



NHS West Yorkshire
Integrated Care Board (ICB)



People's experiences of end of life care in **West Yorkshire**



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Introduction

Listening to people who are dying or have been at a dying loved one's side can feel a little like stepping into a world usually hidden from view.

Some of the people we have spoken to about their own experience of end of life care have described it in similar terms: there is nothing quite like it, either on a personal and emotional level or on a service-based level. Services we might have only vaguely heard of (or perhaps didn't even know existed) suddenly loom extremely large.

But, we shouldn't consider dying a world apart, quite the opposite in fact: it's one of the few experiences we are all going to share. It matters that we listen to dying people and their relatives, friends and carers, and all the more so if our aim is to make dying as peaceful and comfortable as it can be. As one palliative care nurse said to us, "we only get one chance to get a dying person's care right".

For this report, Healthwatch have spoken to well over one hundred people who are dying or have

supported a loved one as they moved towards death, and if we were to leave you with just one observation it would be this: every person's experience is utterly unique.

More than most health and care services, end of life care has to intertwine with some of the most personal and complex aspects of our lives because our experience of dying is inseparable from factors as varied as our religion and belief systems to our family dynamics, our culture and language and our trust in public services. Add to this picture the vast array of organisations that look after dying people, from hospitals, GP surgeries and hospices to the smallest voluntary bodies, and it's hard not to feel that end of life care experiences are almost infinitely complex.

This report doesn't aim to fashion simple answers out of this huge complexity; in fact, we'd be doing a disservice to the people who bravely shared their experience with us across West Yorkshire if we didn't at least try to impart a sense of their total individuality. So even if it doesn't provide any easy answers, we hope this report does give you some impression of what it has been like to experience end of life care in West Yorkshire in recent years, with reference to the six ambitions laid out in the national framework for local action 2021-2026.

See p. 10 for details

By understanding what these ambitions mean to individuals, we can start to find ways forward that should help us to make sure everyone in West Yorkshire ultimately dies in peace and comfort.

On behalf of Healthwatch, we would like to say a sincere "thank you" to everyone who has contributed to this project, and most of all to the West Yorkshire residents who shared their stories with us. We hope you feel this report does you at least some justice and honours your wishes to make sure everyone is cared for well at the end of their life.

Please be aware that this report contains content that some people may find upsetting.



About us

The engagement detailed in this report was carried out by Healthwatch organisations in West Yorkshire.

The role of Healthwatch is to make sure NHS and social care decision-makers hear the voice of people and use their feedback to improve care. Because it has a strong focus on health inequalities, Healthwatch strives to give communities which traditionally haven't been included in engagements the opportunity to say what matters to them in health and care.

West Yorkshire Health and care services are planned and delivered at local level, with each local area being referred to as 'place'. These local 'places' are: Bradford District and Craven, Calderdale, Kirklees, Leeds, and Wakefield District. Within Healthwatch across West Yorkshire, Craven sits within Healthwatch North Yorkshire, so six Healthwatch organisations work together to represent the West Yorkshire area.

With new NHS decision-making at a West Yorkshire level, Healthwatch has ensured people's voices and experiences are heard. The NHS West Yorkshire Integrated Care Board (NHS WY ICB) recognised the crucial role of Healthwatch and created a role to coordinate West Yorkshire Healthwatch.

It is in this spirit of partnership working that we undertook this project focussing on end of life care.

For more information about each Healthwatch involved in this piece of work, please go to the following websites:

Healthwatch Bradford:
healthwatchbradford.co.uk

Healthwatch Calderdale:
healthwatchcalderdale.co.uk

Healthwatch Kirklees:
healthwatchkirklees.co.uk

Healthwatch Leeds:
healthwatchleeds.co.uk

Healthwatch North Yorkshire
(for the Craven area):
healthwatchnorthyorkshire.co.uk

Healthwatch Wakefield:
healthwatchwakefield.co.uk



About the task

NHS West Yorkshire Integrated Care Board (WY ICB) approached Healthwatch after committing to developing an end of life care vision to ensure residents of West Yorkshire receive the support they need and can die in a place of their choice, with consideration given to what and who matters to them. NHS West Yorkshire Integrated Care Board (WY ICB) wants this vision to be informed by the experiences, positive or otherwise, of people who come into contact with end of life care services. In its own words,



to ensure the ICB is compliant with end of life care statutory

guidance, the board agreed that a West Yorkshire Health Needs Assessment is completed, which will include an evaluation of West Yorkshire end of life care services against the end of life care ambitions framework, a focus on people experiencing inequalities across West Yorkshire and conversations with people experiencing end of life care and their families to discuss their experiences of end of life care services."

It particularly wanted to hear the voices of people who experience inequality and inequity. In its initial project proposal, NHS West Yorkshire Integrated Care Board (WY ICB) listed the following groups as being of particular interest:

- **People living in poverty**
- **People with learning disabilities**
- **People living with serious mental health conditions**
- **Unpaid carers**
- **Veterans**
- **People in contact with the justice system**
- **Ethnic minority groups**
- **Homeless people**
- **LGBTQ+ communities**

NHS West Yorkshire Integrated Care Board (WY ICB) commissioned Healthwatch in West Yorkshire to gather the views and experiences of people living in each of the five places who receive end of life care (or have a loved one who does), in relation to the six ambitions set out in the national **Ambitions for Palliative and End of Life Care framework.**

The purpose of the project was to collect and present the experiences of people receiving end of life care and their loved ones, particularly those facing inequality and inequity, so that the NHS West Yorkshire Integrated Care Board (WY ICB) can make changes that improve services for everyone in the region.

NHS West Yorkshire Integrated Care Board (WY ICB) asked Healthwatch to gather:

- **the views and experiences of at least 25 people in each place; and**
- **a minimum of 18 case studies, with three relating to each ambition.**

The findings were to be presented in a written report and the case studies presented using various media, including audio, video and PowerPoint files.

NHS West Yorkshire Integrated Care Board (WY ICB) also asked that Healthwatch produce an “1 statement” for each ambition based on the findings. These can be found under each of the six ambitions located on page 10 of this report.

The six ambitions

NHS West Yorkshire Integrated Care Board (WY ICB) wanted Healthwatch to structure its engagement around the six ambitions set out in the [Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026 \(National Palliative and End of Life Care Partnership, May 2021\)](#).

Each of the ambitions includes a description framed as an "I statement".

1. Each person is seen as an individual

"I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible."

2. Each person gets fair access to care

"I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life."

3. Maximising comfort and wellbeing

"My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible."

4. Care is coordinated

“I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.”

5. All staff are prepared to care

“Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.”

6. Each community is prepared to help

“I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.”



What do we already know about end of life care in West Yorkshire?

Before undertaking any engagement, it's important to understand what work has already been done about the subject. This is so that we can avoid duplicating insight and build on what we already know.

While Healthwatch wasn't able to change the scope of what it was commissioned to do based on the insight gathered by previous projects, we were keen to get a flavour of it nonetheless. The following pieces of work were shared by the West Yorkshire Palliative and End of Life Care Programme Steering group.

How Do People from the South Asian Community View, Use And Understand Advance Care Plans? How Ready Are They to Use these Advance Care Plans Alongside Other Palliative Care Support?

(October 2021)

Authors: The Bradford Inequalities Research Unit

and

Applying the Community Readiness Model to Identify and Address Inequity in End of life Care in South Asian Communities (2023)

Authors: Rachael Moss, Neil Small, Shahid Islam, Jamilla Hussain, Josie Dickerson

Both these reports built on the observation that people from a South Asian background are less likely to access end of life care or have an Advance Care Plan. They sought to understand why this was and how this could be addressed in order to reduce health inequalities.

Both studies based their findings on feedback from people “who were familiar with palliative and end of life care services and with the views of South Asian communities (current patients, carers and relatives were not included)”. They observed that “the South Asian community only have a vague awareness of end of life care options”.

The Leeds Dying Well in the Community Project (2020)

This work was a whole system approach led by Leeds Beckett University with a citizen view gained by Healthwatch Leeds.

There were 105 members of staff from all providers across Leeds including care homes and domiciliary care providers. This resulted in a report and a systems map.

The Healthwatch Leeds work resulted in a report, taken from 31 one-to-one interviews, videos of many interviews (not made public) and a short compilation video of experiences and quotes videos. The target groups for the engagement work were care home residents and minority ethnic groups.

[Leeds Dying Well in the community project resources found on the leedspalliativecare.org.uk website](#)

[A full systems map for Palliative and End of Life Care in Leeds found on the leedspalliativecare.org.uk website.](#)

[The healthwatch report on peoples experiences of end of life care can be found on the Leeds Palliative care website.](#)

[This youtube video shares case studies of people's experiences of end of life care.](#)

Kirklees Community services engagement and consultation mapping, September (2018 – June 2021)

A mapping exercise for community services engagements, including end of life care services.

The Prince of Wales Hospice Engagement (December 2022 and January 2023)

Author: Healthwatch Wakefield

The aim of this engagement was to “increase the number of people in the early stages of a life limiting illness, and their families and carers, who access services and support from The Prince of Wales Hospice”. 36 people completed a survey, with a further six taking part in extended phone interviews. Limited demographic information about participants was provided (ethnicity wasn’t included, for example). The report concluded that not everyone was aware of the full range of services that the hospice offers.

End of Life Care in Leeds Insight Report (2022)

Author: NHS West Yorkshire Integrated Care Board (Leeds)

This insight report summarises the findings from all recent engagements in Leeds about end of life care, as well as identifying communities which haven’t been engaged with as much as others (notably staff and loved ones of people who die suddenly).

Leeds PEoLC Network Bereaved Carers Survey about End of Life Care in Leeds (various dates)

Author: Healthwatch Leeds

This survey is undertaken annually on behalf of the Leeds Palliative Care Network to capture the views of people whose family member or friend has died in a Leeds setting during one quarter of the year. Demographic data is taken and indicates that the vast majority of responses come from people who are White British. When numbers of responses from other ethnic backgrounds were slightly higher, this was because Healthwatch Leeds had actively sought them out.

The engagement asks bereaved carers (i.e.: family members or friends of someone who has recently died) to complete a survey independently online or on a paper copy that they then return by mail. The sample size has changed year on year, falling to 120 people in 2021-22 from a high of 225 in 2020.

In addition to the projects above, Healthwatch Kirklees was due to do its own work looking at bereaved carers' experiences in Spring to Summer 2023. Please refer to the Healthwatch Kirklees website for more information.

We drew the following conclusions from the pieces of work detailed above:

All projects had a fairly small sample size, the smallest being ten and the largest 225. This perhaps reflects some of the difficulties in engaging with people about a subject as sensitive as end of life care.

Some pieces of work haven't collected demographic data, while others have seen the vast majority of their responses from people from a White British background.

One piece of work focussed on a specific ethnic community, but engaged with professionals rather than community members themselves.

Those pieces of work which did engage with the public tended on the whole to be fairly "hands-off" in their approach, relying on people being willing and able to fill in written surveys independently.



What we did

The brief from NHS West Yorkshire Integrated Care Board (NHS WY ICB) and the work already done in the region gave us two starting points. First, we knew that NHS West Yorkshire Integrated Care Board (WY ICB) wanted us to target particular groups of people; second, we recognised that previous engagements had tended to gather views from limited groups of people.

We considered some of the reasons why this might be. We noted that the engagements' methodologies tended to be similar, relying on potential participants being willing and able to complete written surveys independently and submit them to the collector. We thought that we might need to offer more or different ways for people to take part in our project if we were to avoid excluding people.

Moreover, in a great many conversations about the project with colleagues from NHS, Local Authority and third-sector organisations, we were told that people from minority or underserved communities (communities/groups of people that don't get enough help or services through no fault of their own) were

particularly reluctant to talk about death and dying, considering it taboo in some cases.

Some people suggested underserved communities might not feel it was relevant to them, especially if they traditionally looked after dying loved ones at home. This meant we would need to tailor our approach even further so we could make the subject feel relevant to communities and help individuals feel comfortable enough to open up about a highly sensitive topic.

Bearing all this in mind, we came up with several principles to guide the work when designing our engagement:

- **Don't assume people will come to us; instead, go to where people feel comfortable.**
Comfortable, familiar places might include community centres or participants' own homes. It was important those places offered enough privacy for people to feel able to discuss our very personal subject matter.
- **Don't assume that people will trust us automatically.**
Underserved communities sometimes have little reason to trust that services genuinely want to listen to their views. They might also fear being singled out by services if they voice any criticisms. We needed to reassure people about their anonymity, but also explain clearly what will happen because of their giving feedback. For this reason, we asked NHS West Yorkshire Integrated Care Board (WY ICB) to commit to responding to the findings a few months after completion.

- **Don't assume that people will complete surveys independently.** Not everyone is able or confident enough to read and write English, and some people have specific accessibility needs. We put a strong emphasis on engaging with people face-to-face, with the onus on the engagement worker to do the work of filling in the survey. Interpreting and other accessibility needs would be met where required.

We made the choice to concentrate on one-to-one conversations with participants rather than focus groups because of the sensitivities of the subject matter, especially for communities and populations which might find talking about death and dying particularly challenging. We knew that focus groups would not provide the level of privacy many would require to open up about their experiences.

While preparing for the project, we had a conversation with a lead engagement worker at a national hospice charity. One of the things she told us was that if we wanted to hear from diverse communities in particular, we needed to build relationships with them for at least six months before we started talking about end of life care.

We knew we didn't have that kind of time, but we were also aware that colleagues working in third-sector organisations have forged trusting relationships with the people they worked with and could act as a bridge into communities.

It wasn't ideal, but we hoped it would help give participants some of the sense of safety they might get in a more sustained relationship. NHS West Yorkshire Integrated Care Board (WY ICB) was also keen that the project involve voluntary and community sector organisations, with some of the funding to go towards supporting them to take part.

Setting up the project

The managers of each local Healthwatch agreed that each organisation would take responsibility for the engagement in their own place. For the project to work, we knew it was important to take a very local approach, as engaging with people in Leeds, for example, is different from engaging with people in Craven, as their populations are not the same.

Each local Healthwatch was given the flexibility to engage with people in ways that they knew would work most effectively based on their experience, so long as they stuck to the principles for the engagement outlined above. These principles were set out in project meetings and via email.

Each Healthwatch got a share of the budget which was reflective of their workload for the project; for instance, Healthwatch Bradford and Healthwatch North Yorkshire shared the portion of budget allocated to Bradford District and Craven, with Healthwatch Bradford getting the majority to reflect its larger population compared with Craven. Part of the budget allocated to each place was specially assigned to recognising third-sector /voluntary partners' contributions to the project and to help to encourage individuals to take part.

To support the project set-up, the Associate Director for Healthwatch in West Yorkshire appointed a project coordinator. The coordinator's role would be to:

- **Design the practical aspects of the project so that we could meet the brief given by NHS West Yorkshire Integrated Care Board (WY ICB) while also ensuring that the project workers are supported to do what they need to.**
- **Set up and lead project meetings and communications between workers.**
- **Attend meetings with NHS West Yorkshire Integrated Care Board (WY ICB) where needed.**
- **Complete the majority of the case studies.**
- **Produce the final report and other materials.**
- **Carry out the engagement in their local Healthwatch.**

An experienced project worker in Leeds who had been involved in previous local engagements about bereavement was chosen for this role.

While setting up the project, we recognised that there are special sensitivities and challenges linked to engaging about end of life care, and we needed to support the project workers to handle them. By asking people about this experience, we are often asking them to talk about one of the most difficult and painful things they will have ever been through. We wanted to make sure we were all informed about how to do this in a way that looked after the participant: this had to be our first priority.

However, it was also essential the project workers felt able to manage the ways in which they might be emotionally impacted by listening to people describe their experiences of death and dying. We were conscious there was a risk listening to such stories could trigger difficult feelings linked to losses the project workers had suffered in their own lives, especially as the project principles required intensive, face-to-face work.

We reached out to a contact in Leeds who had worked with Healthwatch before on projects about death and dying. Clare Russell is the Director of Transformation and Culture at St Gemma's Hospice. She came to talk to all the project workers about how to engage well with people about death and dying. She also agreed to be a point of call for anyone who needed some support to process the conversations they had had, in addition to the usual support mechanisms at each Healthwatch. (Healthwatch staff are encouraged to approach their line manager for support and can also access free counselling if required.)

This face-to-face meeting with Clare was invaluable, giving the project workers the chance to bring any questions they had. We discussed, for example, the different cultural expectations that communities have around dying and end of life care services, as well as what language to use when talking to people about death.

The project workers questioned how direct we should be in our use of language: was it better for participants if we used terms like "passing away" over "dying", for instance? Our discussions with Clare helped us to feel confident that using clear, language was generally preferable, especially when talking with people from diverse cultural backgrounds or who spoke English as a second language. (One exception might be if the participant themselves used different terms, in which case we would mirror these in our own choice of language.)

Similarly, we decided to use the term "end of life care" over "palliative care", because it was agreed "palliative" wasn't a word everyone would recognise. The language used in this report reflects these choices.

It was felt that some flyers or posters would be a helpful resource for the workers when promoting the project, so these were created by the communications officer at Healthwatch Kirklees. They also provided the basis for the social media posts created and coordinated by the communications officer at Healthwatch Leeds.

