# What's important to me.

## A Review of Choice in End of Life Care

**ANNEX A:** *Summary of findings from public engagement on the National Review of Choice in End of Life Care*

# Annex A of What's important to me: A Review of Choice in End of Life Care

## *Contents*

# Summary of findings from public engagement on the National Review of Choice in End of Life Care

## Introduction

This report sets out the findings from a national engagement exercise which took place to support the Review of Choice in End of Life Care, commissioned by the Government in July 2014.

It summarises the key findings from over 1,000 responses and informs the Review's report What's important to me: A Review of Choice in End of Life Care. This engagement exercise was conducted by the National Council for Palliative Care in support of the Review.

We are immensely grateful to everyone who took the time to share their views and to all organisations involved in promoting it.

The engagement exercise generated a wealth of extremely rich insights, which will not only inform development of the Government's intention to offer greater choice in end of life care but also be shared widely to enhance the quality of end of life care for people in all settings and situations.
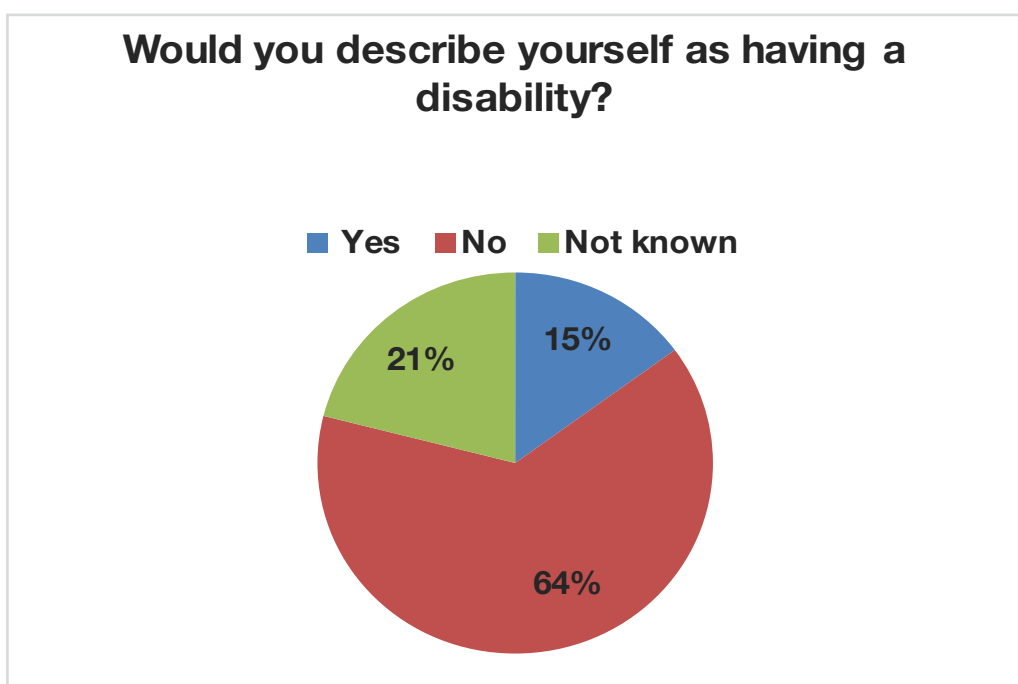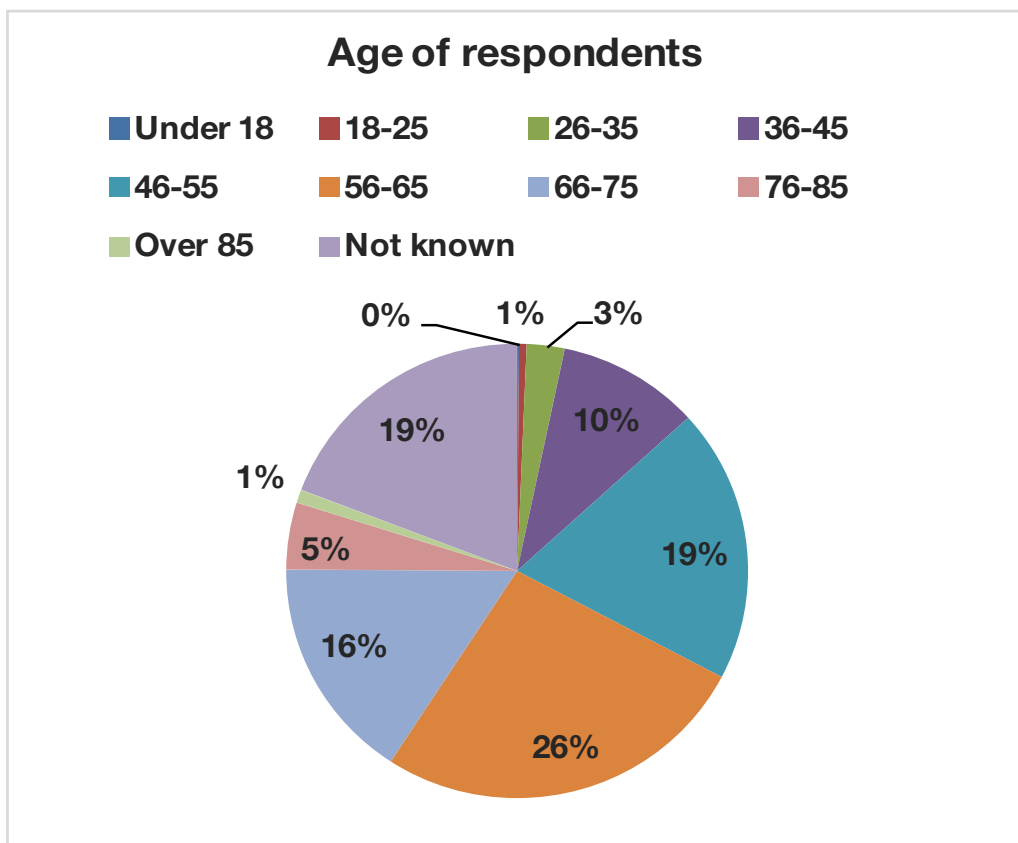
## About the engagement exercise

During August and September 2014 the engagement exercise invited both members of the public and people with a professional interest to share the views and experiences in relation to choice in end of life care by answering the following questions:

1.  What kinds of choices should people be able to make at the end of their life, and what should be in place for these to be achieved?

