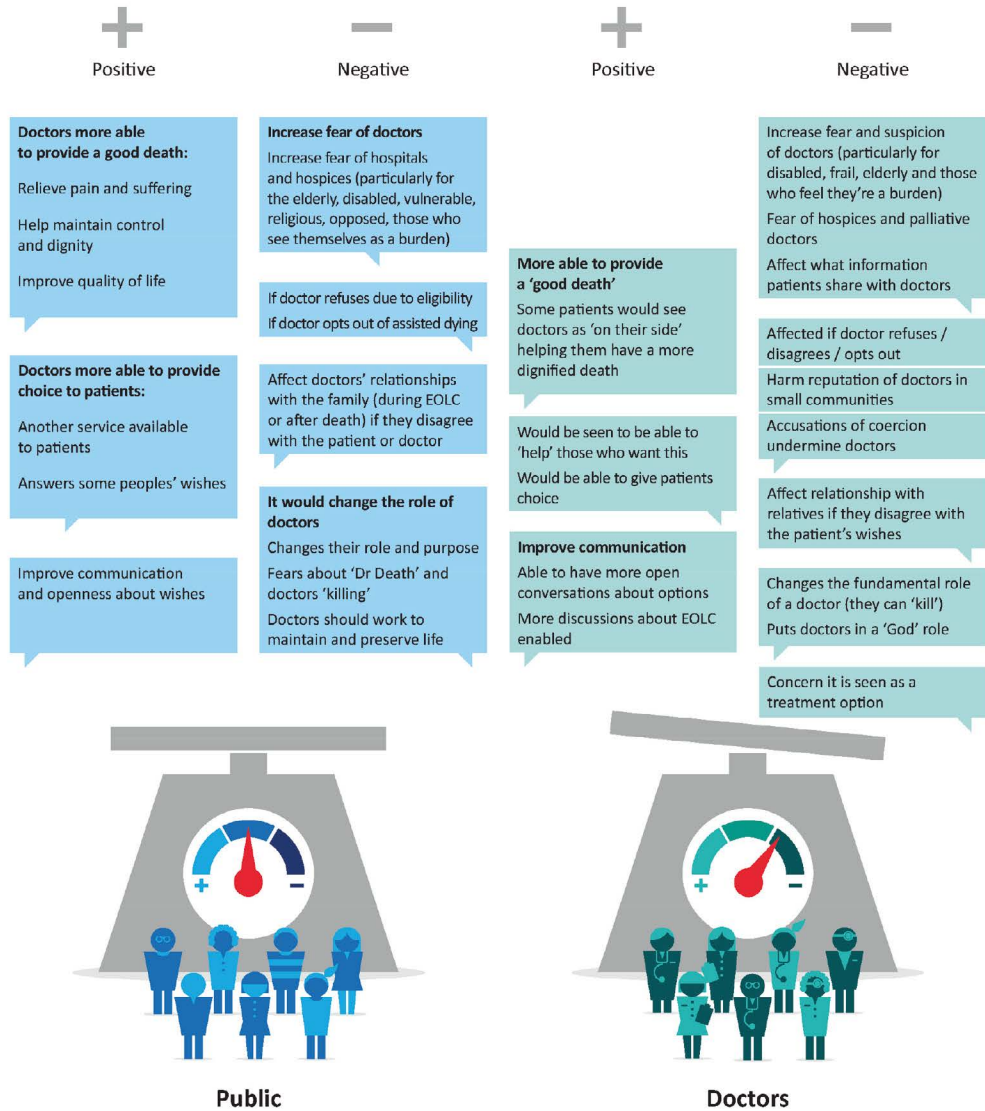
“If they were diagnosed with an illness, they might be a bit more wary of their doctors... They might feel negatively towards their doctors because it’s not an option they want to take.”

Public

Figure 5: The impact of the legalisation of physician-assisted dying on the doctor-patient relationship

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



TNS BMRB
© 2015



“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

Associated with these discussions was the recognition that there were a number of conditions which could affect whether and how the relationship would be impacted. These included the process in place for making the request (whether the request truly originated from the patient, and not someone else); the precise role of specific doctors (whether it would be carried out by an existing specialty or an entirely separate branch of medicine); whether there were financial motivations for the doctors to support assisted dying (whether it was associated with profit making or cost-cutting exercises); and how the media covered the issue.