Because of the challenges of finding participants for the project (linked to both the sensitivities of the subject matter and the narrowness of the criteria), we decided to make the engagement period as lengthy as possible. We set aside eight weeks in which the project workers would go out to have conversations with participants. This period was due to start in the beginning of March but was pushed back due to administrative delays outside of our control. The engagement started on 20 March 2023 and ended on 12 May 2023.

We had conversations and completed surveys (For a copy of the survey questions, please contact info@westyorkshirehealthwatch.co.uk) with 143 people across West Yorkshire who were receiving end of life care and support or with the families/carers of people who were receiving end of life care or had recently died.

We also had more in-depth conversations with 25 families and people were receiving of end of life care about their experiences. These are presented as case studies in a separate report including audio clips of the key messages from these conversations. Where appropriate, participants were offered information about complaints processes.



Executive summary

This is not a report that can be summed up neatly in a few hundred words. We have heard about remarkably varied experiences across West Yorkshire, with services of all types, from GP surgeries to hospitals, hospices, care homes and more, all having served their communities well in some cases, and less effectively in others.

As is so often the case in patient engagement, staff tend to be the most highly valued aspect of people's experiences. It is clear that there are many highly experienced and knowledgeable people working in end of life care around our region, each of them making a great difference to individuals and families. The challenge, as always, is to ensure this level of staff expertise is the norm, especially in services which are under great pressure, which don't specialise solely in end of life care or which are more likely to rely on temporary workers.

One of the things very good staff do is see the individual human being as well as the patient. This is a universally appreciated skill, but it will perhaps become only more and more vital as the makeup of our diverse region evolves in years to come. It certainly isn't for staff alone, however, to understand people's different and individual needs: systems must be built for diversity if they are to serve communities well.

As a region, we need to do better at asking people about their wishes for the end of their life, and doing so well before death has become an imminent reality for them. We also need to improve how we guide patients through what can be an extremely complex landscape of end of life care services, so that none are left not knowing what will happen next at what is so often an overwhelming time.

We could also think more about the impact of caring for a dying loved one at home on whole families, and have better, more honest and more frequent conversations with them about what dying at home can entail. Those conversations with families shouldn't necessarily stop after a person's death. Indeed, for this report we heard from many people who had lost loved ones in different settings who were coping with loss without bereavement support.

At times, the pain that this can leave behind comes through in their testimony.

A great amount of work has been done, and continues to be done, in West Yorkshire to understand people's experiences of end of life care. However, that work only has value if it is transformed into action and change – and the time for action is now.



The overall picture: data from across West Yorkshire



In 40% of cases, people had spoken to services about their wishes for the end of their life.



39% were consistently told what to expect from their end of life care.



64% said their services fit in with and respected all aspects of their life.



59% said staff always checked that care met their or their relative's needs.



62% felt care met their or their relative's specific needs.



68% knew they could ask for help at any time of day or night.



71% felt sure that staff had all the skills they needed.

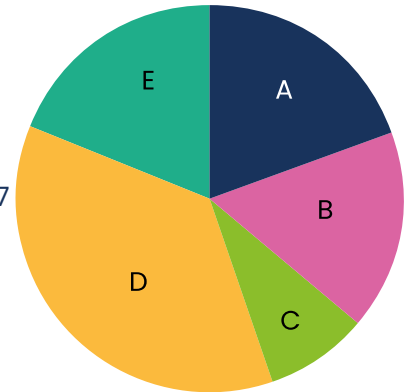


80% felt staff were kind and caring.

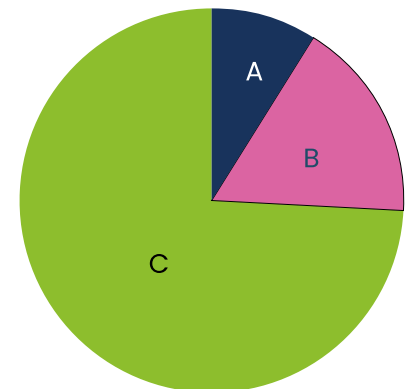
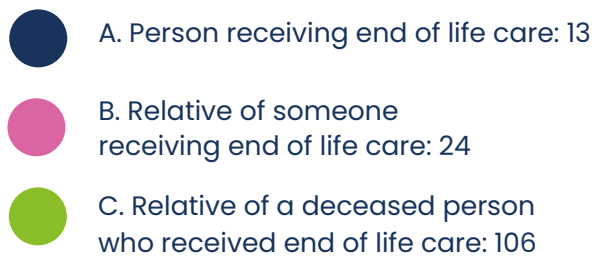
143

Total number of responses

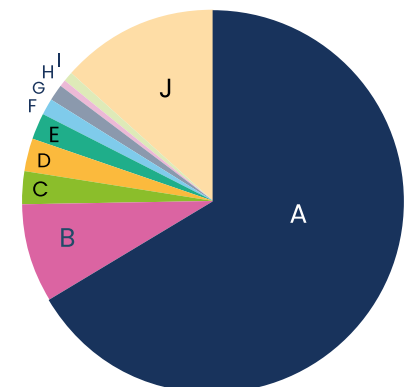
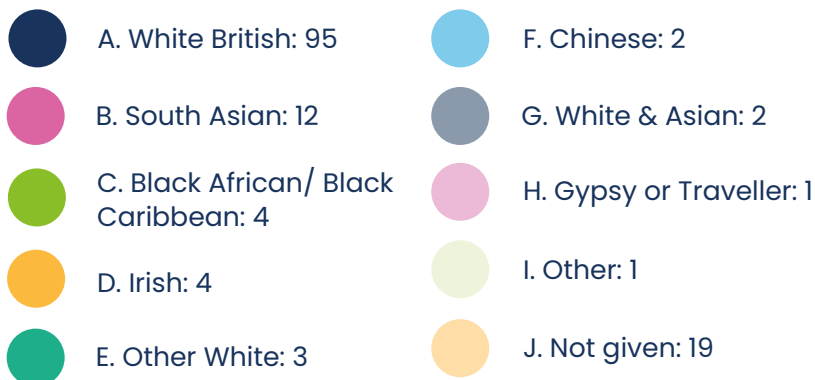
Number of responses by place



Our respondents' experience of end of life care



Our respondents' ethnicities



The region as a whole: a few initial conclusions

The area in which the region is performing most strongly is **ambition 5** ("all staff are prepared to care"). A high proportion of respondents said that staff were kind and caring; that said, there was greater variation from place to place in terms of the proportion of people who felt staff always had all the skills they needed.

The area in which the region is performing least strongly is **ambition 1** ("each person is seen as an individual"). Fewer than half of our respondents said they had spoken to services about their wishes for the end of their life and that they were consistently told what to expect from their care.

More than half of respondents said **ambitions 2** ("each person gets fair access to care"), **3** ("maximising comfort and wellbeing") and **4** ("care is coordinated") were being met.

Responses regarding **ambition 6** ("each community is prepared to help") were consistent across the region. The majority of people told us they were not receiving bereavement counselling or support. People largely looked to family or, secondarily, to friends for emotional support with dying and bereavement, but there was widespread acknowledgement that many people are uncomfortable with talking about these issues.

Health inequalities review

In the following section, we draw together learning about some of the populations we were asked to include as part of this project. However, we ask readers to bear in mind that these categories should not be viewed in isolation. They overlap and intersect both with each other and with other factors not identified for this project; indeed, it is often impossible to say that one factor alone has had a defining influence on a person's experience of end of life care.

For example, being a veteran might have an effect on an individual's mental health, which in turn might lead to homelessness, which in turn might make them more likely to come into contact with the justice system. These various factors cannot be set apart from each other.

As we emphasised in the introduction to this report, every experience is unique. Furthermore, when we approached people to be part of this project, we were not asking them to act as representatives of a particular community or population. Not only would this have given us a one-dimensional view of communities, but it would have been an unfair burden to place on participants' shoulders. They were asked simply to represent themselves and their own experience.



People living in poverty

“People living in poverty” covers a highly diverse and no doubt growing group of people. Poverty can be defined in all kinds of ways, and it means different things to different people. Poor people’s circumstances can vary enormously. Some people who are poor are in work, some are not; some have dependents, some do not; some were born in this country, while others were not. Poverty is an exceptionally complex and multi-faceted reality which never stays static, driven as it is by changes in society, and therefore poor people’s experience of end of life care is without doubt similarly varied.

Based on the conversations we have had with people, we recommend the following should be taken into account when considering how end of life care intersects with the lives of people living in poverty:

- **The expense of travel is harder to cope with.** This can be particularly problematic for people living in border areas, who may be required to travel further distances and to a wider variety of locations.
- **Poorer people’s housing conditions aren’t always good** and sometimes allow less space and privacy for the dying person. People sometimes aren’t in a position to manage problems with their home such as mould (if they are renting their property, for example).

- **In some cases, people living in poverty will work unsociable shifts**, physically and mentally exhausting jobs, unpredictable zero-hours roles and sometimes more than one job at a time. Not only does this have an impact on their ability to make appointments with services, it also has a wider impact on their health and wellbeing.
- **Some people living in poverty have to deal with the benefits system** – which can itself be difficult and time-consuming – at the same time as managing end of life care.
- **People living in poverty have to worry about money.** This has all kinds of impacts, from stress to debt and reliance on food banks.
- **Parents living in poverty may find it more difficult to get childcare**, making sticking to health-related appointments more difficult.
- **It is well documented that poor people are more likely than other groups to develop health conditions at an earlier age.** Several members of the family might be dealing with serious health conditions at the same time as one person is receiving end of life care.
- **A minority of people living in poverty might also have to handle other issues such as homelessness.**



People with serious mental health conditions

As with poverty, above, the experiences of people living with serious mental health conditions are bound to vary enormously, depending on all kinds of factors. The term “serious mental health conditions” covers a great number of different diagnoses. In addition, people’s experience will be affected by factors such as how well managed their condition is, how long they have had the condition for, and the level of support people get from services, family and wider social networks. Again, we are talking about a highly varied group of people.

Based on the conversations we have had with people, we recommend the following should be taken into account when considering how end of life care intersects with the lives of people with serious mental health conditions:

- **Some people with serious mental health conditions might have had experiences with health services in the past which have affected their level of trust in them.** One example of this is people who have been involuntarily sectioned in the past, but we know from other work that they aren’t the only group. They might feel that services don’t listen to them or take them seriously, so they might be less likely to place their trust in end of life care services.

- **Dementia can impact on a person's mental health at the end of their life.** Some of the carers we spoke to described how their loved ones had struggled with depression linked to their dementia or became paranoid and violent towards them and others.
- **If a person has a mental health condition which isn't managed, this can make decision-making about end of life care highly complicated and difficult.**
- **Some people living with mental health conditions can be isolated from family and friends,** although this is by no means always the case. We have heard what an immense role family members and other unpaid carers can play in dying people's care, so isolation can have a real impact on an individual's experience.
- **Mental health conditions can intersect with other factors, such as drug or alcohol addiction, homelessness and poverty.**



Unpaid carers

The vast majority of the bereaved people we spoke to had been an unpaid carer, in some cases for many years. Their circumstances varied enormously: for example, some people were in employment, others were not; some had multiple caring responsibilities; and some had health issues of their own. There was immense variation in their experiences across the region, but in all cases, these unpaid carers had to balance the huge emotional turmoil of losing a loved one with all the practicalities of caring for a person at the end of their life. These practical considerations are detailed in people's stories throughout this report, but they include coordinating services and providing daily care.

The great majority of the unpaid carers who spoke with us were women. While they tended to be aged 50 or above, this wasn't always the case by any means.

Some of the unpaid carers who told us their stories said they didn't always feel knowledgeable enough about how to look after a dying person, but also that they weren't fully informed about what the dying process can entail. When an individual chooses to die at home, this will often mean that unpaid carers are providing particularly extensive care and support.

The provision of bereavement support for people who have cared for a dying loved one was very uneven; only when a person had received hospice care or when a parent had lost a child did we regularly hear that bereavement support was offered. Moreover, carers do not necessarily know where to turn for support for themselves while their loved one is alive (and in some cases might be too overwhelmed and time-poor to reach out anyway).

People from ethnic minority backgrounds

When talking about people from ethnic minority backgrounds, it's crucial we don't generalise about people's experience. This population is extremely broad and includes people of all different ages, nationalities, religions, social classes, professional backgrounds and much more besides. As always, it is important to be as specific as possible when talking about individuals' experience.

One key lesson we drew from our conversations was how important it is not to make assumptions about a person based on their ethnic background and, again, the importance of treating an individual as an individual. One family's cultural needs will often vary from the needs of a family from the same background. One example of this related to decisions about resuscitation. Some people needed to consult a specific local religious leader about this, while others made the decision independently, based on their religious beliefs or not.

Several of the people from ethnic minority backgrounds expressed a preference for dying at home, but the reasons for this varied. In some cases, there was a deep-rooted cultural expectation that people would be cared for at home by family members, as was the case for the members of the Chinese community we spoke with (although it should be noted that their loved ones actually died in hospital or in a hospice). In other cases, past experiences of racism played a large part, as was the case with the people we spoke to who came from a Black Caribbean background.

It is important to note, however, that a great many of the people we spoke to who were from ethnic minority backgrounds were of retirement age and, in many instances, were born outside the UK. People from ethnic minority backgrounds who are younger and / or born in the UK may well have different perspectives so, as time goes on, we will likely see attitudes to death and dying shift among ethnic minority populations.

First language can be a factor that differentiates the experience of some people from an ethnic minority background from others'. Some people who don't speak English as their first language rely on interpreters when accessing end of life care, or they have to count on family members to interpret for them. When family members become a means of communicating in this way, this can have implications for both the dying person and the family too. The family have greater sway over what the patient hears, but also have to be much more intimately involved in crucial discussions.

People didn't express any expectation that services take responsibility for organising faith-based practices in end of life care settings – instead, they ask simply that services don't get in the way of what they need to do from a spiritual point of view. Positively, people very often told us that services weren't obstructive in any way. They also said that in the rare moments when they did need services to actively facilitate their religious needs, services were helpful. This was particularly the case regarding burials, which need to happen quickly according to certain faiths.

For information on the experiences of homeless people, people in contact with the justice system and veterans, please refer to the sections on pages 42–45.

People we weren't able to speak to

We were not able to speak to people with learning disabilities or people from the LGBTQ+ communities in large enough numbers to be able to sketch a picture of their experiences. We wanted to understand why this was, so we spoke to colleagues who specialise in working with these groups.

One factor suggested by a specialist learning disabilities worker related to wider inequalities. She pointed out that the leading cause of death among people with learning disabilities was aspiration (difficulties in breathing), followed by chest infections; COVID-19; heart disease and failure; and gastrointestinal conditions and sepsis. In other words, many people with learning disabilities will die sudden deaths, caused by factors that are less prevalent in the wider population. The worker commented that “the narrow criteria [of this project] is actually helpful in highlighting the health inequalities people with a learning disability face”.

This suggestion was further borne out by some of the other learning-disability-oriented third-sector organisations we contacted, who said that they simply didn't know of anyone who had experience of end of life care relating to the past year or two. In other cases, it ceased to be appropriate to stay in touch with families of people receiving end of life care because their loved one died as we were in the process of arranging an interview. Healthwatch Bradford in particular suggested it would have been helpful to be able to build a relationship with people over longer periods of time.

Our contacts who specialise in working with people from the LGBTQ+ community also supported the project by reaching out to their contacts, but returns were low. One person, who reached out to his group members several times, commented that “I think it’s possibly too sensitive a subject for most”.

Another worker suggested that the project could have benefitted from a longer timescale, so that staff could build up relationships with people gradually. This might have helped people feel more at ease and less daunted by the task of opening up about what is often an exceptionally painful and personal experience.



Health inequalities: a few examples

Below you will find a few examples of some of the work we did to reach out to some of the populations detailed in the project plan. For more examples, please refer to the place-based sections of the report from pages 54-128.

Feel Good Factor (Leeds)

We visited Feel Good Factor's Saturday social group to talk to people about their experiences of end of life care.

A large proportion of group members either grew up in the Caribbean or are from a Black Caribbean background and are local to Chapeltown, which has historically been a home to Leeds' Black Caribbean population. Most were women and aged 50+, and several had long-term physical or mental health conditions.

Before meeting the group, we were told that death and dying could be a taboo subject in Black Caribbean communities, and we might find that few people would be willing to speak with us. However, when

we got to the group, we found that plenty of people were happy to share their experiences, provided we could guarantee them privacy and anonymity. Some told us that this was the first time they had ever spoken to anyone about losing a friend or relative, with one saying at the end that she felt "so much lighter" having been able to express what that experience meant to her.

One of the key themes to come out of our conversations at Feel Good Factor was the way past experiences with health services shaped people's attitudes to end of life care. People frequently told us about loved ones' deaths dating back years or even decades, and it was clear how the (often negative) impact of this shaped their trust in services today.

People told us about how they had experienced racism, not always directly from health services but in their wider lives, and this led them to fear they could expect the same from services. We repeatedly heard that group members felt that health professionals often dismissed what they had to say because of racial prejudice, which could again make them reluctant to approach services. One member said that health professionals didn't often understand that Black people might talk in a different way from White British populations, and they misinterpret this aspect of Black Caribbean culture in unhelpful ways. One member told us of her fears for a young member of her family, who had been diagnosed with a life-threatening condition but was refusing to engage with services or take medication because they didn't trust services' intentions and believed the medication would be too expensive.