2.  Do you have examples of where people have been able to make choices about the care and support they receive at the end their life?

3.  How would we know if a 'national choice offer' improved people's experience of care at the end of life? For example, how we might be able to measure and evaluate the impact on the quality of care and support received?

The engagement exercise was publicised widely through local media, and local and national organisations. People were able to respond by telephone, post, email, through an online survey and as part of engagement events and group discussions.
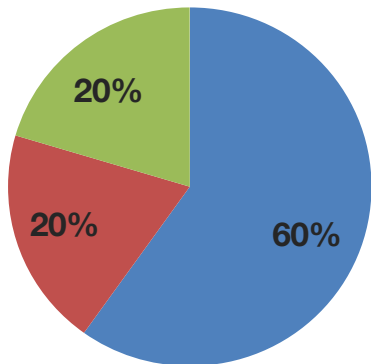
To reach as wide a range of people as possible, we received support from charities and national organisations, and commissioned several focused activities to better understand the thoughts and experiences of people with learning disabilities, lesbian, gay, bisexual and transgendered people and people with sight and hearing loss.

The following graphs provide demographic details for respondents from all methods of response.

### Age of respondents

**Legend:** Under 18 | 18-25 | 26-35 | 36-45 | 46-55 | 56-65 | 66-75 | 76-85 | Over 85 | Not known

- 0%
- 1%
- 3%
- 10%
- 19%
- 26%
- 16%
- 5%
- 1%
- 19%

### Would you describe yourself as having a disability?

**Legend:** Yes | No | Not known

- Yes 15%
- No 64%
- Not known 21%

## Sex of respondents

■ Female ■ Male ■ Not known

- Female: 60%
- Male: 20%
- Not known: 20%

## Ethnicity of respondents

■ White ■ Non-white ■ Not known

- White: 75%
- Non-white: 2%
- Not known: 23%
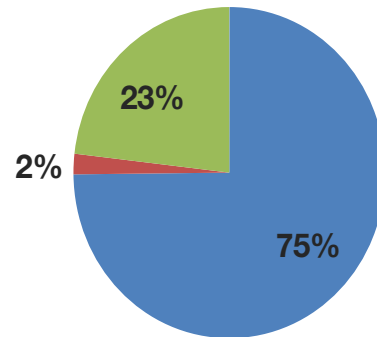
## Is your gender identity the same as the gender you were assigned with at birth?

■ Yes ■ No ■ Not known

- Yes: 79%
- No: 0%
- Not known: 21%
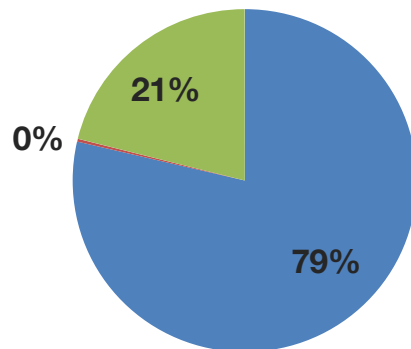
## Which of the following best describes how you feel about yourself?

■ Lesbian
■ Bisexual
■ Gay
■ Heterosexual/straight
■ Not known

- Lesbian: 1%
- Bisexual: 2%
- Gay: 1%
- Heterosexual/straight: 72%
- Not known: 24%
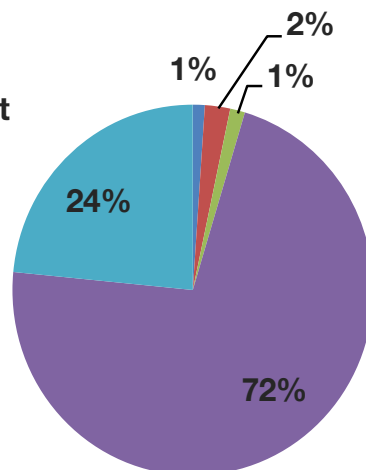
# How we analysed the data

Online, post, email and telephone responses were analysed collectively because they contained the same questions in the same format, whereas group and workshop responses were analysed separately because although the covered the same broad areas, they provided additional information and allowed people to express themselves in more depth. Commissioned reports on focused experiences were also analysed separately.

A set of codes were developed to break the data down for analysis. These codes were derived from the data as it was analysed; we did not approach the data with a pre-formed set of codes. Where possible, the codes used language used by respondents, although code descriptions were kept as short as possible:

| Code | Description |
|---|---|
| Where to die | Being able to choose a place of death |
| Preferred place of care | Where to be cared for leading up to the moment of death |
| Information | The need to be informed about prognosis, available services, etc. |
| Control of treatment | Being able to control all aspects of treatment such as when, where, for how long, etc. |
| Refusal of treatment | Being able to make the choice to refuse further treatment |
| Honest conversation | Having honest conversations with professionals about treatment and care options; having honest conversations with family members about death and dying |
| Care planning | Having conversations about and developing a care plan |
| Patient involvement | Being fully consulted in aspects of treatment and care |
| Patient choice | Allowing choice of service, professionals, treatment options |
| Advocacy | Having a third party to advocate for the dying person if they are incapable of doing so themselves (not necessarily a family member) |
| Time to consider options | Being given time by professionals to make decisions about treatment and care, instead of being rushed |

