# Insight Report: **End of Life Care**

Understanding the experiences, needs and preferences of people at end-of-life, their carers / family / friends, and staff

September 2023 V4.1

## **What is the purpose of this report?**

This paper summarises what we know about the end-of-life population in Leeds. This includes the experiences, needs and preferences of:

* People at end of life
* Their carers, family, and friends
* Staff working with people at end of life

Specifically, this report:

* Sets out sources of insight that relates to this population
* Summarises the key experience themes for this population
* Highlights gaps in understanding and areas for development
* Outlines next steps

This report is written by the [Leeds Health and Care Partnership](https://www.healthandcareleeds.org/about/) with the support of the [Leeds People’s Voices Partnership](https://www.healthandcareleeds.org/about/working-with-our-partners/). We have worked together (co-produced) with the key partners outlined in [Appendix A](#AppendixA). It is intended to support organisations in Leeds to put people’s voices at the heart of decision-making. It is a public document that will be of interest to third sector organisations, care services and people with experience of end-of-life support. The paper is a review of existing insight and is not an academic research study.

## **What do we mean by end-of-life care and support?**

End of life care is defined as care that:

“helps all those with advanced, progressive, and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met through the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual, and practical support” (Department of Health, 2008).

Palliative care is defined as:

“The active holistic care of patients with advanced progressive illness. It is the management of their pain and other symptoms together with the provision of psychological, social and spiritual support” (National Council for Palliative care)

Leeds has a long and successful history of developing and delivering high-quality palliative and end of life care and is well placed to address challenges as they evolve. We have a service we can be proud of. We will build on that to develop services that are equitable, sustainable, informed by evidence and integrated into all health and social care systems where people require them.

It is our aspiration that Leeds is a great place to live out our final years, months and weeks of life, to have great confidence in our care and comfort, and to have the assurance we will die with dignity and peace.

You can find out more about end of life care by reading the ‘Leeds Adult Palliative and End of Life Care Strategy - 2021-2026 here: <https://leedspalliativecare.org.uk/leeds-adult-palliative-and-end-of-life-care-strategy-2021-2026/>

## **Outcomes for end-of-life care in Leeds**

Over the last year, people planning health and care services in Leeds have worked with providers and the third sector to produce a set of draft outcomes for end-of-life care. These outcomes explain what we want to achieve to improve the lives of people at end of life and their carers, family and friends.

1. People approaching the end of their life are recognised and supported on time
2. People approaching the end of life live and die well according to what matters to them
3. All people approaching the end of life receive high quality, well-coordinated care at the right place at the right time and with the right people
4. People approaching the end of life and their carers are able to talk about death with those close to them and in their communities. They feel their loved ones are well supported during and after their care.

Each outcome has a number of ‘measurables’, these are ways we check that we are achieving our outcomes. The full framework can be seen in [Appendix B](#AppendixB).

## **4. What are the key themes identified by the report?**

The insight review highlights a number of key themes:

* People tell us that they are generally **satisfied** with their experience of using end of life services and support.
* People tell us that they want end of life care to meet their individual needs (**person-centred**). People tell us that the end of life care they receive in Leeds is kind and compassionate.
* People at end of life and their carers / family / friends tell us that they value kind and compassionate staff. The majority of people are very happy with the staff who work in end of life services in Leeds. **(workforce** and **person-centred care)**
* People tell us that **information** about services and support for people at end of life is sometimes poor quality and inconsistent
* Some people tell us that services that provide end of life support do not always work well together. (**joint working**)
* People at end of life and their family / friends tell us that privacy and dignity is very important to them (**person-centred care, environment**)
* People from diverse ethnic communities had views consistent with the wider population. However, they reported having particular difficulties accessing an interpreter (**health inequalities**)
* The health needs assessment in 2019 suggests that some communities are less likely to have record of, or die in, their preferred place of death. This was particularly the case for people from diverse ethnic communities, areas of deprivation, men and people under 65. (**health inequalities, choice**)
* There are some potential gaps in our insight including feedback from staff and the needs of families and friends of people who die suddenly. (**workforce**)

This insight should be considered alongside city-wide cross-cutting themes available on the Leeds Health and Care Partnership website. It is important to note that the quality of the insight in Leeds is variable. While we work as a city to address this variation, we will include relevant national and international data on people’s experience of end-of-life care.

## **5. Insight review**

We are committed to starting with what we already know about people’s experience, needs and preferences. This section of the report outlines insight work undertaken over the last four years and highlights key themes as identified in [Appendix C](#AppendixC).