Nearly everyone told us that there was a strong preference in Black Caribbean communities for dying at home, but there was also acknowledgement of some of the difficulties that can come with this. People told us the quality of care could sometimes vary depending on how well prepared the family was to look after their dying loved one. There was also acknowledgement of how hard it could be to watch a family member or friend deteriorate. As we heard in conversations with people across Leeds from all different backgrounds, it wasn't rare for people who had supported a family member or friend through death to be left with feelings of guilt, because they weren't sure they had done enough for them.

Very few people had accessed bereavement support or counselling. One woman told us she felt it was her role to be strong and supportive to others, which made it harder for her to reach out when she needed help. Another said that she felt services expected their users to fit around them, whereas it would be better if services came to people.

Key conclusions:

While death and dying are reputed to be very difficult subjects to broach with Black Caribbean communities, it absolutely is possible to have in-depth conversations so long as people are given privacy and anonymity.

- **By the time they come into contact with end of life care, people's levels of trust in services will have already been shaped by decades of experience**, some of it negative. People are likely to bring an expectation that they will be treated differently because they are Black, and it is up to services to challenge that expectation. One way to do this is to reassure people that they are being listened to and their views taken on board.
- **Communities where there is a strong preference for dying at home are affected disproportionately by the pressures which come with that.**
- **People from Black Caribbean communities might benefit from being actively encouraged to access bereavement support** that is within close, easy access to where they live. It's important people are informed about how bereavement support can help them, as well as being reassured that it is private, non-judgemental and a place where people can talk about their experience of prejudice and racism if that's something they would like to do.



End of life care for people experiencing homelessness (Leeds)

We went out with one of the nurses from a team at St Gemma's Hospice which works with people who have experienced homelessness. This was a precious opportunity for us to meet four patients cared for by this very specialised community service.

The service has two nurses and, when we visited, had about 19 patients, all of whom were homeless, sofa-surfing or had recently experienced homelessness and were now in temporary or settled accommodation all around Leeds. A great many of the service's patients either have an addiction to drugs or alcohol, or they are in recovery. On the whole, the service's patients are younger than the average patient receiving palliative care. All the people we spoke to were male and had a history of substance dependency, and at least one was diagnosed with a serious mental health condition.

The service has been designed to meet the needs of the homeless population. All the men we spoke with talked about how they had a

long history of finding it difficult to engage with mainstream health services. For example, "Alan" had very recently discharged himself from hospital almost immediately after surgery. He explained that, over many years, he had found that other services didn't listen to him and felt very disjointed, to the extent that he now felt it was pointless to engage with them.

Another, "Chris", explained how past negative experiences with mainstream services made him feel paranoid when he came into contact with them, and that paranoia would turn to embarrassment, which would then make him want to leave no matter the cost. He felt that most services didn't live up to their promises, saying that he felt like



if they can't be arsed, I can't be arsed".

All the men noted how the homelessness service from St Gemma's worked in a different way, which made it possible for them to engage and get the best out of it. Chris told us that the nurse "doesn't come in saying 'are you drinking, are you drinking?'" This was helpful because he didn't feel judged, which in turn meant he could open up more. He described the service as "more give than take", because the staff go to extra lengths to stay in touch with him. For instance, the nurse will text to remind him she is coming. He said they "don't just give me medicine, they give me support", and this made him want to stop using drugs and alcohol even more.

"Matthew", who said he didn't like being passed from person to person by other services, said the fact the nurses came to him was really helpful. Alan notes that the nurse was even willing to come to Bradford to see him when he happened to be there, and this is one of the things that show him they "really care, they're not just doing a job".

He said that, with them, he can speak the way he normally would without worrying (which for him means using bad language) because he knows the staff accept that about him.

Matthew swears a lot, but this is accepted as part of his personality (although his sister notes that staff from other services haven't always accepted it in the same way). Relatives play a big role in the lives of most of the men we spoke with, and home visiting helps to connect the service with the person's wider family life. On one occasion, a nurse helped a patient buy a mother's day gift, because the nurse realised there was a risk he would discharge himself from hospital at a crucial moment if he wasn't able to give his mum a present.

The nursing team explained to us that often they will have conversations with a patient for as long as several months before they even touch on their end of life care.

They find that this is vital if the patient is to engage, because it helps to rebuild some of the trust in services that many have lost over the years. The men we spoke to said they appreciated the “personal touch” inherent to St Gemma’s service. Sometimes the nurses have to persist, reaching out to people several times before they can start to build a relationship with them. The nurses will give out their phone number to the patients so that they can reach out to them if needed, and they will eventually ask them about what they would like to happen at the end of their life. Not everyone feels able to have that conversation, but some do; for instance, Matthew has said he wants to stay at home for as long as physically possible.

This kind of approach clearly requires time, something that other services aren’t always in a position to give people. Alan notes that the nurse doesn’t “rush in and out”. It was thanks to a conversation with the nurses that he made the decision to try treatment which might extend his life; before he spoke with them about it, he had resigned himself to dying of his condition, in part because

he felt it was impossible to get over the “defence mechanisms” that overwhelm him when he is interacting with hospital services and make him want to leave as quickly as possible.

Another patient, “Robert”, has been able to start engaging independently with other services because of the support he received from a St Gemma’s nurse. Robert speaks very little English. Due to this and other factors, he was reluctant to get important hospital treatment on his own, so the nurse accompanied him to his first appointment. Since then, Robert has been able to go to his next appointment independently. The nurse also gets his prescription for pain medication and helps him to use it, knowing that it would likely be stolen from him otherwise.

Chris has also started independently attending social groups run by St Gemma’s, where he can also get lunch. He explained that boredom is a “trigger” for him, so it’s important for him to keep busy.

Chris has surprised himself by taking part in activities like seated Zumba or mindfulness: as he put it, as a former bouncer with multiple convictions, he didn't think he'd be interested in those kinds of things. Like Robert, he has expanded his horizons by coming into contact with this end of life service.

Another perspective on end of life care for people experiencing homelessness (Calderdale)

The following experience was shared with Healthwatch Calderdale by a woman whose husband was a former veteran who had experienced homelessness, alcoholism and drug use since he left the military in 2013. He had undiagnosed PTSD before his death.



My husband had many health issues which contributed to his death in 2022. He had ongoing drug use, used alcohol, was depressed and I believe he had post traumatic stress disorder but that was never taken seriously as doctors thought it was his drug and alcohol use."

She continues:

"He was seen as trouble. No-one we ever saw had experience of dealing with someone with military-related health issues so there was a lack of empathy or understanding of what he may have been through.

"Everything felt like a battle, he needed someone to pull the strings together for his treatment but different services can't do x, y or z so he's sent somewhere else. If he went where he was told to, he'd have to start again. I felt like his carer but there was only so much I could do and it was wearing me down too."

"The issues that led to his death were quick: he had been on methadone which was given to him by drug teams in Manchester as he felt he got better care over there. He then had too much to drink after being sober for a few months, so it affected him and the deterioration was quick, I knew when he was in Calderdale that he was dying, he had taken too much for his body to cope with. The nurses were good at the end, the Intensive Care Unit ICU team explained his situation and I felt they were brilliant, but the services he needed in the community weren't there, so it led to this."

Lychee Red (Leeds)

We visited Lychee Red to talk with three of its group members who had recently lost a husband.

Lychee Red is a group hosted by Health for All in Beeston aimed at the Chinese community in Leeds. Most members are of retirement age, and the group provides a very welcome social space where people can join in cultural activities, eat together and converse in their own language. Very few of the group members speak English.

Because of the language barrier, we had to speak with group members via an interpreter. As a result, we had to keep our questions short and fairly simple, and the conversation couldn't flow as easily as it might if we shared a language. Our conversations were one-to-one in a private room and participants were anonymous.

As we heard in discussions with the group leader and others, talking about death and dying is considered very "unlucky" or taboo in Chinese communities. Some of this is linked to a real reluctance to talk about personal matters such as ill health outside the family. Family privacy is highly prized, and there can be a certain amount of shame linked with becoming a source of gossip. People might not tell people outside the family when they get a diagnosis.

We were told that there is a strong expectation among older Chinese people that families will support them to die at home, as well as a feeling that they should avoid being a burden on wider society. That said, the husbands of the women we spoke to didn't die at home; two died in hospital, while the third died in a hospice. Nonetheless, it was clear that the members we spoke to relied heavily on their adult children to liaise with services because of the language barrier, although remote interpreting was provided in the different settings.

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The members of Lychee Red were all very contented with the end of life services their husbands received. Perhaps in part because of the disjointed nature of the interpreted conversations and the difficulty of the subject matter, it felt like the women we spoke to didn't want to express anything other than satisfaction with services. After the interviews, we asked people familiar with Chinese culture why this might be. They suggested that older, Chinese-born people tend to be more likely to compromise than complain (or, if that isn't possible, disengage from services entirely). The group leader also commented that some might have experienced racism or bullying during their working lives.

Comparing findings across places

In this section, we present the proportion of people who said that services had met the ambitions in each place.

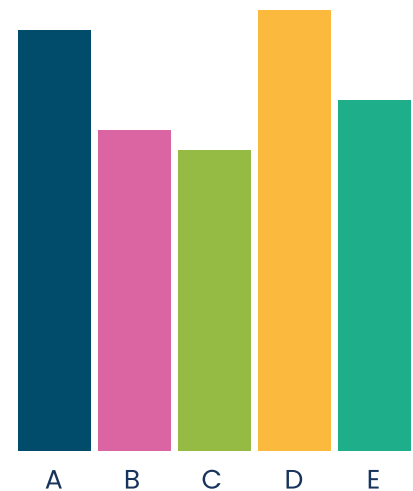
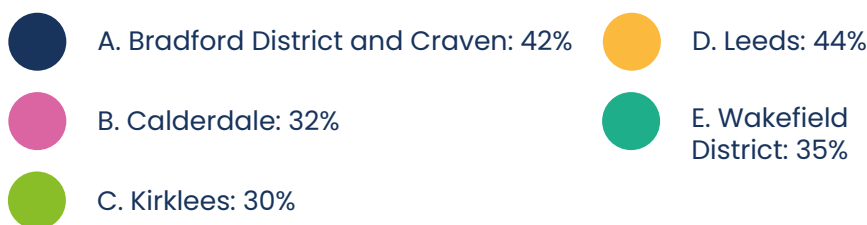
Please note, however, that these comparisons should be handled with great care. The numbers of respondents in each place varies, with Kirklees in particular having a low sample size. The samples in each place are large enough to give us an impression of what it can be like to be a person receiving end of life care in an area, but this project is not designed to produce statistically reliable results.

Furthermore, different places have different services, so we are not comparing like with like. We do not suggest that these comparisons offer a definitive answer as to how well services in each place are performing.

A few initial conclusions

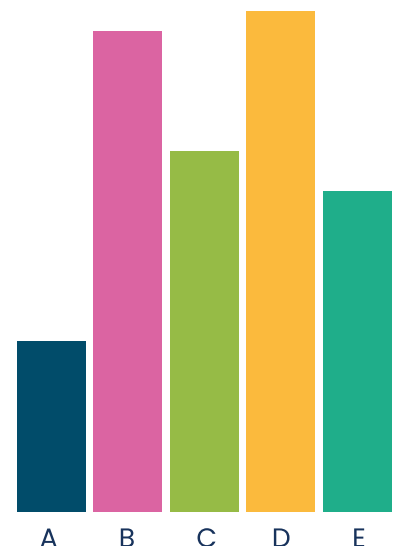
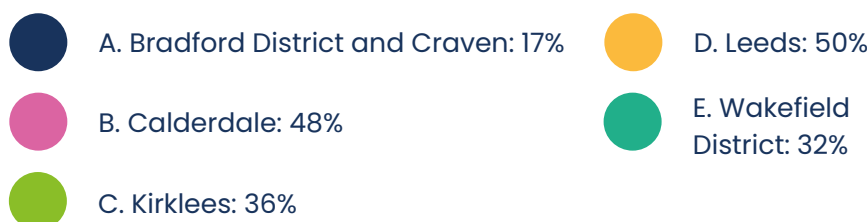
Ambition 1: What proportion of people had spoken to services about their wishes for the end of their life?

In all places across the region, fewer than half of our respondents had spoken to services about their wishes for their care at the end of their life.



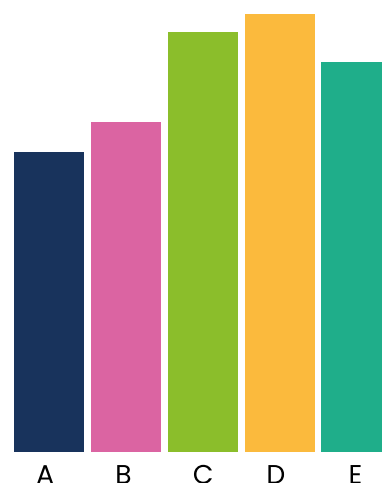
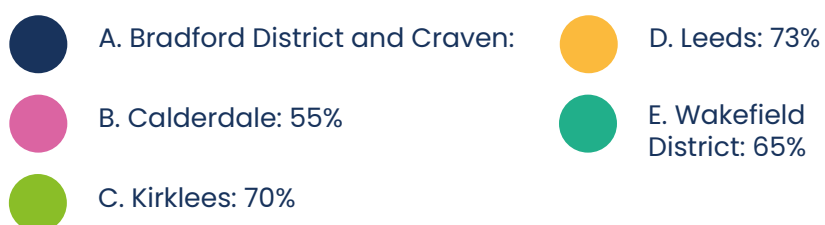
What proportion of people were consistently told what to expect from their end of life care?

In all places across the region, no more than half our respondents were consistently told what to expect from their end of life care, with numbers particularly low in Bradford District and Craven.



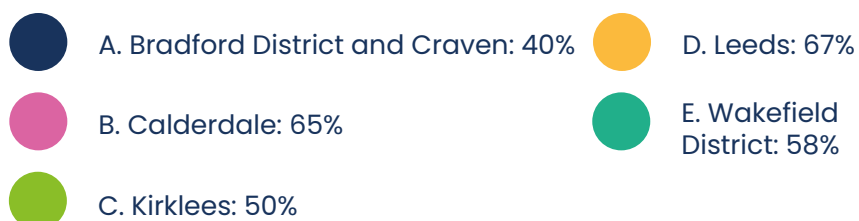
Ambition 2: What proportion of people said the services fit in with and respected all aspects of their life?

Most people felt that services fit in well with and respected all aspects of their life, although proportions were notably lower in Bradford District and Craven (50%) and Calderdale (55%).



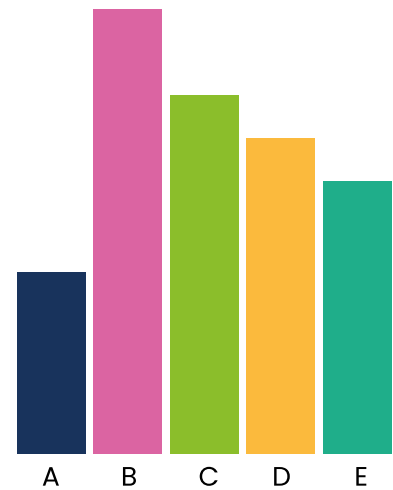
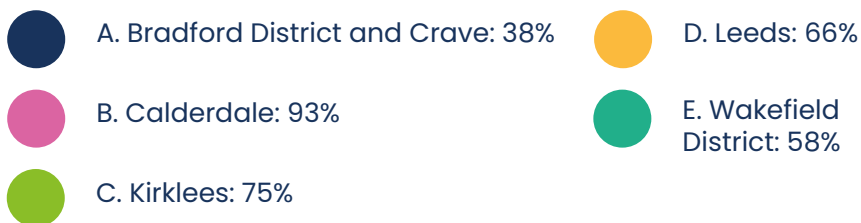
Ambition 3: What proportion of people said staff always checked that care met their or their relative's needs?

There was inconsistency across the region in terms of whether staff always checked care met people's needs. In Leeds, 67% of respondents said they did, while in Bradford District and Craven, only 40% said this was always the case.



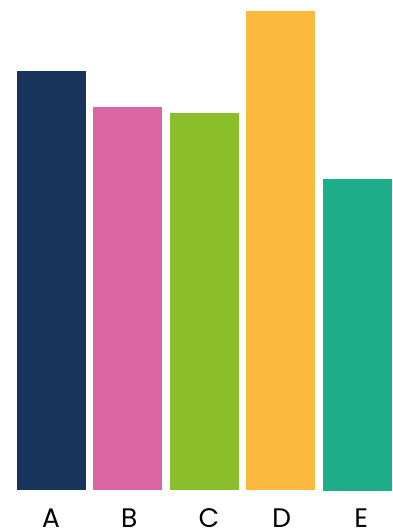
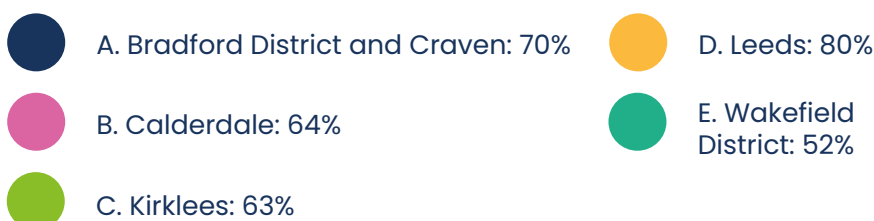
Ambition 4: What proportion of people felt the care met their or their relative's specific needs?