| Code | Description |
|---|---|
| Staff training | Training staff to deliver high quality care with compassion |
| Respect | Being respected as a individual by professionals |
| Dignity | Being able to maintain dignity throughout the end of life |
| Personalised care | Being able to tailor care to your needs i.e. choose when professionals visit |
| Quality of care | Ensuring care is of a high quality |
| Governance | Using various tools to ensure a standardised level of care; having someone accountable when care is not of a high quality |
| Access to specialist palliative care | Being able to access specialist palliative care services at any location |
| Community care | Having access to care that can be delivered in a community setting |
| Hospice provision | Having access to hospice inpatient beds |
| Access to 24 hour care | Having care available 24/7 |
| Access to equipment | Being able to obtain equipment in order to be care for at home |
| Funding for care | Funding to support paying for care on an individual level; funding for service provision across the country |
| Pain management/symptom control | Being able to access medication to alleviate pain or treat symptoms whenever required |
| Holistic support | Care that takes account of all aspects of a person, including social and emotional needs |
| Spiritual care | Access to spiritual care when required |
| Quality of life | Being able to preserve quality of life for as long as possible |
| Coordinated care | Care that is joined-up across services |
| IT systems | Systems that support sharing of information between services |
| Ability to change plans | Reactive services that allow quick changes to care |
| Support for children | Specific pre- and post-bereavement support tailored for children |

| Code | Description |
|---|---|
| Support for carers | Supporting carers to deliver care while the person is dying including respite, training, and monetary support |
| Bereavement support | Access to bereavement support where required |
| Family involvement | Letting family be as involved in treatment and care decisions as far as the dying person wants them to be involved |
| Funeral planning | Support with organising funerals |
| Legal support | Support with writing wills |
| With people | Having people present at the time of death, regardless of location |

In many of the responses, there was overlap between the different codes. Where this was the case we combined information from different codes to avoid duplication. For example, where someone had mentioned "patient choice" and "information" in the same quote, we moved the information part into the "information" section.

All the feedback received from the engagement exercise questions was coded. Single responses which covered several areas were allocated more than one code. This approach allowed us to identify a number of themes, to which each of the coded responses were allocated.

Answers to question 2 *Do you have examples of where people have been able to make choices about the care and support they receive at the end of their life?* were incorporated into findings from question 1.

A number of responses were either primarily or totally concerned with issues that were outside the scope of the review. Details of these responses are available at appendix 1.

Whilst we were delighted with the number and range of responses, we must be mindful that they reflect the views only of those who participated. Nevertheless, the findings of this exercise strongly echo research carried out to date. They give us an indication of the kinds of things that are important to people and clear messages about ways to ensure that people receive high quality care at the end of life.
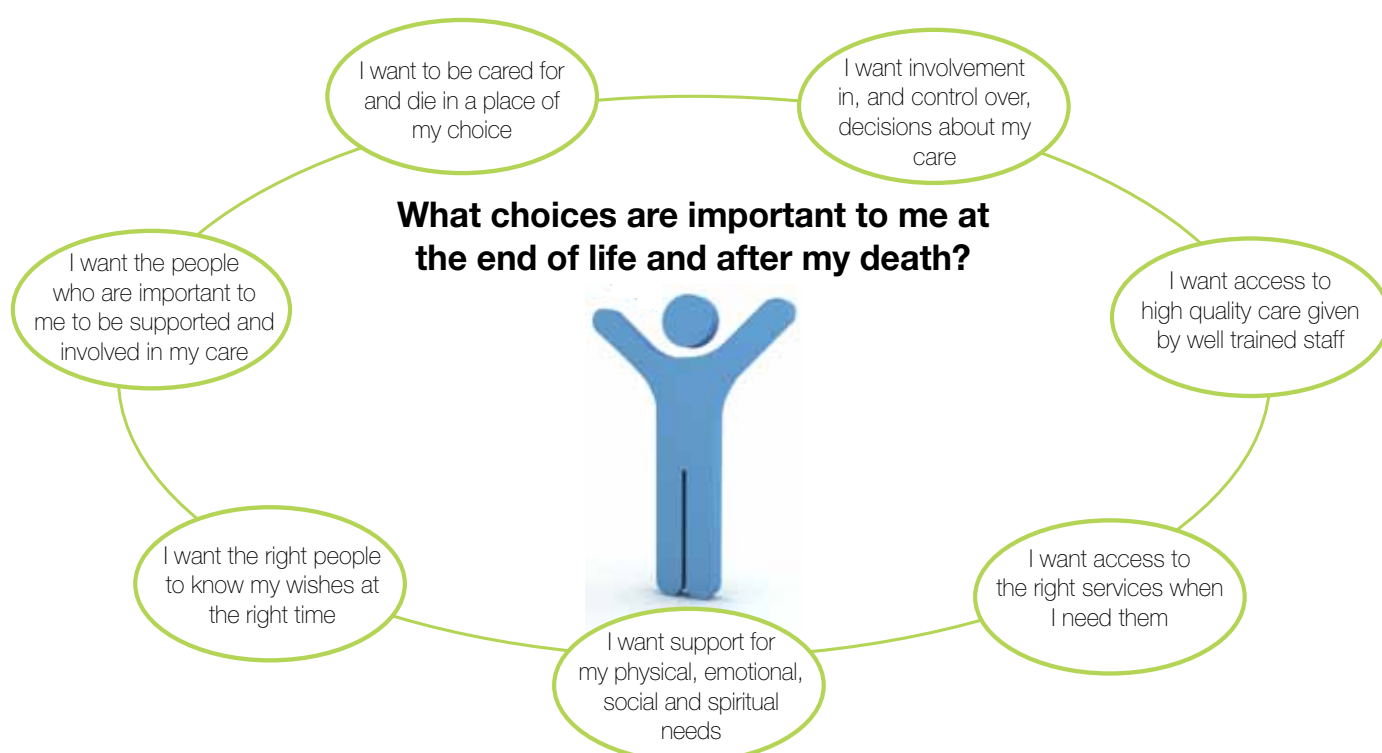
# Our findings

## *Overview*

Overall, the majority of people said that they wanted choice about their care but that this should be informed by important considerations about their individual needs, their illness and its trajectory, and other considerations such as the involvement of those close to them. Over half of all engagement responses focused primarily on place of care and death, reinforcing the importance of this issue to people, with choices on control over treatment and involvement of family and those important to them also featuring strongly.