| **Source** | **Publication** | **No of participants and demographics** | **Date** | **Key themes relating to end-of-life experience** |
| --- | --- | --- | --- | --- |
| **Leeds Palliative Care Network and Healthwatch Leeds** | **Bereaved Carers Survey about End-of-Life Care in Leeds** People’s experience of end-of-life care and support for their friend / relative in hospices, hospitals, in their own homes and care homes <https://healthwatchleeds.co.uk/wp-content/uploads/2022/09/Leeds-Bereaved-Carers-Survey-Report-2021-2-Final.pdf> | 115 peopleRepresents 6% of deaths between Oct – Dec 2022Demographics available in report | Oct 2022 | * **Joint working –** one third of people were not satisfied with how services worked together
* **Choice** – one third of people report that they and/or their loved on did not get an opportunity to discuss their wishes
 |
| **Datix**  | **Complaints and compliments report for Wheatfields Hospice** | 8 people7 carers/family1 health professional | May 2022 | * **Person-centred care** – all participants reported experiencing person-centred care
* **Workforce** – all participants reported experiencing kind and compassionate staff
 |
| **National Library of Medicine** | **Patients receiving palliative care and their experiences of encounters with healthcare professionals**<https://pubmed.ncbi.nlm.nih.gov/35235482/>) | Semi-structured interviews with 20 palliative care cancer patients (Finland)13 women 7 men aged between 58 and 94 | 2022 | * **Person-centred care -** Caring for a patient receiving palliative care requires care beyond tending to a patient's physical needs.
* **Person-centred care -** Patients should be encountered holistically and as equal human beings without highlighting their roles as patients.
* **Workforce** - The healthcare professionals and the organisations should also acknowledge the importance of time and effort spent for encounters and conversations with patients instead of concentrating resources mainly on physical care.
 |
| **Leeds Palliative Care Network** | **Leeds Adult Palliative** **and End of Life Care** **Strategy****2021-2026**<https://leedspalliativecare.org.uk/wp-content/uploads/2021/06/PEOLC-Strategy-Document-2021-2026-FINAL.pdf>) | 60 people from 21 health and care organisations | 2021 | To support the strategy development, the Leeds Palliative Care Network (LPCN) organised and facilitated two events in November 2018 that engaged more than 60 people from 21 health and social care organisations, including statutory and third sectors. The outcome statements were further refined following feedback from the Leeds People’s Voices Partnership, facilitated by Healthwatch Leeds.**Outcomes:**People in Leeds who need palliative and / or end of life care will:* **Person-centred care** - Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care
* **Health inequality** - Have their needs and conditions recognised quickly and be given fair access to services, regardless of their background or characteristics
* **Person-centred care/Involvement in care -** Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing
* **Joint working** - Receive care that is well-coordinated
* **Workforce and resources -** Have their care provided by people who are well trained to do so and who have access to the necessary resources
* **Communication and resources -** Be assured that their family, carers, and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
* **Communication** - Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed
 |
| **Healthwatch Leeds (1 of 3)** | **Bereaved carers survey about end-of-life care in Leeds**<https://healthwatchleeds.co.uk/wp-content/uploads/2020/11/Final-Report-Bereaved-Carers.pdf>) | 225 peopleDemographics available in report | 2021 | This report reviewed people’s experiences of end-of-life care and support for their loved ones in hospices, hospital, in their own homes and in care homes. Themes are broken down by location.**Hospices -** 92 responses were received from the hospice setting* **Choice** - Almost all respondents (99%) felt their relative/friend had died in the right place.
* **Satisfaction** - Every respondent expressed satisfaction with the care provided.
* **Workforce**
	+ People talked highly of the staff and their professionalism.
	+ The feedback was very positive, with staff kindness and compassion and the high standard of care valued by many.
 |
| **Healthwatch Leeds (2 of 3)** | **Bereaved carers survey about end-of-life care in Leeds**<https://healthwatchleeds.co.uk/wp-content/uploads/2020/11/Final-Report-Bereaved-Carers.pdf>) | 225 peopleDemographics available in report | 2021 | **Hospitals -** 104 responses were received from the hospital setting* **Choice** - The majority of respondents (85%) felt their relative/friend had died in the right place.
* **Workforce** - There was praise for the kindness and compassion shown by staff.
* **Satisfaction -** There were high levels of satisfaction in most areas of care.
* **Person-centred care -** Some people felt the care was not as good as it could be. However, when it was known that the treatment was not working and the person was dying, there was an improvement in the level of support and care for the person and their family
* **Environment -** The lack of privacy on wards was a concern for some.
* **Information** - Respondents felt information about practical issues could be better, e.g. parking charges and access to toilet facilities.
 |
| **Healthwatch Leeds (3 of 3)** | **Bereaved carers survey about end-of-life care in Leeds**<https://healthwatchleeds.co.uk/wp-content/uploads/2020/11/Final-Report-Bereaved-Carers.pdf>) | 225 peopleDemographics available in report | 2021 | **Community -** 34 responses were received from community settings* **Choice -** Most respondents (97%) felt that their friend/relative had died in the right place.
* **Involvement in care -** Most people had the opportunity to discuss their wishes about care/treatment, where this had been appropriate.
* **Information** - There were mixed responses about the level of information people were given about other services.
* **Workforce** - There was praise for the level of care given at the end of life and the kindness of staff
 |