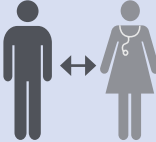

When we explored in more detail the impact on the doctor-patient relationship of various different people making the decision on eligibility (the individual’s own treating doctor; a doctor with no pre-existing relationship with the patient; or a judge) participants again struggled to articulate their views, having never previously considered this issue. Once this was overcome, the public and doctors had a wide-ranging and evolving discussion. The key points are summarised in the illustrations below (figures 6 and 7).

Many members of the public and doctors also agreed that the risk of coercion was an important consideration in any discussion on the impact of physician-assisted dying – but this was often only when prompted to consider this, rather than raising it of their own accord. Members of the public generally interpreted this as coercion by family members or a doctor, whereas doctors also considered the risk of self-imposed coercion amongst those who might feel they were a burden on their families.

“If they’ve been diagnosed with a terminal illness they may be too scared to approach a doctor about other things... 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.’”


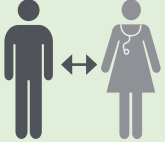

Doctor

Figure 6: Potential positive and negative impacts on the doctor-patient relationship of three options for deciding eligibility (the individual's treating doctor; a doctor with no pre-existing clinical relationship with the individual; a judge, on the basis of information provided by doctors) – public

+		–
<ul style="list-style-type: none"> – 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 		<ul style="list-style-type: none"> – 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
<ul style="list-style-type: none"> – Balances subjectivity and objectivity – Patients must raise the issue – Less pressure on family doctor – Have medical knowledge – Could be a separate branch/specialist 		<ul style="list-style-type: none"> – 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
<ul style="list-style-type: none"> – 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 		<ul style="list-style-type: none"> – Bureaucratic/a burden/upsetting – Loss of time – prolongs pain & process – Costs – who pays? – Strain on family – Impersonal – Fear of courts/associated with crime and punishment – Lack of medical knowledge

There were differences of opinion about which option for deciding eligibility would have the least impact on the doctor-patient relationship, and there were some noticeable differences between the public and doctors – particularly in their views of the role of a judge. Whilst both doctors and patients thought that involving judges in the process would protect the doctor-patient relationship, doctors were far more likely than members of the public to favour their involvement. Reasons given for this included the independence and objectivity a judge would have; the separation between the decision on eligibility and its administration; and the extra layer of protection this could give to doctors. Whilst members of the public recognised the protection that a judge could provide to doctors, and recognised their ability to assess evidence, detect coercion, and manage disputes, they had a different view of judges. Many of them associated judges and courts with crime, wrongdoing, and punishment, and as such, felt it would be inappropriate to involve them in any assisted dying decision-making process. There was a recognition, however, that there may be a role for judges in cases where there were disputes about eligibility or where coercion was suspected. Both members of the public and doctors also thought that a judicial process had the potential to be bureaucratic, and could perhaps be costly and time-consuming – adding to the stress already felt by seriously ill individuals and their families.

Figure 7: Potential positive and negative impacts on the doctor-patient relationship of three options for deciding eligibility (the individual's treating doctor; a doctor with no pre-existing clinical relationship with the individual; a judge, on the basis of information provided by doctors) – doctors

+		–
<ul style="list-style-type: none"> – 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 		<ul style="list-style-type: none"> – 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
<ul style="list-style-type: none"> – Less pressure if responsibility is shared – Separates the decision and the administration – Could involve specialists – Could involve specialists to assess depression and capacity 		<ul style="list-style-type: none"> – 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'
<ul style="list-style-type: none"> – 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 		<ul style="list-style-type: none"> – 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

“In terms of maintaining the therapeutic relationship that is there, there is something that frees the doctor to continue in that supporting role if that decision is taken out of medical hands.”

Doctor

Unprompted, some participants (both doctors and members of the public) began to express a view that in terms of deciding eligibility, a panel or committee, made up of various individuals with different expertise, might have the least impact on the doctor-patient relationship. It was suggested that a panel or committee would be able to reach a better decision, by hearing and taking into account a range of views, from family members and doctors who knew the patient, to specialists who could provide information on the patient's condition. It was also seen as sharing the burden of decision making amongst multiple individuals. As this issue was raised spontaneously it was not raised on all tables and participants did not discuss it in any detail.