However, many respondents said the most important consideration was that they received good quality care. This is reflected in what people said about wanting access to high quality care, wanting the right people to know their wishes at the right time and wanting access to the right service when needed. Some of these responses identified "good care" as their choice and regarded other choice suggestions as peripheral and inessential in comparison. A minority of respondents were negative about the concept of choice and felt it was more important to focus on the delivery of good basic care. Respondents raised the issue that choice is multifaceted and has an impact on people who are important to the person who is dying.

## *Question: What kinds of choices should people be able to make at the end of their life?*

The responses to this question were grouped into seven key themes:



**What choices are important to me at the end of life and after my death?**

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

I want involvement in, and control over, decisions about my care

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

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

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

I want access to the right services when I need them

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

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

This theme was comprised of responses which were classified under two codes: *where to die and preferred place of care*. The proportion of the responses for each code is shown below:

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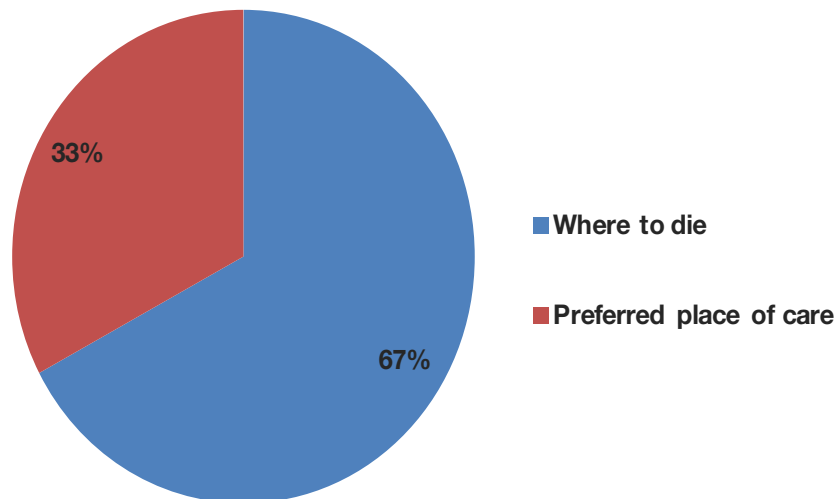


Choosing where to be cared for and where to die were mentioned in the majority of responses and most people saw them as of the highest importance. People perceived the main choices of location to be home, hospice, hospital and care home (including specialist housing, nursing homes and residential homes) and often listed them after having said "people should be able to die in a place of choice, whether that is.......", rather than stating them as a preference in their own right.

Although home was mentioned more than any other location, very few described it, unreservedly, as the best place to be cared for or die. Experience of care was often described as being more important than the place itself, and people wanted to be sure that the right support was available wherever they were cared for.

*"Emphasis on place of end of life is not enough. The quality of experience is crucial"*

Certain aspects of the environment were described as being more important than the physical location, such as it being peaceful, quiet and dignified. Although respondents associated these environmental factors more readily with home, they said that similar conditions could be created in other settings, such as by having individual rooms or dedicated palliative care wards in hospitals.

The quality and personalised nature of care provided in hospices is widely praised, but with concern about the limited number of hospices, beds and care for people with conditions other

than cancer.

> *"I believe that the Hospice model is beneficial for end of life care, because it is small and personal. The added benefit is that staff are specialised and often very experienced"*

Care homes, nursing homes and specialist housing were mentioned as possible places where people might choose to be cared for and die. People described the need for staff to be trained and supported by specialists, hospices and community services such as District Nurses and GPs.

> *"Elderly people may be able to die in the care home but this only works if a care home has caring and experienced staff"*

> *"All care homes should have 'normal' access to physiotherapists, occupational therapy and a full time activity coordinator"*

## Theme: I want involvement in and control over decisions about my care

This theme was comprised of responses which were classified under six codes: *information, control of treatment, refusal of treatment, honest conversation, care planning and patient involvement*. The proportion of the responses for each code is shown below:

**I want involvement in and control over decisions about my care**



- Information
- Control of treatment
- Refusal of treatment
- Honest conversation
- Care planning
- Patient involvement
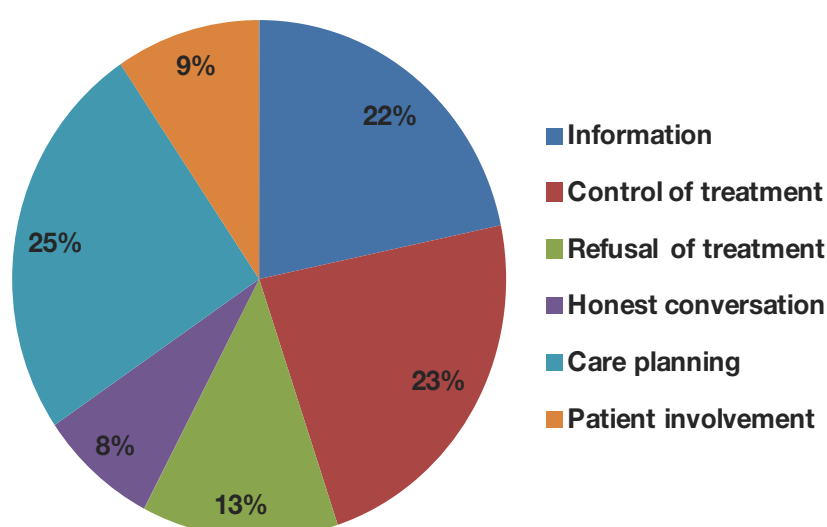
To a greater or lesser extent, respondents wanted to have control over and involvement in in decisions about their care. At the very least, they wanted to choose how involved they would

like to be. To enable this to happen, respondents highlighted the need for timely access to information.