While people in Calderdale, Kirklees, Leeds and Wakefield were very or somewhat likely to say that care met their needs, only 38% of people in Bradford District and Craven felt it did.



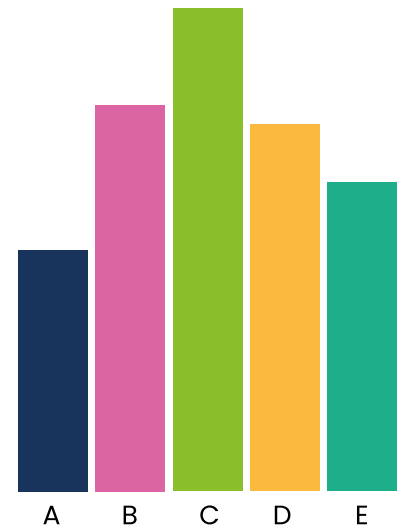
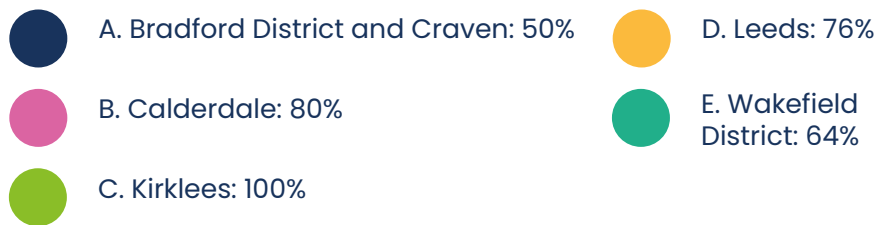
What proportion of people knew they could ask for help at any time of day or night?

Most people in West Yorkshire knew they could ask for help day or night. The proportion was highest in Leeds (80%) and lowest in Wakefield (52%).



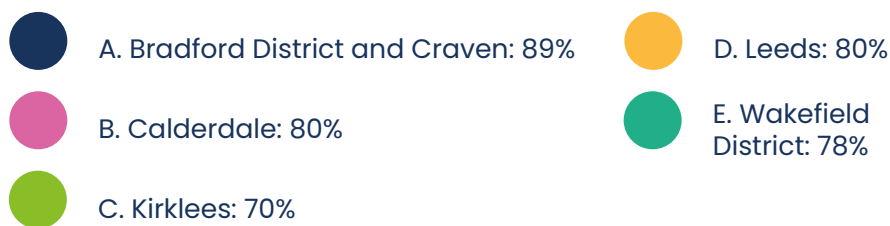
Ambition 5: What proportion of people felt sure that staff had all the skills they needed?

There was some inconsistency in terms of the proportion of people who felt staff had the skills they needed. The proportion was lowest in Bradford District and Craven, where 50% felt staff were sufficiently skilled.



What proportion of people felt all staff were kind and caring?

Most people across the region felt all staff were kind and caring.



Ambition 6: Each community is prepared to help

[For ambition 6 stats please refer to p.28](#)



Bradford District & Craven

Findings by local area



In 42% of cases, people had spoken to services about their wishes for the end of their life.



17% were consistently told what to expect from their end of life care.



50% said their services fit in with and respected all aspects of their life.



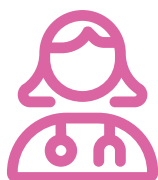
40% said staff always checked that care met their or their relative's needs.



38% felt care met their or their relative's specific needs.



70% knew they could ask for help at any time of day or night.



50% felt sure that staff had all the skills they needed.



89% felt staff were kind and caring.

Bradford District & Craven

Findings by local area

28




Total number of responses

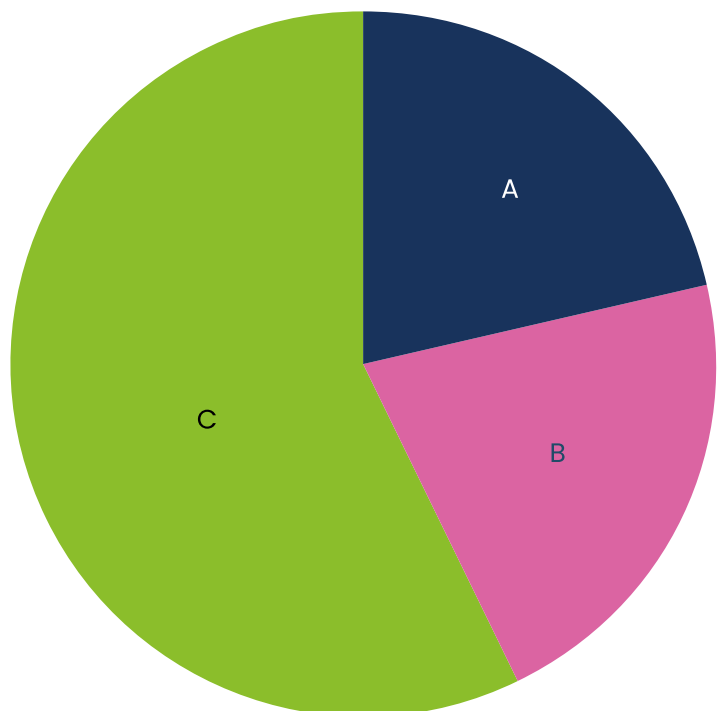
Note: Please note that the number of responses for this place reflects the number of completed surveys received; Healthwatch Bradford and Healthwatch North Yorkshire report that the number of conversations they had with people is higher than 28.

82%

of respondents were White British.

Our respondents' experience of end of life care

-  A. Person receiving end of life care: 6
-  B. Relative of someone receiving end of life care: 6
-  C. Relative of a deceased person who received end of life care: 16





Bradford District & Craven

The methodology

Healthwatch North Yorkshire sought responses from people in Craven, while Healthwatch Bradford sought responses from people in Bradford.

The Methodology in Craven

“We attended meetings where organisations who support under-represented communities were present and talked about the project to see if any organisations were interested or could help us find people who fit the criteria for the project. Through this we linked up with Carers Resource who support carers across North Yorkshire, including in Craven.

“In terms of taking a trauma-informed approach when having conversations, the surveys we inputted were collected via Carers Resource, so they were the ones who had the conversations. We discussed with Carers Resource, and they thought the best way to approach the task was for them to complete the surveys with

the people they support as that would be more comfortable for people rather than us having those conversations (we paid Carers Resource a set fee to do this).”

Healthwatch North Yorkshire would particularly like to thank Carers Resource for their support with this project.


For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.

The feedback in Bradford

"Feedback from our Pakistani community leader who helped us have conversations in the Asian community.

(He did also explain that he was not at all surprised to hear that we had received a strong no to engagement from the Bangladeshi community leaders.)

He told us:-

 **This is a very emotive and somewhat taboo subject in the Asian culture (Pakistani / Bangladeshi). It is rarely discussed and it's seen as a family matter and the responsibility lies with close family members and asking outsiders is seen as shameful and it could result in being seen as irresponsible and losing your standing in the community. So Asian families rarely ask for help or support. One key issue is finding access to services is a main barrier."**

He highlighted these standout comments from the respondents he surveyed around end of life care and palliative care -


Client A

"I was afraid to ask for help and didn't know what to do. It seemed really hard."

Client B

"My Friend was ignored, he kept phoning his GP for a face to face consultation but was told ring again. 3 months later he was dead. His last few weeks were painful and finally when he was seen, it was too late. The whole system of end of life care is a shambles. It doesn't have enough information for people to access services for support etc."

Client C

 **The information is given at the wrong time, also family is reluctant to involve others, as it will be seen as they don't care for their loved one who is receiving end of life care."**

"A review into more information for South Asian communities in end of life care is needed especially. For loved ones and friends who are diagnosed with conditions which are terminal, talks and workshops in how to encourage families to access these services are helpful, as are community groups to encourage Mosques, community leaders and patient groups to openly talk about end of life services and work around barriers such as stigma and shame attached to using services for support."

Our Pakistani community leader (From Highfield Food Coop as well as a few other organisations listed below) feedback separately that he found the whole experience of talking to his community about this subject incredibly traumatic.

"I have made several calls and visits with him to help him process his experience and reassured him that his work was valued and appreciated.

We reached out to the Bangladeshi community leader to ask if they could help us engage with their community, as mentioned above we had a very hard no, that they WILL NOT engage with us on this subject."

For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.



Bradford District & Craven

Ambition 1: Each person is seen as an individual

Some of the comments from people in Bradford alluded to the extensive role family find themselves playing when services haven't provided enough personalised information and support.

"I have spoken to the private consultant who was very honest and clear but didn't want to overload me with information, so I had to go away and do my own research. Then we have had a visit from a specialist nurse and she told me about what I should expect [regarding] my condition but no one has given us any kind of a plan regarding my actual care. My family are just left to make their own plans and arrangements"

"We have struggled with a change to our GP but generally we are coping at the moment with me doing most of the caring myself. I am not sure what will happen exactly though as that changes, I'm hoping we will have that chat as

soon as it is looking like my husband is getting harder for me to care for."

Families and friends cope in their own ways when they are acting as a mediating role between people and services, and this can impact on the dying person's ability to make their own decisions.

"It was very hard to ask questions because we didn't want to upset my friend."



My family chose to not tell my mum she was dying so she wasn't able to tell us things she might have wanted. It was hard because my family had kept from my mum how poorly she was so she couldn't say what she wanted because she didn't know she was dying."

When communications aren't sufficient, some families can feel like they're having to battle with services, rather than work with them.

“This has usually been a very traumatic experience with too much fighting to get people to hear what we needed. We kept having to complain about the services we are receiving and being told tough basically. We have not been spoken to or heard.”

Good individualised care and communications are sensitive to the individual's emotional needs and ability to take in information at a point in time. When communications aren't pitched right in terms of what the patient is ready to hear, they aren't as effective.

“Took our feelings in to consideration. Care plan was done at our pace.”

“I did feel it was more about the service than the patient. Services didn't speak to each other and assumed patient knew more than they could possibly do. I felt if we were proactive we could get answers but really were expected to just know what was happening.”

“Our [specialist] nurse was very blunt and just said that they had no idea how long my mother-in-law had left or if or when she might deteriorate. I thought she was quite harsh in how she described what was going to happen to her physically, especially at a time when she was still dealing with the recent unexpected news that she was dying. We are still not sure she has fully grasped the seriousness of what is going on.”



Bradford District & Craven

Ambition 2: Each person gets fair access to care

People in Bradford didn't generally refer to how well services met their religious or cultural needs.

A few people spoke about how they wished services had come into play earlier, suggesting this would have made them more useful within their wider lives.



“I wish we could have some conversations sooner rather than later but as a whole we seem to have everything covered at the moment.”

“We have had to pay for a speech therapist privately as the waiting list for NHS one was too long.”

One person told us how being located at the border of several Trusts meant services didn't fit into their life as easily as they should have.

“It hasn't been easy. It seems that we have missed a step somewhere. My husband's cancer care is managed through Leeds Trust whereas our local teams are managed through Airedale and Bradford NHS Trusts. This seems to have made a difference i.e. to the awareness of our situation. Now the district nurses are involved they are wonderful.”

A few people felt that services didn't aim to fit in with patients' lives.

“Just got a leaflet on end of life care. My husband just took on board what they said, not asked questions. [It's all been] very matter of fact. Your life completely changes - you have to fit around the care/treatment.”



Bradford District & Craven

Ambition 3: Maximising comfort and wellbeing

A lot of the responses we received from Bradford spoke of the role of the family in keeping people comfortable, especially when services aren't at hand.

"I think as a whole we are doing ok. I know we are trying to get my husband to gain some weight to keep his strength up and he is having issues with this. But I'm not sure if there are any ways they can help. I am putting cream in all his food etc but not sure what a GP can do."

"My daughter-in-law and son care for me with lots of love but my paid carers are always rushed. They don't usually talk to me at all, they have left me in dangerous situations many times and I have also heard them being rude to and about my family and daughter-in-law."

One person told how their relative's comfort was compromised as services didn't respond fast enough.

"A hospital bed should have been offered earlier to prevent the awful bed sores dad got."

Sometimes services were able to keep people comfortable over time because they were good at responding to issues flagged by family carers, although this wasn't always the case.



I believe they did everything they could. I wish someone had made sure that we as a family understood more as I did a lot of research myself online."

"The palliative care team knew I was struggling to change dad in bed, so they ordered a hospital bed that would be put in another room at home."



We know we have a good care company that is reviewing our care plan every month to check on anything changing etc. Before with other companies they never asked what we needed or how they can help. We were given the minimum possible and even when I have made formal complaints I get nowhere."

"The care home was so experienced and prepared for the quick deterioration in my relative's condition."

Some responses highlighted the stresses and practical difficulties of being a carer to a person receiving end of life care, and how these can potentially impact on a person's comfort over time.

"I didn't know what he was entitled to so I didn't feel able to challenge anyone."

"I think they tried to give her everything she needed but it was hard to make dying not scary. Sometimes I didn't want to visit because I was scared."

"We have managed to get the incontinence team to help but that took me calling and pushing. No one has listened to anything I have tried to share with them. Being the person that is primarily caring for her, and especially given that we have been told that part of her condition is that she will make poor choices/ bad decisions, I hate to have to call my mother-in-law a liar in front of medical staff when they ask her questions and she isn't honest with them and I know it. I really wish the voice of carers was heard more and taken into account and factored into care."



Bradford District & Craven

Ambition 4: Care is coordinated

Again, some of the comments from respondents in Bradford spoke of the key role played by family carers. A couple of people described their or their relative's condition as rare and suggested this meant there was less support available for them.

"I can ask family for help anytime. My condition is rare and so not many people have any training or knowledge of what is happening to me so no one can meet my specific needs. My care is solely organised by my family."

"Because [relative's] condition is considered rare, there is only one specialist nurse that has had any training on the condition. She has been off sick and we have only had 2 visits from any specialist nurse anyway, with no clear plan on when they are going to be visiting. Plus they appear to only work 2 days a week so I have to leave answerphone messages for them that are sometimes not responded to for over a week. The only

organisation to [relative's] care is that, that I personally have organised."

Several people told us about the Goldline service and how that service has made their care feel a lot better organised, although a number of people said they would have liked to have heard about it earlier or were only made aware of it by chance.

Only very recently have we been referred to the Goldline service and this came about through a comment made by a nurse on a course we are attending at our local hospice. Prior to this we accessed day and night input through contacting oncology [at hospital] which often led to a drive to Leeds (over an hour) to be assessed."

“It wasn’t until the last month that Goldline was told about us. It should have been introduced earlier so we didn’t feel so helpless.”

A couple of people told us about having to travel long distances for support, while another said that their relative’s accessibility needs weren’t accommodated.

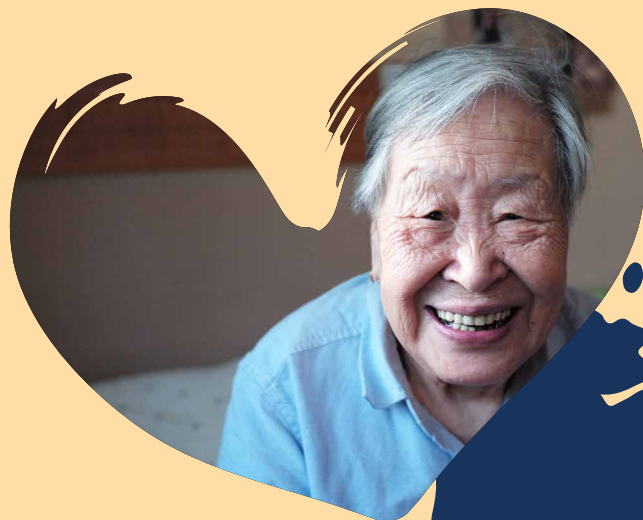
“My husband has particular needs relating to his condition in that he is completely blind. This has been a management issue when he has been an inpatient and also when it has come to me acting on his behalf, like making and taking phone calls.”

Two people’s answers suggested how important it is that support from services is proactive, as relatives can’t always fill the gap when support isn’t offered.



Apparently we were supposed to have been introduced to the hospice so we would have had a 24-hour contact point but someone forgot to do it.”

“I’m sure at the hospice there was help all the time. I didn’t know I could ask for help.”



Bradford District & Craven

Ambition 5: All staff are prepared to care

When people praised staff, it was often for their caring manner and their willingness to bring something extra to their role, beyond the required practicalities.

“The GP who has been involved in my husband’s care has actually been an advocate for him on a number of occasions and has shown great care and empathy.”

“Always very considerate, helpful and informative about supportive living which may be of help.”

People referred to understaffing and time pressures being a problem.

“[The hospital] was severely understaffed. Most staff spent their time on computers in the corridors when I visited for weeks each day – not once was [my relative] checked on. I was not impressed. I even did some care for other patients.”

“Understaffed and lacked time to perform basic nursing care, checks, bed baths, feeding, repositioning, often relative identifying and informing nurses when condition had deteriorated.”

“They are supposed to visit for 45 minutes on each visit 3 times a day but have sometimes been as short as 6 minutes from getting out of their car door to back into the car.”

Some people said that language barriers had been a problem, with staff not speaking clear English or the patient not speaking English.