The impact on doctors

At the events, doctors were asked about the possible professional and emotional impact being involved in physician-assisted dying might have on them. The majority of impacts identified were negative, and 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; they felt it could divide the profession; and both prompt people to leave the profession and discourage some from entering it. At the same time, however, some doctors reported that there would be positive emotional and professional impacts on themselves and the profession. These were mainly associated with feeling able to relieve pain and suffering, maximising patient choice in this area and being more able to discuss the dying process with their patients. Many doctors assumed there must be, and would support, a conscientious objection clause which would allow those who did not agree with physician-assisted dying to opt out of the process in some way.

“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

It was interesting that, despite not being asked specifically about the impact on doctors, some of the discussions by the public on the doctor-patient relationship offered up unprompted concerns for doctors involved in the process and the emotional impact it might have on them.

The findings from these research events were not conclusive in respect of the potential impact of legalising physician-assisted dying on the doctor-patient relationship or how this could vary depending on the people or processes determining eligibility. Nonetheless, we were pleased to see that the questions asked and the information provided progressed the debate from binary “yes/no” discussions to much more considered and detailed discussion about the impact and implications of any legislation that might be tabled for debate. The information gathered will be crucial in facilitating more informed discussion within the BMA, but also, we hope, will play an important role in informing the wider public debate.

Key points:

- We hope the information we have gathered will help to inform our internal debate and discussion and will be of interest to wider ongoing public discourse.
- It was notable that despite considerable media coverage, there were significant gaps in both the public and professionals’ knowledge around a number of aspects of physician-assisted dying. We welcome a full and informed debate on this issue, and hope that the information in these reports will contribute to this.
- It was interesting that although there are strongly held views on this topic, very few people (both members of the public and doctors) had given much, if any, consideration to some of the more detailed issues associated with physician-assisted dying. We were pleased to see consideration of some of those issues start to develop through discussion at these events.

Appendix One – Relevant BMA policy on end-of-life care and physician-assisted dying

END-OF-LIFE CARE

- 2015 That this Meeting applauds the DH's concerns regarding the health of older people but insists that growing old should not be wholly medicalised and that people are allowed dignity during the natural dying process.
- 2010 That this Meeting:
- (i) recognises that persistent requests for assisted suicide and euthanasia are very rare when patients' physical, social, psychological and spiritual needs are being appropriately met;
 - (ii) calls on the BMA to campaign for better training in palliative medicine for all GPs and hospital doctors involved in managing dying patients;
 - (iii) calls on the BMA to campaign for better education of the public about what good palliative care can achieve.
- 2009 That this Meeting believes the time has come for the majority of hospice and palliative care funding to come directly from NHS resources.
- 2006 That this Meeting recognises that a significant proportion of palliative care occurs in the out-of-hours setting and therefore demands that:
- (i) all providers of out-of-hours services receive regular training in palliative care;
 - (ii) there are formal mechanisms for hand-over between daytime and out-of-hours services;
 - (iii) there is easy access to essential medications out-of-hours.
- 2005 That this Meeting believes that facilities for terminal care in the patient's own home should be equally good for malignant and non-malignant conditions.
- 2005 That this Meeting believes that advance directives should be available to people who wish to make one and:
- (i) that medical students and junior doctors should have specific instructions on the use of advance directives and asks the BMA to lobby the relevant authorities to provide this information;
 - (ii) that it should be the responsibility of patients to draw the attention of medical professionals to such documents;
 - (iii) that the BMA should include this information in their guidance for patients.
- 2002 That the core teaching of religious traditions and world views, particularly in respect of treatment, death and dying, needs to be strengthened in the curriculum, and that, in a multi-cultural environment, medical schools have a duty to provide this information.
- 1984 That this Meeting calls upon the Government to provide and support facilities for the care of the dying and the relief of intractable pain, in whatever sector such care is undertaken.

PHYSICIAN-ASSISTED DYING

- 2006 That this Meeting:
- (i) believes that the ongoing improvement in palliative care allows patients to die with dignity;
 - (ii) insists that physician-assisted suicide should not be made legal in the UK;
 - (iii) insists that voluntary euthanasia should not be made legal in the UK;
 - (iv) insists that non-voluntary euthanasia should not be made legal in the UK;
 - (v) insists that if euthanasia were legalised there should be a clear demarcation between those doctors who would be involved in it and those who would not.
- 1977 That this Meeting affirms that the position of medical practitioners who are in conscience opposed to euthanasia must be fully protected in future legislation should it occur and that no legal obligation in this respect should be allowed to be imposed unilaterally on any member of the profession at any time.

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