> *"Professionals need to be ready to have the conversation with patients and carers about end of life care plans and be ready to provide information."*

The importance of these conversations happening at the earliest opportunity was noted, as were the difficulties in ensuring that these conversations happen, and that they are open and sensitively handled.

> *"End of life care discussions to be initiated early (or as early as practical/appropriate) with all patients with an incurable, life-limiting illness (i.e. not just cancer) to gauge how far they want treatment to go and what their personal priorities are BEFORE they are too far down the illness trajectory to be able to determine their wishes."*

Respondents expressed the need to feel empowered to make decisions relating to their care. They wanted to know what they were entitled to, how to express their views, and that these views will be listened to.

> *"I want to be sure that I am really listened to and that my prior wishes are clear and understood by all"*

Many of the decisions that respondents said they wanted related to specific elements of their care, such as whether to resuscitate, sedation, tests and other procedures and pain management.

> *"I'd like to be able to focus treatment on comfort, symptom control, time with family and to avoid unpleasant and intrusive investigations procedures and treatments.*

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

This theme was comprised of responses which were classified under six codes: staff training, respect, dignity, personalised care, quality of care and governance. The proportion of the responses for each code is shown below:

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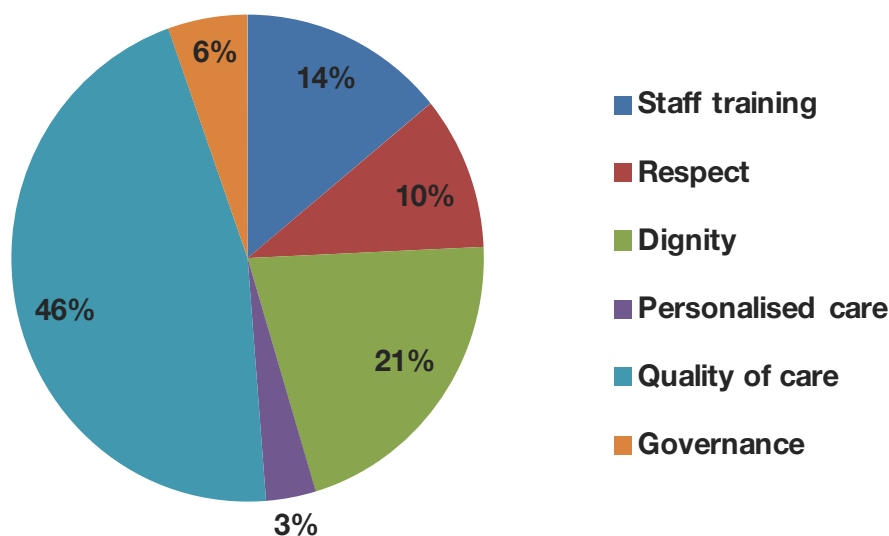


People valued access to high quality care delivered by skilled and well–trained staff.

> *"People should have access to emotional, social, spiritual and psychological support for themselves and their families to enable them to process and to deal with the impact of illness, disability and impending death, including the both the practical and relational implications of this."*

> *"Every patient must get all the appropriate medical and nursing care that they need, They must be given food and fluids for as long as he or she is able to assimilate it. This is ordinary care – an entitlement."*

Staff treating people as individuals, and having the time to listen to them and dealing with them compassionately was seen as vital.

> *"A kind, understanding, empathetic approach to caring for those who are dying and their families"*

> *"The person facing the end of their life needs the doctor, nurse, care home worker who is looking after them to know how to listen properly to their spoken and unspoken needs and wishes."*

This was seen as key to being able to maintain the dignity of the person who was dying.

> *"Everything about the care provided should be done in order to honour the dignity of the person who is dying and those who are important to them. All those involved should be afforded the highest dignity, including professionals"*

However, respondents acknowledged that staff needed the right support and training to be able to offer the best care at all times.

*"Those involved need to be skilled, knowledgeable and aware of end of life care issues, to allow the person who is dying and their family to be confident in the people caring for them"*

In particular, they should be trained in:

- Communication skills

- Recognise symptoms and managing them well

- Supporting people who are dying

- Medical and clinical skills"

*"There should be good appraisal systems."*

*"People should have continuing professional development."*

*"There should be mentoring in place so that staff can support each other."*

# Theme: I want access to the right services when I need them

This theme was comprised of responses which were classified under six codes: access to specialist palliative care, community care, hospice provision, access to 24 hour care, access to equipment and funding for care. The proportion of the responses for each code is shown below:

## I want access to the right services when I need them



**Legend:**
- Access to specialist palliative care
- Community care
- Hospice provision
- Access to 24 hour care
- Access to equipment
- Funding for care
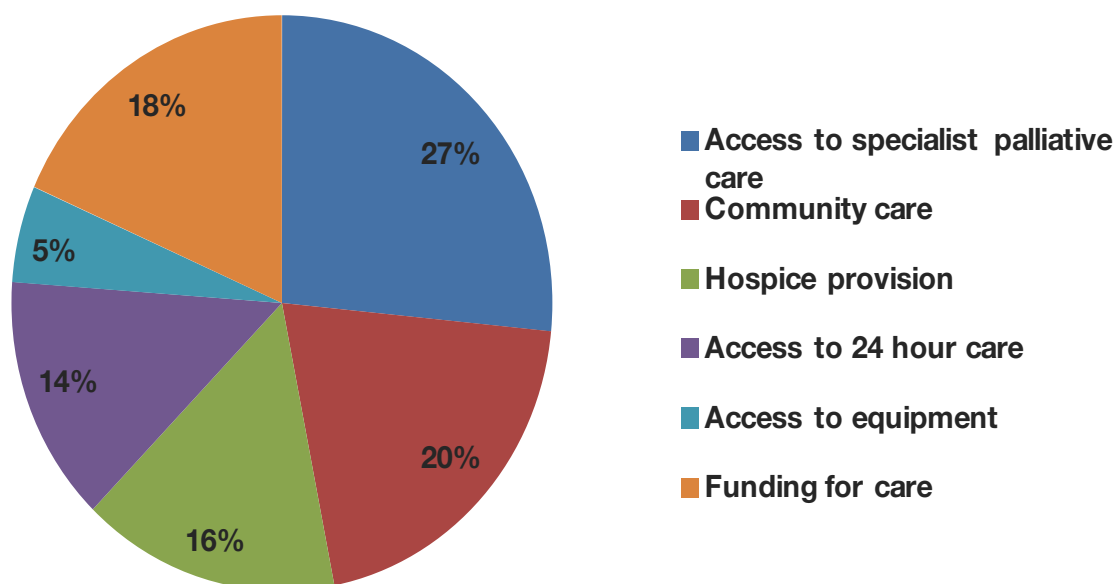
Respondents particularly highlighted the need for access to specialist care, delivered by both the NHS and through hospices, as well as care in the community on a 24/7 basis.