The nurses were lovely but obviously mum didn’t know she was dying and mum didn’t speak English so the staff just talked to my siblings or my dad.”

Bradford District & Craven

Ambition 6: Each community is prepared to help

There had been a real mix of experiences in Bradford, with some people feeling amply supported by family and friends in particular, but others struggling to get the help they wanted. Very few mentioned bereavement support from services (and when they did, they said they had had to actively seek it out.)

There was a strong sense in some people's responses that family didn't want to talk about dying and bereavement, which sometimes left respondents feeling isolated.



Some people didn't know what to say when my relative was diagnosed and then when they passed away they avoided talking about it. We've had some help but at times could have done with more."

"No one wants to know what dad's final days were like. It was a privilege to care for him but lonely."

"My family don't want to talk about mums' death. There was upset about not telling my mum she was dying. On one hand I understand they didn't want to scare her, but it meant she didn't get to say things she might have wanted to say. No one has offered me any support. And I had to Google terms the nurses used and I also Googled what happens when someone dies. I read lots about the death rattle."

Sometimes families are geographically distant, making it harder for them to support each other.

Calderdale

Findings by local area



In 32% of cases, people had spoken to services about their wishes for the end of their life.



48% were consistently told what to expect from their end of life care.



55% said their services fit in with and respected all aspects of their life.



65% said staff always checked that care met their or their relative's needs.



93% felt care met their or their relative's specific needs.



64% knew they could ask for help at any time of day or night.



80% felt sure that staff had all the skills they needed.



80% felt staff were kind and caring.

Calderdale

Findings by local area




24

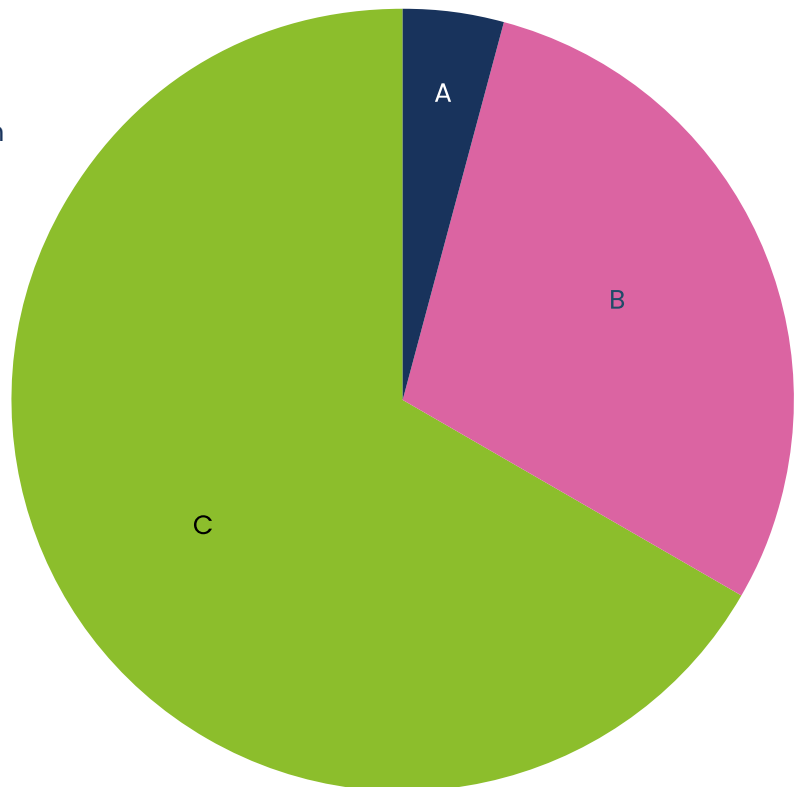
Total number of responses

79%

of respondents were White British.

Our respondents' experience of end of life care

-  A. Person receiving end of life care: 1
-  B. Relative of someone receiving end of life care: 7
-  C. Relative of a deceased person who received end of life care: 16





Calderdale

The methodology

"We used existing contacts already made in diverse communities and we visited new organisations first to introduce ourselves and explain our project and more about Healthwatch asking people if they would like to be involved and provide a case study. We sat with many people and did the surveys with them as it meant we could have a chat with them about their experiences and fit that to the survey questions.

We used our skill and experience in listening, showing empathy, compassion, sensitivity, mirroring, reflecting back."

For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.

Calderdale

Ambition 1: Each person is seen as an individual

Some of the conversations we had with people in Calderdale spoke of the sense of uncertainty people approaching the end of their life care experience. While many people have spoken to services, it seems that, in some cases at least, further or longer conversations might help alleviate some of that sense of not knowing what the future holds.

“We are at an early stage, we know there is no more treatment but we feel the decline will be gradual. At this stage we've begun to talk about care and we want hospice care, but all services tell us it's too far to plan.”

“It is all very up in the air, we have no certainty of what will happen and how long we have to prepare. We have many questions but often we don't have long enough in the appointments to ask questions, or the right person is not there at that time to answer them. There are a lot of appointments and we do not always know what they are for or who (clinicians) will be there.”

“We got the news [that relative's condition was untreatable] in

person, the staff were supportive but I felt afterwards that we had more questions and it was a while before the next appointment, so obviously we started looking online which worries you more. We feel when breaking this, an appointment sooner after breaking this news would help. We don't yet know what end of life care planning looks like, what timescale we're looking at.”



A care plan has been started and I have been allowed to input to that.

She has chosen a hospice but we do not know how long it will be, so there does seem uncertainty but we have begun to talk about it and try to make it seem real."

One person spoke to us about the "necessity for honesty" in conversations with professionals, while another noted that "there has been no conversations; we have been passed around with no service really accepting responsibility for delivering care."

Time pressures and their impact on quality communication came up a number of times.

"The hospital nursing staff were exceptional and open to speaking with us anytime; the doctors seemed very busy and were not around a lot to answer questions."

"Rushed conversation called in middle of night, was not expecting this conversation. Mum had suffered stroke. We felt pressurised to agree to non resuscitation. It felt like they wanted to get it done and dusted."

"It was very quick when my brother died, so communication from the hospital wasn't as good or quick as it could have been."

On the other hand, when staff take their time and are attentive to the patient's understanding, communication is very effective.



The staff took their time to explain everything and continuously checked our understanding. They are doing an amazing job."

"The nursing staff especially were kind, caring and respectful. The doctors seemed very treatment, factual focused, the nurses brought the human-touch to conversations."



Calderdale

Ambition 2: Each person gets fair access to care

Several respondents told us about how hard it is or could be to arrange end of life care around children and wider family life.

“Very difficult. It doesn't consider the lives of carers: I have children under 10 so am looking after them and my mother at the same time. I struggle financially so cannot afford to get carers in. The cost of driving to mum's is expensive, so petrol costs are now mounting and I am struggling. I applied for Carers Allowance which has helped but I am very worried about how to care for her as she gradually dies.”

“Very little consideration of the impact on the broader family, e.g. ability for parents to work.”

 **The appointments have been local, at suitable times. I think if we had children we'd have struggled with juggling them and their needs.”**

One person told us their Imam wasn't able to visit the hospital, although it isn't clear why this was. A couple of other respondents indicated that, while their religious or cultural needs haven't been obstructed, they weren't sure what services would do to actively support them.

“I know my faith will be considered at home, I do not know if the staff know what this means for me.”

“We have been respected but I'm not sure there has been anything linked to our faith.”

One respondent described how “It was very hard, we both felt we were seen as old.”

Calderdale

Ambition 3: Maximising comfort and wellbeing

For some of our respondents in Calderdale, people's comfort had been impacted when intervention wasn't as timely as it could have been.

"Due to the sudden nature of his death, there was little care, only pain medication. It all seemed rushed, confused, panicked. There was no time to get him into a hospice where the environment may have been more fitting and caring."

"It was a shock when he died. They called me to say he had been moved to another area Intensive Care Unit (ICU). My brother spoke with them and we visited but he could not breathe by himself. It all happened very quickly and was distressing, he was struggling and looked in pain. It wasn't cancer, it was the breath issue that he died from so that wasn't what we were expecting."

"The bed and commode could have been planned sooner to ensure my mother's comfort."

One person told us how advance planning was helpful to both the patient and their family's sense of comfort.

"We were given lots of notice of him moving into the hospice. I understood the process too. He was made as comfortable as possible during the move."

Another respondent described how their relative wasn't comfortable upon their death.



I feel that the end of life care needs a great deal of updating as I feel that denying food and water is dreadful. It makes the last days of the process painful, not peaceful. Basically, end of life patients are ignored, not cared for and left to die a painful not peaceful death."

Another described how a child patient's quality of life wasn't attended to by services.

"No understanding of communication or posture and mobility and impact on life expectancy or prevention of things like aspiration pneumonia. No hopes or expectations of life or quality of life, for example nursery, pre-school and school or any social/leisure time. Clinical interventions seemed to be limited to those relate to drugs."



Calderdale

Ambition 4: Care is coordinated

While not many people in Calderdale spoke to us specifically about how well organised care had been, we did receive a couple of examples of when things hadn't been particularly clear for people.

"It was all very disorganised, my sister was 87, lived alone and with no children or husband alive. I did not have power of attorney but she became too unwell so I started to care for her, but it felt like a battle all the time to get information or an idea of who should be dealing with what. I am 2 years younger, disabled and struggle financially so I couldn't pay anyone to care for her but the NHS we used weren't providing a link to any care (pathway) either."



Appointments are at different times and days. It feels difficult to manage when we need to be where and when. It is hard fitting it all in around the children [aged 13+] and sometimes they have been left at home alone because we are still at the hospital."

Calderdale

Ambition 5: All staff are prepared to care

When asked about the staff who looked after them or their relative, one person told us how helpful they had been.



The two overnight nurses made their visit as late as possible

following my phone call so that they could stay with me and my daughter as they knew my mother was about to die. This made it far easier for me as the nurses were then present and could make the necessary arrangements for the doctor to visit and I could then initiate funeral care."

Three people told us about how the way staffing is organised limited the quality of their experience.

"Many of them went absolutely above and beyond the call of duty and cared deeply for us and our family, but they were so constrained and restricted by the system and various rules that they could do nothing to actually help us to get the support we needed and they were siloed into very restrictive roles. Some of our staff were even told off for attending my daughter's funeral."

"Staff on ward should have the skills to administer medication and know the policies, but I was told they were bank staff."

"Staff seemed very busy, so I feel they were not able to give the time to provide care. That isn't their fault, but it's sad."

Calderdale

Ambition 6: Each community is prepared to help

A number of people in Calderdale told us how they had found the people around them reluctant or unable to talk about people who are dying or have died.

“Yes [I have spoken to friends and family], but not everyone is able to express. It is a very difficult time, and requires special skills and approaches to be able to communicate effectively.”

“No, it felt very lonely and seeing a sister die makes you think of your own life and what it will be like. I live alone so who will do for me what I did, or tried to do, for my sister?”

“Family yes and friends who have been bereaved yes. Others no I feel they don't know how to ask about him or wonder if they should talk about him even 9 months on.”

“Not really, on occasions like birthdays, Christmas he is remembered, but day to day I feel he is [remembered] by only the closest family and friends.”

People supporting loved ones through the dying process are sometimes torn by competing emotions which can make it harder to reach out to others for support.

 **It's a worrying, anxious time and I feel very alone. I feel I am complaining all the time about how hard it is to care for my children and mother.”**

“[I can talk to] staff yes. Friends/
family no; it feels like it is something
we are finding hard to talk about.
Sometimes I want to forget about
it too, pretend it won't happen so I
don't say anything so friends don't.
We haven't asked [about support
from services] I worry about the
money side as we both get benefits
and I don't know if what I will get will
cover. Also worry about the cost of
a funeral.”

In terms of approaching services,
one person told us they weren't sure
where to turn.



I think we were all in shock until after the funeral and a while after. By then involvement of the NHS is long gone so you feel forgotten but that's when with time and space we have questions. But we can hardly turn up at the hospital and ask what happened weeks or months later.”

Kirklees

Findings by local area



In 30% of cases, people had spoken to services about their wishes for the end of their life.



36% were consistently told what to expect from their end of life care.



70% said their services fit in with and respected all aspects of their life.



50% said staff always checked that care met their or their relative's needs.



75% felt care met their or their relative's specific needs.



63% knew they could ask for help at any time of day or night.



100% felt sure that staff had all the skills they needed.



70% felt staff were kind and caring.

Kirklees

Findings by local area




12

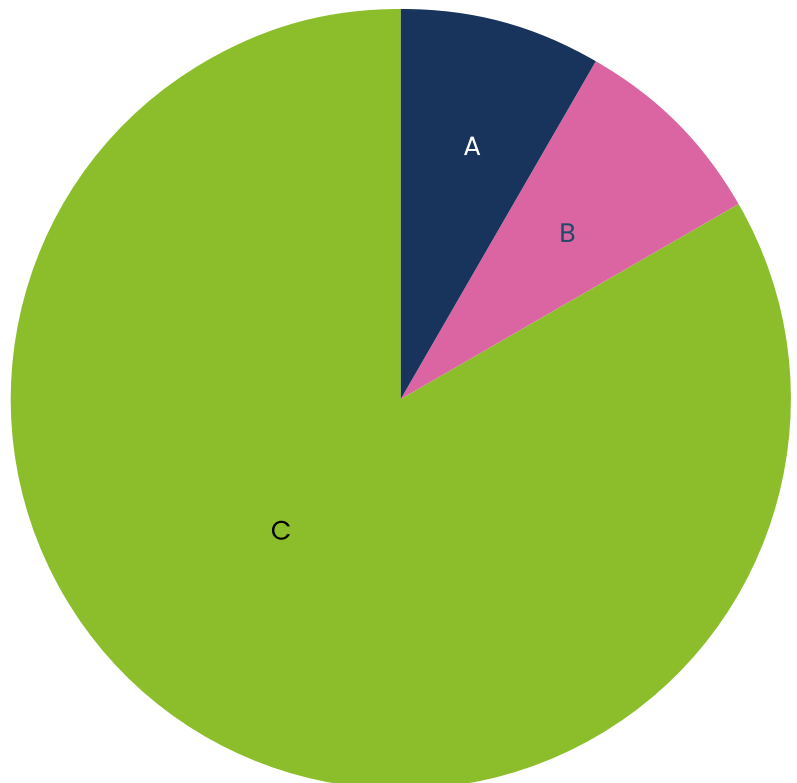
Total number of responses

75%

of respondents were White British.

Our respondents' experience of end of life care

-  A. Person receiving end of life care: 1
-  B. Relative of someone receiving end of life care: 1
-  C. Relative of a deceased person who received end of life care: 10





Kirklees

The methodology

“In Kirklees, we had a locally commissioned piece of engagement on end of life care and bereavement taking place at exactly the same time as the West Yorkshire end of life care engagement.

Our engagement for the West Yorkshire work took place in the following settings:

The priority for our face-to-face engagement was to speak to people receiving end of life care as this was different to the other end of life care engagement we had running at the same time.

The survey link was emailed out to lots of our contacts to try to get representation from our diverse community.

Our social media efforts were scheduled from 23 April to 12 May 2023 to avoid sending confusing messages when both pieces of engagement were live.

The Kirklees end of life and bereavement report, **‘Dying in Kirklees – what matters’** was launched on 4 October 2023 at a Dying Well event.”

For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.

Kirklees

Ambition 1: Each person is seen as an individual

One of the strongest themes to come out of the responses in Kirklees was a sense that individualised conversations weren't held early enough.

"We were told my husband's cancer was terminal the first week of January. He was discharged from hospital and I cared for him at home for 2 weeks without hearing anything from anyone. Eventually I called the GP who told me to get in touch with [the multidisciplinary service that supports people receiving end of life care] and then from there on things have been fine and we have had visits from the community nurses."



18 months before she died the GP came to visit her at home and tried to get me to sign a DNR (do not resuscitate) and said she would be too weak to bring back if she had a heart attack or stroke. She was bed bound but still relatively strong (eating drinking fine) so I was confused as to why everyone kept telling us she didn't have long to go."

“My husband fell ill and died within 3 months. It all happened very quickly and we didn't know he had an end of life prognosis until the very end. We kept expecting help, support and communication throughout the end of my husband's life. The staff didn't work with the family to keep us informed. My husband apparently was told alone, in a corridor, that he had an end of life prognosis. But due to his ill health he didn't remember all of the details and we weren't informed.”



Family were not told very much information about possible care coming out of hospital, we were also told that hospice care was not appropriate even though my grandma had stage 4 cancer. We were given a book by the hospital with possible nursing homes and no more information. We had to do the research as to where she should go. She went to a nursing home which could fit her in, not the one we would have liked which was closer to our home for visiting.”

Kirklees

Ambition 2: Each person gets fair access to care

The 12 responses from Kirklees didn't provide much information about ambition 2.



Kirklees

Ambition 3: Maximising comfort and wellbeing

Some people in Kirklees were able to report that their relative had been kept comfortable.



The nurses who came to the house initially arranged for him to

have a hospital bed at home and a commode so he didn't have as much walking to do. We've also been fitted with a shower chair which really helps. They are very good at making sure I have everything I need to keep him at home which is where he wants to be."

"They always came in to check he was comfortable and that we had everything we needed."

"The carers always made sure she was comfortable and the occupational therapist got her a new bed and chair to make her comfortable. Just wish we would have had them sooner."

Others said this wasn't the case for them.

"For various reasons my husband received very little care. We didn't know what to expect and didn't know he was dying until the very end, so we couldn't give him a peaceful last few months. He was in pain and discomfort and was worried right up until the end. My husband wasn't kept comfortable. We were waiting and waiting for support from the multi-disciplinary team (MDT), but it didn't come until after he died. The MDT was due to meet 2 days after my husband passed away. They still met and I received a phone call that day to say that they were going to offer chemo and immunotherapy. They were unaware that he had passed away.

I know now what the prognosis was for [my husband] but if there hadn't been delays in referrals he may have been well enough to have the treatment to ease his suffering. He didn't have this, and we saw him suffer and could do nothing to help him."

"Without having us to advocate for our relative, I'm not sure she would have been kept comfortable. We really had to insist on certain things happening. We knew her better than anyone so staff should always listen carefully to relatives."



Kirklees

Ambition 4: Care is coordinated

Several of the responses from Kirklees suggested that services didn't coordinate well, or only did so thanks to the effort and time on the part of family members.

"It is [well-organised] now but took a little while to get there."

"It was organised as it could be because of us speaking up for our relative."

"Not easy to organise as we had to call many nursing homes all of which had a waiting list. We would have liked hospice care but were told this was not an option by the hospital"



It was thoroughly disorganised and appalling. I left unable to grieve properly because I feel I need answers about why he didn't receive the help he should have done at the time."

kirklees

Ambition 5: All staff are prepared to care

Some of the respondents in Kirklees had very positive experiences of interacting with staff.

“Always very lovely and chatty when the nurses come to the home. They don’t baby him and treat him like a child just because he is ill.”

In other cases, the experience was rather more mixed.

 **Some were absolutely fantastic, kind, compassionate, doing things above and beyond for all the family. Others should not be in a caring profession.”**

“Admiral nurse and occupational therapist were great, everyone else just seemed ready to write off my wife at every opportunity.”

“The ones who came regular to do a wash/change 4 times a day were like robots and didn’t think about my dad - I refused them coming.”

Kirklees

Ambition 6: Each community is prepared to help

As in other places, few in Kirklees told us that they had received bereavement support or counselling.

“The nurses always take the time to ask how I am too and see what else I might need. My daughters are here daily helping out and they always ask how I’m doing too.”

“Initially, but I may need more support.”



Leeds

Findings by local area



In 44% of cases, people had spoken to services about their wishes for the end of their life.



50% were consistently told what to expect from their end of life care.



73% said their services fit in with and respected all aspects of their life.



67% said staff always checked that care met their or their relative's needs.



66% felt care met their or their relative's specific needs.



80% knew they could ask for help at any time of day or night.



76% felt sure that staff had all the skills they needed.



80% felt staff were kind and caring.

Leeds

Findings by local area




52

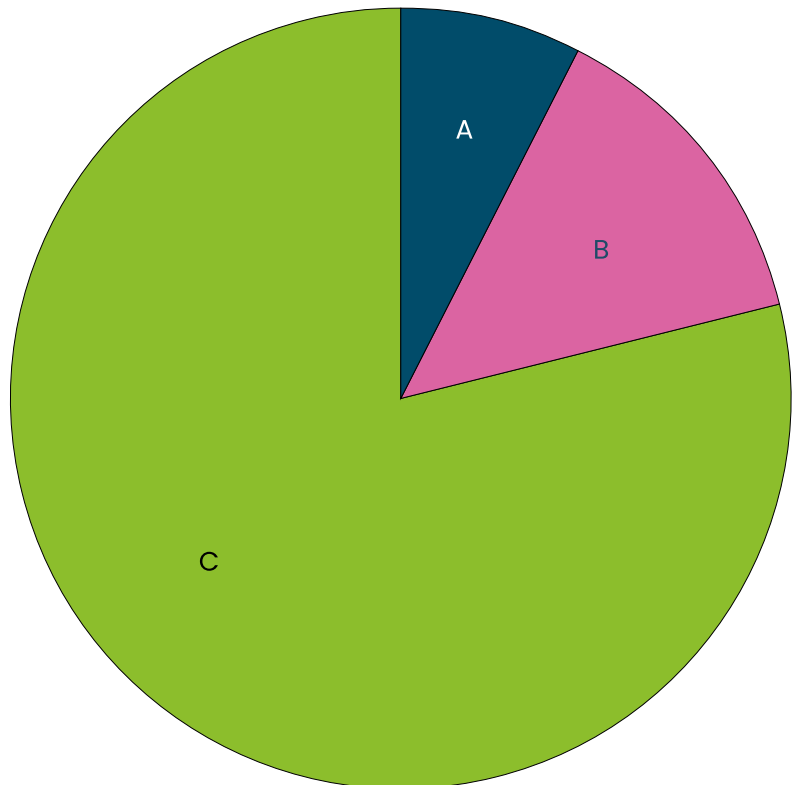
59%

Total number of responses

of respondents were White British.

Our respondents' experience of end of life care

-  A. Person receiving end of life care: 4
-  B. Relative of someone receiving end of life care: 7
-  C. Relative of a deceased person who received end of life care: 41





Leeds

The methodology

"We recognised that one of this project's biggest challenges would be finding the right contacts in a very short period of time, especially if we wanted to speak with people from diverse communities. For that reason, we decided to cast our net as widely as possible."

We contacted well over 100 organisations directly.

See Appendix on p.144

We attended meetings to make other professionals aware of the work and ask for their help with finding participants, including meetings of care home and home care managers and the Dying Matters partnership.

We attended community fairs to make contacts in communities, including events dedicated to the deaf community, events put on for Dying Matters week, a community fair for the South Asian community in the Hindu mandir, and events about death and dying targeted at people with learning disabilities.

We also asked our professional contacts to include an item about the work in their bulletins to make staff aware of the work and ask them to get in touch with us if they knew of any relevant potential participants. Examples included bulletins from the Leeds Health and Care Partnership, the Local Care Partnership team and the Communities of Interest Network. The latter bulletin goes out to about 150 organisations working with all kinds of communities in Leeds, including some of the smallest and most excluded.

News about the project also went out in public-facing bulletins, such as Carers Leeds' monthly newsletter, the West Yorkshire Voice newsletter and Healthwatch Leeds' own newsletter.

We also followed up on the contacts provided by members of the West Yorkshire Health and Care Partnership Palliative End of Life Care programme which commissioned the project.

The contacts we made with community organisations were by far the most productive. Reaching out to NHS organisations did not lead directly to any conversations with participants, whereas our conversations with people working in community organisations did. One reason why our contacts with statutory partners were less productive is that they are much less likely to see individuals regularly or retain their information. (And even if they do keep patients' information, they are not necessarily permitted by data protection regulations to share their details. For them to do this, they would have to contact individuals to ask for permission – another task on top of their already heavy workload.) We

often found that NHS contacts would forward us onto other professionals, and on a few occasions we found ourselves ultimately being referred back to our initial contact. One exception to this was the hospices in Leeds (who have charitable rather than statutory status), who were able to get us in touch with people with relevant experience.

That said, it's important to note that most of the contact we made didn't result in us speaking with participants. There are various reasons for this:

Statutory and third-sector organisations and their staff are exceptionally busy. In the case of the latter, issues with funding and staffing are well known, so many organisations simply won't have the time to assist. This is even more the case when a single organisation covers a whole community.

In many cases, organisations simply didn't know anyone who met the criteria for participation. Lots of professionals who worked directly with communities told us that death was a very taboo subject for the people they worked with. Although we reassured them that we would handle the conversations in the most sensitive way we could, it's also possible that they didn't want to make the approach to their groups about the subject in case it caused offence.

It should also be noted that a number of participants dropped out at the last minute, more so than we would normally expect. This was particularly the case for people who were receiving end of life care themselves or who had a relative or friend who was still receiving care, as opposed to those who were already bereaved.

The reasons for this are undoubtedly linked to the subject matter: they told us that they didn't feel up to having the conversation on the day, or their loved one's condition had changed so they could no longer prioritise speaking with us.

We were very conscious of the need to take a trauma-informed approach to the work so, rather than running through the survey with participants, we had conversations with them about their experience. These might start, for example, with a few questions about the basic facts (where a person is or was cared for and by whom, their circumstances and so on), before we asked a few open-ended questions about the quality of their experience.



The great advantage of this approach is that it meant the participant had a lot of ownership over where the conversation went and, as a result, we were in less danger of pushing them into areas which they felt were too painful to talk about. It also enabled us to get a real sense of what mattered most to the individual and gave them the freedom to really explore what they wanted to talk about. The person became the focus of the conversation, rather than the survey. This hopefully helped participants feel truly listened to, and created a sense of trust. The conversations were recorded in written notes or audio.

While we felt this was the right approach given that our top priority had to be participants' wellbeing, it's important to acknowledge that it came with challenges too. First of all, conversations take much longer than surveys, both in terms of the time the engagement worker spends face-to-face with each participant, and the work required afterwards to read through the conversation and enter the relevant parts into the survey.

It also takes skill on the part of the worker to make sure the participants' contributions respond to the commissioner's requirements for the project, in the sense that they must listen attentively, react to what they are hearing, have in the back of their mind what is needed and steer the conversation as gently as possible when required, all at the same time.

Healthwatch Leeds would particularly like to thank the following organisations for their support:

- **Armley Helping Hands**
- **St Gemma's Hospice (and Clare Russell and the Health Inclusion team in particular)**
- **Feel Good Factor**
- **The BME Dementia Hub at Touchstone**
- **Carers Leeds**
- **Swan Song**
- **Lychee Red at Health For All**

- **The Dying Matters Partnership**
- **The Association of Blind Asians**
- **Leeds Involving People**
- **Forum Central**

For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.



Leeds

Ambition 1: Each person is seen as an individual

Our conversations with people in Leeds indicated how important it is that professionals give patients and families a very clear idea of how the individual's condition is likely to change and use clear language.

"I wasn't informed my wife was receiving end of life care."

"The communication wasn't clear. Many of the staff on the ward had limited English, which made things harder. They also weren't clear about what was going to happen with dad – they said he's "not likely to be around for long", when actually they should have made it clear that he was very near the end. It would have been better if they'd spelt it out for us."

"The staff prepared me for my husband's death, so I knew it was coming, although you don't quite realise what that means until it happens."

"The best conversation we had was with the doctor when mum was in hospital. She made it clear that

mum was on a slow but steady journey towards death, a bit like a staircase [which meant] there would be times when she was the same, but there would also be times when she would decline suddenly."



It was really inconsistent, we were constantly going backwards and forwards and never getting any answers. We didn't know how serious it was until it was too late."

When professionals actively indicate that they are open to being approached, this can make a difference to people's experience.

"I did appreciate and value being able to call someone day or night with regards to the welfare of my relative's health and pain management."

QQ I spoke to the care home manager on many occasions. Her office was right next to the entrance, so she used to be there quite late when people were walking in and out and she'd leave her door open unless she was in a meeting. And the nurse and the care home staff were also really approachable."

Some people told us how communications can be more complicated when multiple services or professionals are involved.

"There was a flurry of activity for 24 hours which was totally overwhelming but then things settled down. A slightly slower pace might have been easier as I just felt I was repeating myself."

"Disjointed at times, it isn't clear who to go to or who (if anyone) is co-ordinating the delivery of care."

"Different teams meant separate communication even from day to night teams. Would have preferred one single point."

People in Leeds often emphasised that communication is, in part, about professionals effectively imparting their knowledge to people and families – but it isn't only that. Very good communication feels two-way. Good communicators are also ready to listen and respond to what they hear.

"The nurses were good at keeping us in the loop, but they were also good listeners."

“Generally it was good, but it would have been helpful to have more communication between the nurses and family about visiting. There were times when they visited and we didn't need them to, so it would have been helpful if we could have told them not to come that day. As a family we were busy caring for my brother, looking after our own families and working, so having to tidy up the house for their visit when it wasn't needed wasn't ideal.”



Our request for the need of medication was ignored.”

“Lots of people in our family have medical training, so they know what to ask services. But most people don't know that.”



Leeds

Ambition 2: Each person gets fair access to care

When we asked people how well services fitted into their wider lives, sometimes people spoke about how lengthy processes got in people's way during their final weeks or months.

"Everything seemed to take ages. Getting her diagnosed with dementia was taking forever, and it was only when mam was admitted to hospital that the doctor said she had it. She ended up in hospital for a month because they wouldn't discharge her until all the care she needed was in place. Ideally this would have been done a lot faster."



Communication with hospital for the bed was difficult and

took too long."

"There was about 9 months between my brother's diagnosis and his death. In the last months, he wasn't able to be active at all, but they didn't get the medication right during those months when he was able to get about. It was a shame because it meant we didn't get to

make use of that brief time [when he was still able to be active]. We used a company to take him to a few gigs, which gave us some good memories."

Some people observed that services understood the importance of having lots of family around. Some also commented that services hadn't got in the way of families carrying out religious practices.

"We had carers come in 4 times a day so that the family could be family, rather than carers. The carers were always fine with us being there, even though we are a big family."

Leeds

Ambition 3: Maximising comfort and wellbeing

Some of the people we spoke to in Leeds credited staff for keeping not just the patient comfortable, but the wider family too. However, a few people told us how delays impacted on individuals' comfort, notably regarding pain relief and at times such as bank holidays when staffing levels might be lower.

“Near the end, the care team made a referral for pain relief, but the locum GP covering the bank holiday never phoned back. The locum GP really let us down, he wasn't interested, he didn't seem to understand the urgency. Because of this delay, everything else was delayed, including getting the nurse out.”

“At the beginning of being in the hospital, my husband's pain was not managed well when he needed the toilet. It took a few days before they finally fitted a catheter. This was before he got worse and it has been managed very well since.”



My dad experienced unnecessary pain and agitation due to the one nurse's decision to hold the medication which had been prescribed by the Doctor to be available when required.”

“My brother-in-law had dementia and he had too many tests at the end. By the time they knew what was wrong with him he was too far gone and he died not long after. He wasn't comfortable during that whole time.”

“Dad was in so much pain, but they said there was no one on the ward who could administer the pain medication, so they took him to A&E. I found him on a stretcher in A&E, where all kinds of stuff was going on around him, it's not a nice environment. I had to fight to get him out of there, I didn't want him to die on a stretcher. They moved him into a bay at 4am, the middle of the night, and within hours he was dead.”



Leeds

Ambition 4: Care is coordinated

People had a range of experiences in terms of how well organised care was, from “seamless” to “disjointed”. In some cases, it was clear that families played a key organising role and, when services are responsive and understanding, this can work well. On the other hand, when services don’t feel responsive or communicative, families can be left feeling like they have to do everything themselves.

“Doesn’t feel like there is any one person ‘in charge’ so trying to co-ordinate input from the various services/speciality teams involved feels like it’s down to us which can be stressful when you don’t know what you don’t know.”

“It was organised. At times agency staff were late but on the whole they let us know.”

“The [care] home was very reluctant to call GP.”

Again, speed of decision-making was sometimes a factor in people’s experience.

“Quite organised but again the delays of medication and syringe driver and top ups resulted in extensive distress for both my dad and my brother and myself who were with him at all times.”

“It didn’t feel well organised because he had to have so many tests. It seemed to take so long.”



Leeds

Ambition 5: All staff are prepared to care

People praised staff's knowledge and the confidence and authority they brought to their job.

"The doctor on the ward and a nurse were fantastic. They paid a lot of attention and watched over my husband. They noticed a difference in his breathing and contacted me straight away so I could visit him. They were very on the ball."

"[The professional from the community team] was amazing, gentle and kind in her manner and authoritative when needed."

"When I asked if they could provide end of life care they were confident in stating they could. This gave me the confidence to trust the team."

Some people commented that the staff were caring and attentive not just to the patient, but the patient's family too, with two respondents noting that care staff had attended their relative's funeral, which meant a lot to the family. It was clear from many responses that the staff

hadn't just looked after people's physical needs, but brought warmth, moral support and even "fun" into their role.

A few people noted that changes in staff and staffing levels could impact on experience.



The staff were kind, but the nurses kept changing, which made it harder to develop a rapport with them. It's important to have the same staff every time for end of life care."

“The Christmas period was when staffing changed and not all the staff had the skills to care for my relative.”

“They were very short staffed. Some did their best but there are limits to what one person can do.”

On the occasions when people said their experience with staff hadn't been as positive, describing them as being inattentive or distant.

“Some of the nurses seemed rather distant and made no attempt to connect with him.”



Some of the staff were kind, but some of them just weren't attentive at all. It felt like I had to push even for basic things for him, they didn't seem to observe things.”



Leeds

Ambition 6: Each community is prepared to help

On the whole, people's experiences of getting support from family, friends and other members of their community had been very mixed, with some feeling very supported and others not at all. Mostly, people looked to family for support (but didn't always find it forthcoming); few had bereavement support from a service.

A few people pointed out how the stresses caused by looking after a dying relative had put families under a level of strain that now made it difficult for them to support one another.

"Some of my siblings helped out with mam, but not all of them. That makes things a bit more difficult."

"My mum and auntie had a falling out mostly about the care for my grandad in his last few years."

"It would have been nice if somebody had offered to visit [my relative] in hospital but other than his 2 sisters (one of whom came once and the other twice), I visited alone every day for two and a half weeks."