> *"All patients should have access to the excellent palliative care services that already exist in our area."*

> *"Genuine equity for provision of excellent palliative and end of life care whatever the diagnosis. The care available is still better for cancer patients. Availability of palliative care for non-cancer patients is still very patchy."*

> *"There needs to be adequate support for people to spend the final days of life at home (or preferred place) so that dying outside of hospital becomes a realistic option."*

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

This theme was comprised of responses which were classified under four codes: pain management/symptom control, holistic support, spiritual care and quality of life. The proportion of the responses for each code is shown below:

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



- Pain management/symptom control — 55%
- Holistic support — 16%
- Spiritual care — 14%
- Quality of life — 15%
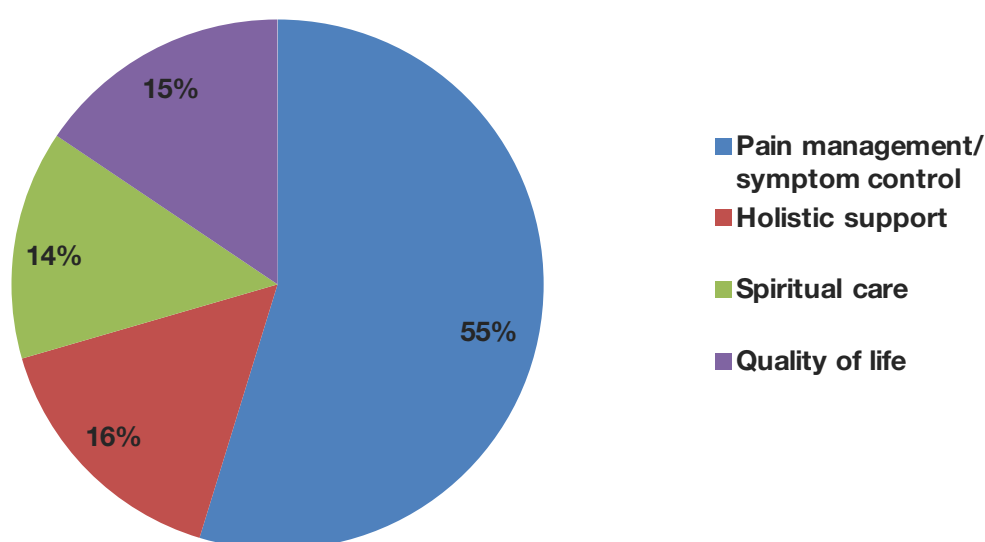
Many responses under this theme placed a strong emphasis on pain control and symptom management.

> *"People should at all times be pain free with their medication being constantly monitored to ensure this is maintained"*

*"Staff should have the ability to provide pain and other symptom relief and meet patient hygiene requirements (e.g. assistance to get to a toilet or use a commode) whether in home, hospital or hospice settings"*

*"If being cared for at home ensure pain alleviation in place 24 hours a day"*

Respondents also valued wider elements of support which focused on their emotional and spiritual needs.

*"Emotional support including no fear, anxiety or stress. Being able to be at peace."*

*"People should be able to choose how best to meet their spiritual and emotional needs. This might be going to church or having a chaplain visit or it might be about having access to yoga."*

## Theme: I want the right people to know my wishes at the right time

This theme was comprised of responses which were classified under three codes: coordinated care, IT systems, and ability to change plans. The proportion of the responses for each code is shown below:

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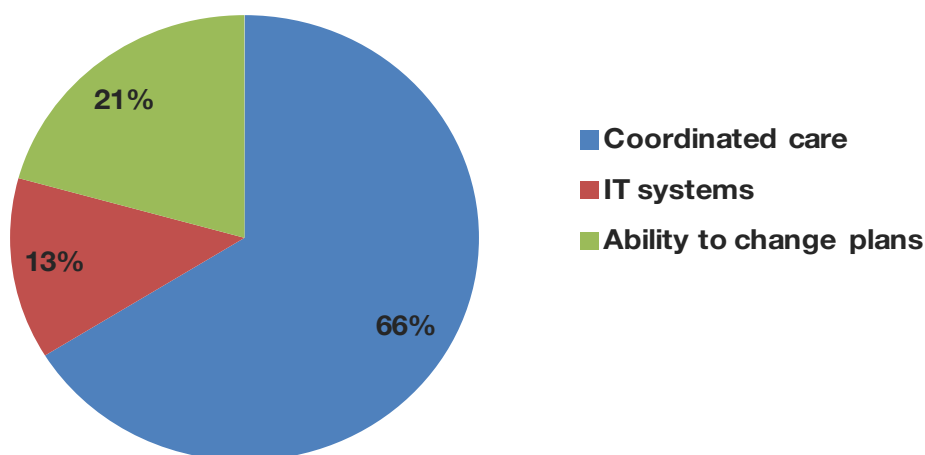


The issue of coordination of care was raised by respondents. Many examples were given of the range of statutory and non-statutory services which can be involved in individual cases, and respondents placed great emphasis on these organisations and individuals working together to deliver joined up care.