Some people noted that, when a person had died peacefully, this made the grieving process a little easier. On the other hand, people sometimes carry guilt and pain associated with more difficult deaths for years.

"I think my siblings and my daughter would agree with me that Mum had a 'good' death and so as upsetting it is to talk about Mum dying, we feel it was managed as well as it could have been."



I was able to accept my father having had a good death which has helped my grieving process as well as my family."

"I had a friend who was dying before and I couldn't bring myself to see her at the end, I just couldn't see her like that. I still beat myself up about it."

"I don't talk about it to people, but the experience never leaves you. I've lost a few relatives in horrible ways and I remember them all. I remember when my mum was dying 20 years ago, the staff said "We can wake her up for you to say bye but she will be in pain". We said no, why would we want her to be in pain? When you want help dealing with the bereavement, they [services] tell you to go to different places, but they should come to you. That would be more helpful."

A couple of people noted how bereavement support could be better tailored to people's needs. It is worth noting that the grieving process doesn't necessarily start for families after they have lost their relative, but before.

"We could have done with bereavement support during their active dying we were grieving while caring"



My brother's death was a shock because he was so fit and he died young. I'd recommend that services helping with bereavement reach out to siblings. There was nothing to recognise that brothers and sisters were grieving, but that feels so important. You assume your oldest siblings will go first."

Wakefield District

Findings by local area



In 35% of cases, people had spoken to services about their wishes for the end of their life.



32% were consistently told what to expect from their end of life care.



65% said their services fit in with and respected all aspects of their life.



58% said staff always checked that care met their or their relative's needs.



57% felt care met their or their relative's specific needs.



52% knew they could ask for help at any time of day or night.



64% felt sure that staff had all the skills they needed.



78% felt staff were kind and caring.

Wakefield District

Findings by local area




27

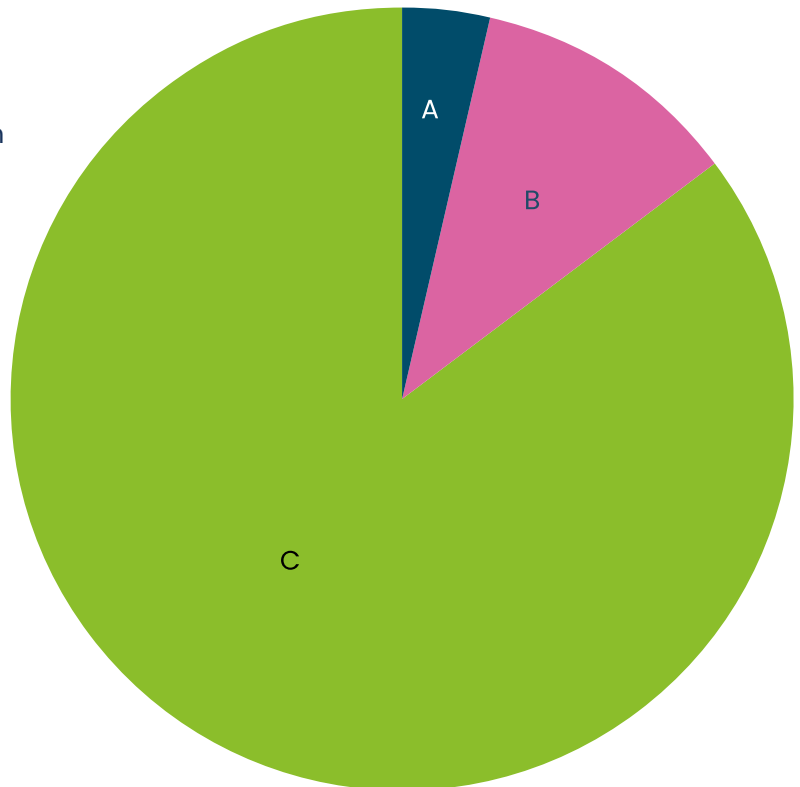
Total number of responses

81%

of respondents were White British.

Our respondents' experience of end of life care

-  A. Person receiving end of life care: 1
-  B. Relative of someone receiving end of life care: 3
-  C. Relative of a deceased person who received end of life care: 23





Wakefield District

The methodology

“Throughout our work, Healthwatch Wakefield work extensively across the district, involving a wide range of age groups and other demographics. Utilising a partnership approach, we work closely with a variety of organisations, such as health and social care services like large hospital trusts, to small the third sector organisations.

To deliver this programme we engaged with a number of recent service users from different backgrounds across the district, and supported our partners across the district to identify individuals from their services who would be able to complete the survey. We particularly approached organisations that support high numbers of individuals from seldom heard groups.”

For a full list of the organisations contacted by Healthwatch Bradford, please refer to the Appendix on page 144.

Wakefield District

Ambition 1: Each person is seen as an individual

Some of the comments from people in Wakefield reflected some of the positive experiences they had of getting personalised support from services.

“Initially the anticipatory medication was sent out without any conversation prior to this which was a shock. When the palliative care team became involved things improved significantly and conversations were open and issues explained more thoroughly.”

“It was all excellent. They got all the aids, bed, drugs etc straight away. When he (my husband) needed meds changing or upped they told us how to go about this including at bank holidays. The GP rang up every week and also came out a few times. They were all really caring. Apart from the chemist - they ran out of morphine and my husband was desperate for this. I had to send a letter to the Chemist highlighting this but I received no reply.”

When communication hadn't been as effective, this was often

due to delays. People sometimes identified the root of this problem in procedures that didn't respond quickly enough.



Dad was on palliative care and when dad deteriorated had to wait over 12 hours for a GP to come out to see him to say he was end of life. Dad was in pain whilst waiting.”

“Sometimes it was disjointed. My family member hadn't received a definitive diagnosis; therefore there were lots of different teams involved and end of life was then swift. Services do not seem to be activated to respond until there is a diagnosis, therefore pre diagnosis support could be improved. Also, once diagnosis happened there were lots of things happening to support my relative, however this was in the last week of life so it made the situation even more chaotic.”

“Morphine was needed urgently but a change in nurse shift and protocols meant morphine wasn't available. My friend went to the local medical centre to ask for help as nobody was available to answer the phone. Sadly, my friend's wife died whilst he was trying to get morphine prescribed.”

Sometimes, the discussions about end of life care specifically came too late to be truly helpful. In a few cases, it appeared that not all services were in agreement that the patient was at the end of their life.

“Although my relative was end of life the health care professionals did not have any discussions around this until my relative was very end of life. He did not receive any support in regards to advance care planning or finance. One time I was trying to ring a ward for over 4 hours with no response.”

“The care home apparently did not anticipate that my relative was dying although they were elderly, frail and bed bound so did not make any arrangements for family visits or end of life care.”



We asked about end of life care towards the end and we were told no he wasn't on this even though he was really unwell. They didn't say he was end of life [or rather] they did and they didn't. It felt disjointed that some services treated him as end of life but others didn't.”



Some people shared examples of when communication was insufficient.

Some people also remarked on how important it is that conversation is two-way and truly attentive and empathetic towards the individual's needs.

"A conversation was had in hospital, my mother-in-law was alone and did not realise she was organising her end of life care."

"There was no discussion either with my husband or myself. I was informed and that was all."

"The consultant was very blunt and lacked any empathy whatsoever. They did not attempt to have any sort of conversation and just presented the key facts with little compassion considering we had been just told 'you won't survive'. The same consultant asked later about a DNR (Do Not Resuscitate), my dad didn't want to make this decision on his own and said 'I'll ask my daughter'.



The consultant did not speak to me but put on the form my dad has

agreed. The named nurse was lovely and apologised for how it was dealt with when we were initially told as she was there. Unfortunately it was virtually impossible to contact her when needed for support or guidance as she was nearly always in the clinic."



Wakefield District

Ambition 2: Each person gets fair access to care

The responses we received to this question tended not to focus on how well care met families' particular cultural or religious needs, perhaps because the vast majority of respondents came from a White British and Christian or non-religious background.

The responses we received often focused on the bridging role that carers sometimes need to take on between services and the individual who is dying.

"I feel that not all professionals and services think about the impact on the family member(s) left with the responsibilities of caring (practical and emotional) for a dying relative."



There is a lot of information to provide, take in, remember all

whilst dealing with the news of a dying relative and all the care that this brings. There are too many people involved and it can be confusing who is supporting you for what. Whilst the internal systems are in place to organise and manage this support this doesn't translate always for the people living with the condition."

Wakefield District

Ambition 3: Maximising comfort and wellbeing

Some people's responses suggested that they associated how effectively services kept people comfortable with how proactive they were. Often, they referred to pain medication.

"Marvellous. They came out day and night to make sure he was comfortable. They came out to change medication, to ensure he was not in pain in so far as they could. As pain free as possible. They got more help plus aids etc as he needed it, including physio. It was brilliant."

"When meds were due, a lot of times I had to go find the nurse to get more meds. This left a time period where he was in pain and uncomfortable. This should not have happened, meds should have been ready at the right time so they could be administered. Dad was in pain and as he didn't always know how to describe it as he had dementia they said he wasn't as he would say he didn't hurt. Yet he would scream in pain."

"[Services kept my relative comfortable] Only when I arrived each morning, I had to fetch staff if I needed help."

"My relative was taken to A&E on a Friday and despite leaving contact information (no one was allowed to stay with her due to remaining covid restrictions) we were not informed where my relative was taken and only got to visit them on the Sunday after phoning the hospital to find out where they were. My relative was scared and not sure what was happening or why other patients had visitors and not them, they were very distressed."



Wakefield District

Ambition 4: Care is coordinated

Again, when people in Wakefield had issues with how well organised services were, they often referred to families having to chase up help rather than it being provided proactively. Ineffective links with GP surgeries were referred to on a few occasions.



**Only available
Monday to Friday. Not
accessible weekends**

and very little support over weekends or bank holidays. The palliative care team send requests for changes to prescriptions to the GP who never seem to act on these without family ringing the GP, also they never seem to get the prescriptions correct. It's very stressful trying to sort this out with the GP causing delays to getting medication that is needed, i.e. pain relief."

"I had to find the nurse on many occasions. As the care home had nurses, GPs didn't see the need to come out. I would raise things a lot but because he was in care the nurses were left to deal with it. Which it wasn't dealt with unless I raised it over and over."

"It was very well organised. They gave us phone numbers to call at night, daytime, holidays, bank holiday-days. They seemed to talk to each other - the community nurse had meetings with GP and district nurses. They seemed to have good communication. If something was said it would be done, it was done."

Wakefield District

Ambition 5: All staff are prepared to care

Often people praised the staff who cared for them or their loved one, and referenced how they had seen not just the patient but the person.



The hospital staff were all really good with him - they managed to get

him out of bed as he wanted that. They kept him clean and hygienic etc and were caring towards him."

"Even in the final 24 hours, Dad was spoken to directly and not in the third person for which I am grateful."

"The GP was very caring - would phone to make sure things were OK but also to see if I was OK too. Two of the community nurses were absolutely fantastic - they were always there to help and went over and above what was required of them - they left extra dressings; came out when they could at all sorts of hours of the night. Wonderful staff, all of them."

When people criticised staff, it was sometimes because they felt they didn't have the experience or seniority required, or their manner was uncaring.

Wakefield District

Ambition 6: Each community is prepared to help

In terms of getting support during a person's death and after, the picture was very mixed in Wakefield. Some people had been able to reach out to family or friends, while others hadn't, or had only been able to do so many years later.

A few people told us how it wasn't possible for them to seek support from family, because they felt it wasn't their role to help them.

"Thank goodness I had some good friends that could see how stressed and heartbroken I was, I had to be strong for the rest of my family. I don't want to burden them as they have their own problems to deal with."

Very few people referenced getting bereavement support from services (but when they did, they said it was helpful). Some of our respondents were still living with the pain of seeing relatives die a difficult death.



Yes, they have supported me, but they don't understand on how difficult it was to watch my dad die. I am now contacting the GP. I am struggling with what happened, no one should be left in pain especially when he had end of life meds in the building."



What have we learned about end of life care in relation to the six ambitions?

The following learning has been identified in relation to each ambition, and should be used to help inform improvements and identify actions to ensure that everyone gets the best possible experience at the end of their life.

This learning isn't definitive. It should be seen as one step forward, at a specific moment in time, as we collectively work to better understand what it is like to be a person receiving end of life care or someone caring for a dying loved one.

Ambition One: Each person is seen as an individual

- **When services don't feel personalised enough, individuals and their families will often seek out information independently.** People facing health inequalities may be at a disadvantage in this regard, in that they may have fewer means to access information independently, may face language barriers and so on.

- **Good, personalised conversations reflect the fact that people may not be able to take in all the information they need to straight away.** Everyone needs to have more than one opportunity to have meaningful conversations with professionals, so that they can absorb information at their own pace.
- **Good, personalised conversations are gentle and empathetic, but they give the person a very clear idea of what is happening and what to expect.** Professionals should always avoid misleading language or hints.
- **When a dying person isn't able to communicate directly with services (due to a language barrier, sensory impairments or conditions such as dementia, for example), this often means information has to be shared via carers and family.** This can have implications for carers' wellbeing and the patient's right to make their own decisions.
- **For services to feel personalised, they must be quick and responsive: those fundamentals need to be consistently in place.** This should be the case wherever a person lives and whatever source of care they choose.
- **Not everyone we spoke to knew when end of life care had begun, suggesting that individualised conversations hadn't been as effective as they might be.**
- **Sometimes relatives and friends would benefit from more individualised attention when their loved one is actively dying.** They don't always know what the process of dying can entail, so being told even slightly in advance could make their experience a little less shocking.

Ambition Two: Each person gets fair access to care

- **People with children and wider caring responsibilities can find it difficult to juggle them with their responsibilities linked to end of life care.**
- **People see timeliness and early intervention as key to ensuring everyone gets fair access to care.** When services only intervene later in a person's journey, they can feel less tailored to the individual's needs, especially if their condition has progressed to the point where they can't get the most out of them.
- **Some people told us that they appreciated services' openness to having lots of family around the dying person, which can be an important part of their culture or religious beliefs.**
- **Generally speaking, the people who told us about how services accommodated their faith were broadly satisfied.** People don't necessarily expect services to participate in or actively facilitate faith-based practices (with a few exceptions, such as the expedited burials which several respondents told us had been provided). Instead, they simply want services not to get in the way of what families need to do – and, very largely, people report that services did just that.
- **While decisions around issues such as resuscitation certainly can be influenced by religion, we also need to recognise that people's beliefs can be extremely individualised, and we shouldn't make assumptions based on a person's belonging to a particular faith.**
- **Occasionally, we heard older people tell us they feel their dying relative was written off by services on account of their advanced age, with less being done to help them once they were on an end of life pathway.**

- **People who live on the border of different places can be at a disadvantage**, in that services must coordinate across systems so that people do not have to travel further and to different locations.
- **Some of the responses from people who care (or cared) for a dying loved one at home suggested they faced particular challenges.** Sometimes family carers were providing highly intensive and intimate support, and they felt that they (and their loved one) could have benefitted from more information and support. They didn't always feel well prepared or briefed about the realities of caring for a dying person. We must also acknowledge the immense and lasting practical and emotional toll such experiences can have on families.

Please also refer to the section on health inequalities on [p. 29](#) for more information about this ambition.

Ambition Three: Maximising comfort and wellbeing

- People want to be comfortable enough to use the time they have left to do as much as they can with their families and loved ones. This is another reason why it is important services come into play as soon as the person is on an end of life pathway – people can't get as much out of them if they arrive later, when their condition has already deteriorated.
- **Some families have found themselves playing a primary role in keeping dying loved ones comfortable.** They don't always feel well-informed about how best to do this and could benefit from more guidance and support at the start of the end of life pathway and as the patient's condition progresses.
- **For services to keep people comfortable, they need to be responsive and fast, including out of hours and during bank holidays.**

- Pain relief is an important part of this, but so is the provision of home equipment, the right bed and care that keeps people safe such as turning.
- **The question of eating came up a few times. Sometimes families could be very disturbed when a dying loved one isn't eating.** Where this is the case, it's very important they have the chance to speak with expert staff about this so that solutions can be put in place where they can be, and people are reassured that the dying person is as comfortable as possible.
- **A few people told us how hospital or care home environments hadn't been calm or peaceful,** making patients' last moments less comfortable than they could have been.
- **It was sometimes felt that pain medication had to be actively chased up,** with the responsibility falling on the patient or family to organise it when needed.

Ambition Four: Care is coordinated

- Families can find themselves stepping in to play a key coordinating role.
- Those people who spoke to us about 24/7 services suggested they were helpful and reassuring.
- Levels of coordination can vary greatly depending on which services are involved. There are many different end of life care providers across the region, and people's experiences suggest that some may work together more effectively than others.
- Having to chase up services can be a source of distress, in addition to the emotional pressures people and families naturally face when given a terminal diagnosis. Rarely have people told us they have a single contact they can turn to for help about how services connect up.

- It is well documented that GP services are under great pressure. This can affect their ability to support and play a coordinating role for people who choose to die at home.

Ambition Five: All staff are prepared to care

- **Staff have the power to make a great difference to people's experience of end of life care – and in many cases they do exactly that.** There are staff members across our region who see the person as well as the patient and provide extensive practical and emotional support to them at the end of their lives. They should be commended for the outstanding care they give.
- **People appreciate being spoken to by staff as adults capable of making their own decisions,** rather than being seen only through the perspective of their illness.

- **The expert care offered by experienced end of life care specialists is highly valued.** People and families feel reassured when staff can use their experience to guide them and let them know what to expect, especially as the dying patient is approaching the very end of their life.
- **Sometimes people have encountered problems with staffing levels and the type of professionals assigned to particular roles.** Some have felt that bank or agency staff were less prepared to do the highly skilled and specific role of looking after someone at the end of their life. Others have observed that staff don't have enough time to devote to individual patients.



Ambition Six: Each community is prepared to help

- **Few people told us they had been offered counselling**, with the exception of those whose family members had died in a hospice or parents who had lost children.
- **Many of the bereaved people we spoke to as part of this project told us they were talking to someone about their experience for the very first time.**
- **Most people saw family and friends as the first contacts they would turn to for support through dying and bereavement**, with very few saying they saw this as the responsibility of a wider community.
- **However, not everyone received the support through caring for a dying loved one and bereavement that they would have wanted from family and friends.** Sometimes, the individuals we spoke with felt that others weren't equipped to have conversations about death with them: their families and friends didn't know what to say and tended to avoid the subject.
- **When people don't feel supported through dying and bereavement, another factor can be the impact that caring for a dying loved one can have on families.** As we have seen with respect to other ambitions, caring for a dying person can be an all-consuming endeavour. It can cause resentments within families when some members feel that others aren't contributing as much.
- **Sometimes, people's grief is made more painful when they feel their loved one didn't die a peaceful death**, or they felt they had been let down by services.
- **When families supporting someone through dying don't feel services are working as well as they should, they don't necessarily feel that they have the time or the strength to complain to services at the time, or potentially for some time afterwards.**



Learning from the project:

How to engage with people about end of life care

As you read in the section of this report entitled “What We Did”, for this project, Healthwatch tried to take a somewhat different approach from that used to engage with people about end of life care in other pieces of work in the region.

Overall, we are pleased with the results our methodology has generated. Most places met or exceeded their target numbers and achieved good levels of diversity in their responses, reflecting both the make-up of their local population and the brief set out by the project commissioner, although we acknowledge that the work of seeking out diverse responses is never complete.

There is always more to achieve, not least because our populations are never static. In some ways, we were surprised at how many people were willing to talk to us, given how many professionals said how very difficult it would be to have people open up about what can be a very taboo issue. This was itself important learning: we mustn't shy away from

approaching communities about their experiences of end of life care because of preconceptions.

However, engaging with people about the sensitive subject of end of life care does present particular challenges. We have reflected on how any future projects could be set up to get around these challenges to at least some extent, based on our experience.

The biggest barrier that got in our way was the timeframe. We had a few months to set up and complete the project and, although we made the choice to give the engagement workers as long as possible to speak to people (eight weeks), this still didn't give us time to build relationships with individuals.

We heard from a couple of specialists working with very marginalised communities in end of life care that they don't start speaking with individuals about death and dying until they have spent at least six months building relationships with them. It's also worth bearing in mind that some hospices engage with patients continuously throughout the year. This longer-term approach increases the chances of speaking with people belonging to very small communities

The likelihood of finding participants from communities that might consist of a few hundred people who both have relevant recent experience and are willing to talk about it gets lower when the window for engagement is smaller. Another important part is the target number each Healthwatch agreed to, in that it is sometimes harder to emphasise the need for quality when workers are bound by requirements regarding quantity.

The voluntary and community sector was an invaluable partner in this project. Third-sector organisations, like statutory organisations, are also under exceptional pressure, so increasing the timeframe would potentially have helped more of them to get involved. The timing of the engagement also presented a barrier because it had to take place over the end of the financial year and the Easter holidays. Not only are staff likely to be taking leave during this time of the year, but community organisations are very busy doing events for school holidays, Easter, Ramadan, Passover and so on. Their availability was therefore particularly low.

In two of the places in West Yorkshire, engagements about end of life care were already underway when the project began.

They also had to carefully manage the risks inherent to asking potentially traumatised people to tell their story a second time for our piece of work.

Another issue worth acknowledging is the impact of doing this work on engagement workers. We set up good structures to ensure that the project workers could reach out if they needed emotional support. However, having conversations with multiple people (each one of which lasting as long as an hour) about a very difficult subject was nonetheless draining. This will be considered in greater detail in future similar work.

Finally, the six ambitions are ultimately a tool oriented at services: their purpose is to help them improve practice. However, engagement is by nature a people-oriented exercise, and for it to work optimally, it should start with the needs of people, not the needs of services.

Truly person-centred engagements start with what matters most to individuals, not the tools services use to measure themselves. While the project was designed to encourage open discussions with individuals rather than frame discussions against the six ambitions, future projects might consider how to take this approach a step further.



Learning for future engagements:

- **Be aware of communities' attitudes to talking about death and dying**, but don't view these as reasons to not try to start a conversation; always give people the opportunity to have their say, even when the subject is known to be taboo.
- **Engagement projects should take place over a longer period of time.** The longer the project timeframe, the more likely engagement workers are to be able to reach out to the most marginalised communities.
- **Avoid engaging over the end of the financial year and Easter school holiday period in the same way that you would avoid Christmas, especially if the engagement is short-term.**
- **Make sure similar engagements aren't happening in a locality at the same time.**
- **Build on what we already know about people's experiences of end of life care and only go out to talk to people where we know there are gaps in the information.**
- **Avoid shaping questions around the needs of services whenever possible;** try to start with understanding what the individual's experience has been, rather than what services want to hear.
- **Be realistic about the number of hours work required to reach out** to very small and / or marginalised and to have trauma-informed conversations with people, and budget accordingly.
- **Build in rest periods for project workers to give them time to recover and process what they have heard.**

Next steps

The experiences captured in this report will feed into the WY ICB's Palliative and End of Life Care Programme health needs assessment. This work will inform the development of the WY ICB's vision for palliative and end of life care services, ensuring residents of West Yorkshire receive the support they need and can die in a place of their choice.

For more information, please contact info@westyorkshirehealthwatch.co.uk

Thank you

This report was written by Healthwatch Leeds using data collected by each Healthwatch organisation in the West Yorkshire region.

Healthwatch in West Yorkshire would like to thank the many partners who made this piece of work possible. We are grateful for their support at an extremely busy time for all organisations working in health, care, and the voluntary sector.

Most importantly, we would like to thank the people who shared their experiences of end of life care with us: we are in awe of their willingness to share some of their most difficult experiences in the hope of making services better for everyone. Thank you to each and every one of you.



Appendix: Organisations contacted by Healthwatch

The following organisations were contacted by each Healthwatch as part of this engagement. Please note that not all organisations contacted responded or were able to assist with the project.

Healthwatch Bradford

- Airedale Sight
- BDCT
- Bevan Homeless project
- Bradford Bereavement service
- Bradford people first
- Bradford Talking Media
- BTHFT.NHS Adult safeguarding team
- Carers Resource
- Highfield Food Coop
- Keighley People
- Marie Curie
- New Choices
- Peacemakers international
- Safeguarding Through Communities
- Shared Church Keighley
- SNOOP charity
- Social Prescribers
- Sue Ryder
- The Bridge Project
- The Lotus Project
- WADDILOVES
- Waddiloves clinical team

Healthwatch Calderdale

- 0-25 SEND (CMBC)
- Adult Asperges ASC Support Group
- Age UK Todmorden
- Alpha House
- Alzheimers Society
- Andy's Man Club
- Arch-way Project
- Autism Hub
- Barkisland Active Together
- Barnados Positive Identity
- Basement Project
- Blackshaw Mutual Aid
- Brighthouse Central Foodbank
- Brunswick Centre
- Building Bridges Food Hub
- Calderdale British Muslim Association
- Calderdale Carers Project
- Calderdale & Huddersfield Maternity Voices Partnership
- Calderdale Adult Learning
- Calderdale Community Cares
- Calderdale DART

- Calderdale deaf Association
- Calderdale Deaf Youth Club
- Calderdale Dementia Hub
- Calderdale forum 50+
- Calderdale Frailty Network
- Calderdale Interfaith Group
- Calderdale National Deaf Childrens Society
- Calderdale Stroke
- Calderdale Talking Newspaper
- Calderdale Valley of Sanctuary
- Carers Wellbeing service
- Claremount & Boothtown Community Group
- Clifton Village Community Association
- Community Foundation For Calderdale
- Coram Family and Childcare Trust
- Cornholme Old Library Food Bank
- Creative Minds
- Cruse Bereavement Support
- Curious Motion
- Different Strokes
- Disability Partnership Calderdale
- Disability Support Calderdale
- Ebenezer Food Bank
- Elland Food Bank
- Field Lane childrens centre
- Field Lane Community Hub
- Focus4hope
- Friends of Dorothy
- Gathering Place
- Halifax and Calder Valley MS support Group
- Halifax Central Initiative
- Halifax Food and Support Drop In
- Halifax Homeless and Community Kitchen
- Halifax Macular Support
- Halifax Opportunities Trust
- Halifax Pakistani Group
- Halifax Society For the Blind
- Happy Days CIC
- Healthy Minds
- Hebden Bridge M.E. Support Group
- Hebden Royd Social Isolation Support Group
- Hebden Vale Childrens Centre
- Horton Housing
- Illingworth Methodist lunch club and café
- Illingworth Moor Methodist Church
- Invictus Wellbeing
- Jamia Madni Masjid Halifax
- Jubilee Childrens Centre
- Kirklees and Calderdale Independent ME Support Group
- Lead the Way Calderdale Self Advocacy Network
- Light Up Black African Heritage Calderdale
- Little Stars Childrens Centre
- Living well women's cancer support group
- Lower Valley Elland
- Macmillan Mens cancer support group
- Magpies
- Mayfield Trust
- Memory Lane café

- Mill Bank Group
- Mothershare
- Mums on a Mission
- Newground Together
- Noah's Ark
- North and East Family Support Drop In
- North Halifax Food Bank
- North Halifax Partnership
- Northowram Childrens Centre
- our place
- Phoenix Shed Facebook Group
- Project Challenge
- Project Colt
- Reach 4wards
- Ripponden Parish Council
- Roshani (Healthy Minds)
- Royal British Legion Halifax
- Ryeburn Tuesday 2 o clock group
- sisters united
- Special Stars Family Support Group
- st augustines
- Staying Well
- The Basement Project
- the hive
- Todmorden Food Drop In
- Todmorden Kindness Group
- Todmorden Mosque
- Together Housing
- Together We Grow
- Tourette's Support Group
- Unique Hub (young Asian Communities)www.uc3.com
- Unmasked Mental Health
- Visits Unlimited Accessible Calderdale Project

- VSI
- West Yorkshire ADHD Support Group
- Women's Activity Centre
- Young Carers Service (CMBC)
- Young Deaf People activity group
- Young Onset Dementia

Healthwatch Kirklees

- Active Social Care
- Age UK
- Alzheimers Society
- Aspire 50+ social group, Crossland Moor
- Carers count
- Carers count – After carers group
- Carers count Batley carers get together
- Carers Group Dewsbury Moor Sure Start Centre
- CHFT patient experience
- Community plus
- Denby Dale Cream Tea DD centre
- Forget me not hospice
- Friendship Cafe, Shelley Village Hall
- home from home friendship group, Kirkheaton Community centre
- Huddersfield mission
- Huddersfield Pakistani Association
- Kirkheaton Parish Centre lunch club
- Kirklees Action Network forum
- Kirklees Dementia Hub
- Kirklees public health
- Kirkwood bereaved peer support group
- Kirkwood Drop in – Poppins Cafe Holme Vally Memorial Hospital
- Kirkwood newly bereaved support

group

- Land and Property facilities manager
- Leeds Gate
- Medequip
- Mencap
- Outlookers
- S2R Mirfield Friday Friendship Group
- The Branch Bereavement journey
- The Branch, Jubilee Together- Jubilee centre
- The Kirkwood bereavement peer support group
- The Kirkwood Chorus, Brian Jackson House
- The Memory Cafe, Longwood Mechanics hall
- Tommys lounge
- wellness service
- Yorkshire brain tumour charity Young @ heart

Healthwatch Leeds

- Action for Gipton Elderly
- Advonet
- Age UK Leeds
- Andy's Man Club
- Armley Helping Hands
- Association of Blind Asians
- AVSED
- BAME Hub Chapeltown
- Belle Isle Senior Action
- Better Action for Families
- Black Health Initiative
- Bramley Elderly Action

- Burmantofts Senior Action
- Calm and Centred
- Care & Repair
- Care Quality Team, Leeds City Council (wellbeing coordinators)
- Carers Leeds
- Caring Together in Woodhouse and Little London
- CASYL
- Catholic Care
- Change
- Chapel Allerton Good Neighbours
- Child Bereavement UK - Leeds
- Circles of Life
- Communities of Interest Network
- Community Action for Roundhay Elderly (RVS)
- Continuing Healthcare, Leeds
- Cross Gates & District Good Neighbours' Scheme CIO
- Damasq
- Dying Matters Partnership
- East Side Story (East Leeds magazine)
- EOL matrix team, Continuing Care
- Feel Good Factor
- Flamingos Coffee House
- Forum Central
- Gipsil
- Halton Moor and Osmondthorpe Project for Elders
- Hamara
- Hawksworth Wood Older People's Support
- Health for All

- West Yorkshire Voice
- Holbeck Together
- Involvement Lead, CMHT Transformation
- Kirkwood Hospice, Wakefield
- Leeds Bereavement Forum
- Leeds Black Elders
- Leeds Chaplaincy Service
- Leeds City Council
- Leeds Community Healthcare Trust
- Leeds Dads
- Leeds Directory
- Leeds GATE
- Leeds Grand Mosque
- Leeds ICB
- Leeds ICB Primary Care Team
- Leeds Involving People
- Leeds Irish Health and Homes
- Leeds Jewish Welfare Board
- Leeds LGBTQ+ Community Consortium
- Leeds Older People's Forum
- Leeds Palliative Care Network
- Leep 1
- Lincoln Green Mosque
- Live Well Leeds
- Local Care Partnership Weekly Digest
- Leeds Teaching Hospitals Trust
- MAECare
- Maggie's
- Marie Curie
- Market Place
- Martin House
- Meanwood Elders Neighbourhood Action – RVS
- MESMAC
- MHA Communities Farsley
- MHA Communities Horsforth
- MHA Communities Pudsey
- MHA Communities Rothwell & District
- MHA Communities South Leeds
- Middleton Elderly Aid
- Morley Elderly Action
- Neighbourhood Action in Farnley, New Farnley and Moor Top
- Neighbourhood Elders Team (Garforth & Villages)
- Older Wiser Local Seniors
- OPAL
- Otley Action for Older People
- OWLS
- People in Action
- Planning Ahead Coordinator, LS25/26 PCN
- Richmond Hill Elderly Action
- Sage Men's Group
- Seacroft Friends & Neighbours
- Senior Development Worker - Learning Disability Network
- Senior Pathway Integration Manager, Leeds ICB
- Shantona
- Social Prescribing Link Worker, Woodsley / Holt Park Primary Care Network
- Solace
- Space 2
- St Gemma's Hospice
- STEP (Supporting the Elderly People)

- Sue Ryder
- Sue Ryder Manorlands
- Swan Song
- Swarcliffe Good Neighbours Scheme
- The Old Fire Station
- Touchstone
- Wetherby In Support of the Elderly
- Wheatfields Hospice
- WIFCOS
- Women's Lives Leeds
- WY LeDeR (LAC)/Governance Lead
- Zest

Healthwatch North Yorkshire

- Age UK North Craven
- Anley Hall Nursing Home
- Carers Resource
- Community First Yorkshire
- Craven College
- Craven Nursing Home
- Dementia Forward
- Home Start
- Ingleborough Nursing Home
- Selfa
- Skipton Step Into Action
- The Dales Care Home
- The Place in Settle
- Threshfield Court Care Centre
- Various veteran support groups across North Yorkshire

Healthwatch Wakefield

AGE UK Wakefield & district

Carers Wakefield & District

chair LD&A PEG

Churches Together

- City of Sanctuary
- Community Awareness Programme (CAP)
- FAB
- Health Visitor (who visits Health Common Gypsy & Traveller Site)
- Home Instead Wakefield
- Involving People
- Muslim's Engagement and Development (MEND)
- Nova
- Partnerships Co-ordination Adults and Health (Coordinates LD&A PB)
- Pontefract Live At Home Scheme
- Refugee Council
- Refugee Council Resettlement Team (Leeds, Wakefield, York)
- SMaSH
- Star Wakefield
- Together Wakefield
- Travellers Site Wakefield. Site Manager
- Wakefield & District Sight Aid
- Wakefield Advocacy Together Hub
- Wakefield Street Kitchen
- Wakefield Youth Work Team
- Wave Group. Voiceability (Wakefield Autism Voice for Everyone)
- Well Women Centre
- Yorkshire MESMAC Wakefield
- Young Lives

healthwatch

working together in West Yorkshire

healthwatch
Bradford and District

healthwatchbradford.co.uk

healthwatch
Calderdale

healthwatchcalderdale.co.uk

healthwatch
Kirklees

healthwatchkirklees.co.uk

healthwatch
Leeds

healthwatchleeds.co.uk

healthwatch
North Yorkshire

healthwatchnorthyorkshire.co.uk

healthwatch
Wakefield

healthwatchwakefield.co.uk