*"Care for people at the end of life will often involve multiple health and social care providers, working across commissioning boundaries and in a variety of care settings. Therefore, good communication and coordination between professionals is critical."*

*"Systems to provide shared access to information, a single number to contact and people to 'navigate' the system so that people can make the most of the time left, would be a great help."*

One key element of this was for staff in these different organisations to have access to information about the person in an electronic format.

*"We need a much better system of getting the details to the right place at the right time.  For example, my very elderly mother found herself in hospital for surgery with her surgeon unaware of any advance decision documentation"*

*"The staff should all be on the same IT system so that everyone understands my care, not separate systems that don't complement each other."*

Quick access to up to date information was seen by respondents as key to allowing plans to be quickly changed to reflect changing circumstances.

*"wishes and choices can change so much over time and are dependent upon situations"*

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

This theme was comprised of responses which were classified under seven codes: support for children, support for carers, bereavement support, family involvement, funeral planning, legal support and with people. The proportion of the responses for each code is shown below:

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



Legend:
- Support for children
- Support for carers
- Bereavement support
- Family involvement
- Funeral planning
- Legal support
- With people
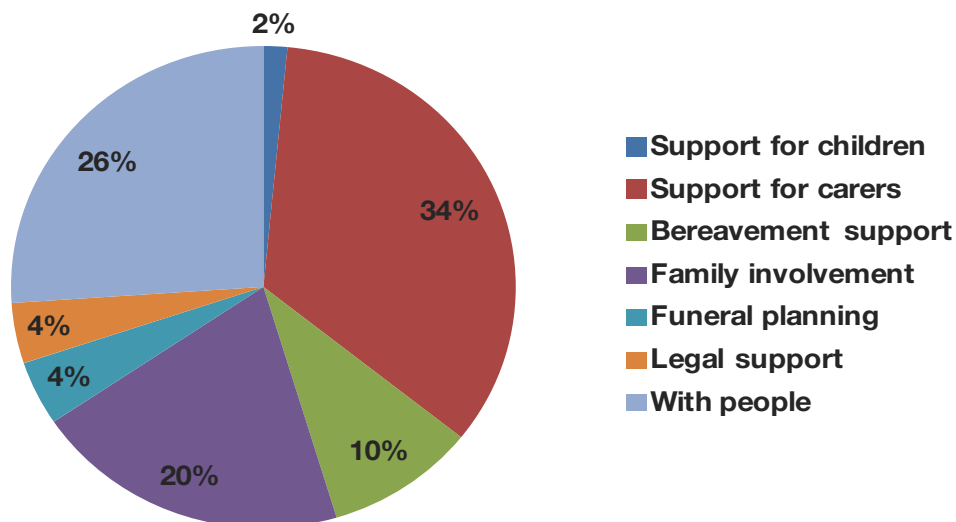
The impact of death on the people who are important to the individual was an important issue for many respondents.

> *"People should be able to be with the people they would like to share that event with."*

Respondents highlighted that carers need support during the period in which they are caring, and also during the bereavement process.

> *"Carers should be seen as key partners in care by professionals"*

> *"Ensure carers can exercise the choice to be included in conversations about care and support. Ensuring that they are fully informed of the requirements of their role."*

> *"There should be a form of 'carers leave' for relatives wishing to take time off with their dying relative, like paternity or maternity leave."*

> *"This should include a pre-bereavement risk assessment and offer of support tailored to level of risk."*

## Question: What should be in place for these choices to be achieved?

The second part of our main engagement question asked what needs to be in place for people's

choices to be achieved. The vast majority of the responses we received fell into three broad themes:

- Care when and where it's needed.
- Co-ordinated care.
- The right care of the right quality with the right staff.

# Theme: Care when and where it's needed

The key issues highlighted in many of the responses grouped under this theme was the need for community care and support to be available at all times of the day and night. Respondents in particular highlighted the issues relating to pain relief and the management of crises, and suggested that services be accessible at all times, at a minimum by telephone.

*"There needs to be a robust rapid response service so in the event of a crisis in a dying person, help is available within as short a time as possible 24 hours a day"*

This linked in with respondents highlighting a need to support carers on a 24/7 basis.

*"We need more staff that can do night sits to allow carers (especially when elderly or have young children) ability to rest/sleep at night, as this is hugely stressful experience for people"*

As well as community care, respondents also highlighted the importance of specialist palliative care in all settings.

*"We need access to specialist palliative care 7 days per week, access to both physical, emotional and social care needs 24 hrs per day, 7 days per week, a mixed skilled multi disciplinary community team, including support from supported volunteers"*

# Theme: Coordinated care

Respondents said clearly that good coordination was central to the delivery of good care. The main enablers of this were specific tools such as electronically shared care records, organisations working in partnership, more aligned funding systems for health and social care and greater information for individuals to enable them to make their choices.

*"Care for people at the end of life will often involve multiple health and social care providers, working across commissioning boundaries and in a variety of care settings. Therefore, good communication and coordination between professionals is critical"*

*"We need a much better system of getting the details to the right place at the right time. For example, my very elderly mother found herself in hospital for surgery with her surgeon unaware of any advance decision documentation."*

*"People need to be made aware of state benefits such as disability living allowance, attendance allowance and carer's allowance"*

*"Social care and health systems should be set up to provide information and support and guide people, illustrating what ongoing costs would be for residential/nursing care, how that would affect them and their families"*

## Theme: The right care of the right quality with the right staff

Respondents stated that everyone involved in caring for people who are dying should have the relevant training and support to enable them to do so well, and should be valued.

Proposals included specialist staff offering training to colleagues who do not care for people who are dying on a regular basis, and more joint-working with specialist teams from other areas of health and social care, in particular when people have conditions such as heart failure or chronic obstructive pulmonary disorder, identification of palliative care needs can be difficult and prognosis uncertain, to enable equality of access to specialist palliative care.

Specifically, respondents said that staff should receive training in the following:

- Communication skills.
- Effective information provision.
- Advance care planning.
- Palliative care.
- How to identify when someone is dying.
- Local services available.
- Communicating with people who have visual or hearing impairments.
- Pain management.
- Specific conditions such as dementia.

There was some debate about whether training should be mandatory. It was proposed that staff

should be given funding and protected time for this purpose.

## Question: How would we measure the impact of a national choice offer?



A variety of suggestions were made regarding what could be measured to assess impact and how measurement could be undertaken, as illustrated below:

## What to measure

Respondents mentioned examples of tools currently in place that try to assess the quality of end of life care and people's satisfaction with access to end of life care. These include the National Survey of Bereaved People (VOICES-SF), individual service consultations of patient opinion or family/carer opinion, and pilots of new approaches:

> *"SR-Vitrucare end of life 'app' - A full evaluation will be undertaken by Salford University following a 3 month period, which will see 250 patients across 3 Sue Ryder hospice communities using VitruCare to make choices regarding their care. The evaluation will focus on 3 main areas: Patient experience, professional and lay carer experience, benefits to the wider health economy."*

People also wanted to look at the possibility of further improving measures that currently exist:

*"In the Quality and Outcomes Framework (QOF), a voluntary reward and incentive scheme for GP practices in England, for example, there are two indicators for palliative care. These require participating GPs to maintain a palliative care register (on which people with CVD are less likely to be included due to identification issues) and hold at least three-monthly multi-disciplinary case review meetings to discuss the people on the register. There are no indicators incentivising improvement in outcomes for all patients at the end of life, such as being cared for in their preferred place."*

*"We want NICE to consider the inclusion of an indicator on preferred place of care and death in the Quality and Outcomes Framework (QOF) and we want NHS England to include that indicator in the QOF."*

*"In addition, the Adult Social Care Outcomes Framework, which sets out the indicators for measuring adult social care outcomes, includes no indicators on end of life care".*

*"We want the Department of Health to include a measure on death in the preferred place of care in the Adult Social Care Outcomes Framework."*

Responses to the consultation mentioned several other potential measures that could be looked at:

### *Care planning:*

- Number of people with an advance care plan in place.
- Whether the individual has been offered an advance care plan.

### *Access to services:*

- Measures of access to condition-specific end of life care.
- Availability of hospice beds.
- Measurement of calls to 'out-of-hours' services that were able to successfully manage an avoidable admission.
- The number of caregivers trained in end of life care.
- Number of non-fatal emergency admissions.
- Number of patients identified as in life-limiting stage by GPs (find your 1%).
- Number of out-of-hours GP/ambulance trust consultations ending in an A&E attendance.

- Measure resources required to deliver care against reduction in use of acute hospital beds and A&E presentations.

- Number of patients at the end of life admitted inappropriately to hospital.

## Location of death:

- Looking at actual place of care and death compared with the place of death listed in the individual's advance care plan.

- Number of deaths in hospital.

## Quality of care:

- Complaints about care facilities and support.

- Absence of pressure sores.

- Measuring the professional's delivery of care, according to the five Priorities outlined in the Leadership Alliance for the Care of Dying People's report One Chance To Get It Right.

- Measurement of symptom management.

- Measure staff confidence levels in discussing end of life issues.

## Information:

- The amount and quality of information on different aspects of end of life care and the choices individuals can make.

## Involvement in care:

- People's level of willingness to talk about how they felt and what they would like with family/friends and all others who are supporting them.

- People should be asked about what choices they have made, how they made them, what help they were given, etc.

- A scale for measuring stress level/contentment etc.; administer before and after choice is made and acted on.

- Ask, "Was the patient (or family member) made aware that they were dying by a professional caring for them?"

- Ask, "as far as possible, was everything done as the dying person would have wished?"

### *Support for bereaved people:*

- Bereaved people prescribed medication vs. IAPT (Improved Access to Psychological Therapies) plans in a locality.

### *Support for carers:*

- Measuring an outcome of carers being better informed and supported, could be evaluated by asking carers of people at end of life "Has anyone asked you if you are able or wish to continue in your caring role?" and "Have you received any information, advice or support for your caring role?"

- Number of carers being identified, referred for assessment and referred to local carers' organisations.

### *Coordination of care:*

- Number of people with full records on IT systems, not just registered.

- Measurement of commissioning contracts and the level of multi-agency working.

# Appendix 1: Out of scope feedback from the engagement exercise

As is the case with many engagement exercises, we received feedback on issues that are related to the subject matter in question (in this case, end of life care) but were not part of the scope of the review. There were two particularly noteworthy issues:

### 1. Children

Some respondents requested a similar review to be undertaken focusing on choice for children and young people under 16, as it important to find out what choices are important to children, young people, parents and those important to them, how they are discussed and what is required to support them.

### 2. Assisted Dying

There were a significant number of comments (130) received either partially or completely related to assisted dying. These were primarily supportive of a change to the law on this issue for people who are terminally ill. This subject was linked to many responses on the importance of an individual staying in control and be able to make their own decisions about when they wanted to die. Comments from responses included:

*"The law needs to be changed to allow assisted dying as defined in Lord Faulkner's (sic) Bill."*

*"Regarding the law obviously this needs changing so that it's not a criminal offence to help a dying person to carry out their wishes. However I hasten to add that regards end of life care in other instances such as when the dying person has not consented to assist dying either verbally or in writing then no I do not agree with that type of ending of life. These are a 2 pronged priority so far as I am concerned and I have indeed personal experience within my own family of such wishes."*

*"The most important decisions are that a person is able to decide when to end their life."*

*"The right to die at a time and place of my choice."*

*"Personally I would want to be able to choose where and how I die. At home and peacefully. This would mean that if I was terminally ill with no hope of cure or remission, then I should be able to end my own life with my loved ones around me, in a place of my choosing, preferably at home."*