| **Health Watch Leeds and Palliative Care Network** | **End of Life Care in the Community –** People’s experience of end-of-life care and support in care homes, hospices and at home[Healthwatch-EOLC-Report-Final-.doc.pdf (leedspalliativecare.org.uk)](https://leedspalliativecare.org.uk/wp-content/uploads/2021/05/Healthwatch-EOLC-Report-Final-.doc.pdf) | 31 carers of people at end-of-life.15 case studiesNo data on demographics | 2020 | * **Workforce** - some good practice, with staff often showing kindness and compassion and providing invaluable support for families during a difficult time
* **Communication/joint working** - insufficient communication (between services and with loved ones)
* **Covid 19** - rigid interpretation of Covid-19 rules and guidelines
* **Workforce** - pressures on services and staff due to Covid 19
 |
| **Leeds City Council** **(1 of 2)** | **Health needs data update end of life care services for adults in Leeds**[Health-Needs-Assessment-for-EoLC-2019-Final.pdf (leedspalliativecare.org.uk)](https://leedspalliativecare.org.uk/wp-content/uploads/2020/01/Health-Needs-Assessment-for-EoLC-2019-Final.pdf) | Review of data | 2019 | This Health Needs Data Review is an update on the Health Needs Assessment (HNA) on End of Life Care Services in Leeds published in 2013* **Health inequality** - From data there is no correlation between deprivation and the percentage of those people who achieved their preferred place of death. However, data samples are small and it is worth noting that two of the three areas that recorded below 60% for the achievement of their preferred place of death were in the most deprived areas of the city.
* **Satisfaction/clinical treatment/satisfaction** - Overall there were high levels of satisfaction with care provided across all settings especially in relation to management of pain and other symptoms, and privacy and dignity
* **Involvement in care** - There has been an improvement in the number of people who have discussed their care preferences and treatment recommendations
* **Choice** - 1 in 3 people who had an EPaCCS record would prefer to die in their own home.
* **Choice** - There is a big gap between the proportion of people who said they would prefer to die in a hospital (1.4%) compared to those that did die in a hospital (19.9%)
 |
| **Leeds City Council** **(2 of 2)** | **Health needs data update end of life care services for adults in Leeds**[Health-Needs-Assessment-for-EoLC-2019-Final.pdf (leedspalliativecare.org.uk)](https://leedspalliativecare.org.uk/wp-content/uploads/2020/01/Health-Needs-Assessment-for-EoLC-2019-Final.pdf) | Review of data | 2019 | * **Health Inequality/Choice** - People aged under 65 are slightly less likely to have a preferred place of death recorded or die in their preferred place of death
* **Health inequality** - Males are slightly less likely to have a preferred place of death recorded. Males are also less likely to die in their preferred place of death when compared to females(70% and 76% respectively). A higher proportion of males die in hospital when compared to females
* **Health inequality** - Lower proportions of Mixed (e.g. Mixed - Any other mixed background; Mixed - White and Asian; Mixed - White and Black African; Mixed - White and Black Caribbean) and Black ethnic groups have a preferred place of death recorded and die in their preferred place of death when compared to other ethnic groups.
 |
| **NHS Leeds CCG****(1 of 2)** | **Frailty -** Engagement was to understand what matters to people living with frailty, those at end of life and their carers[https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/](https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https%3A//www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/) | 134 people, of which 96 were people living with frailty, and 38 were carers.Demographics available in link | 2018 | The Frailty engagement received feedback from people about end-of-life care. People told us that what matters to them is:* **Involvement in care -** People’s wishes are taken into consideration.
* **Choice -** Choice in the place of death mattered – many people recognised the importance of establishing people’s wishes in good time.
* **Clinical treatment -** Good symptom Management is important to people
* **Workforce -** Staff providing care should be caring, considerate and supportive.
* **Environment -** it is important to have a private space for clinical staff and people at end of life or relatives to communicate.
* **Information -** Information to people and their carers/family’s needs to be consistent
 |
| **NHS Leeds CCG****(2 of 2)** | **Frailty -** Engagement was to understand what matters to people living with frailty, those at end of life and their carers[https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/](https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https%3A//www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/) | 134 people, of which 96 were people living with frailty, and 38 were carers.Demographics available in link | 2018 | **Feedback from people with protected characteristics:*** **Health inequalities - Age -** The majority of people (74%) involved in the engagement were over 60 years old and their feedback reflects the view of the wider population. 26% of responses came from younger people whose answers also reflected the wider views.
* **Health inequalities - Disability -** The majority of people involved in the engagement had disabilities and their views were consistent with the wider population.
* **Health inequalities – Ethnicity -** 13% of the people we spoke to were from diverse ethnic communities. Their feedback was consistent with the views of the wider population. Some people from this community told us that:
	+ it can be a struggle to book appointments with GP for people who do not speak English
	+ they would like for GP consultations to be longer for frail older people
	+ it is important to them to be able to speak in their own language.
* **Health inequalities – Gender -** The majority of people (61%) involved in the engagement were female. Their views were consistent with the views of the wider population.
* **Health inequalities – Deprivation -** Only 50% of the responders shared with us their post code. Out of which 24% were from deprived areas. Their views were consistent with the wider population.
 |

### **Additional Reading**

* ‘Measuring Experience in end-of-life care – An overview’

<https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/Measuring_experience_in_care_in_end_of_life_care_-_An_overview.pdf>

## **6. Inequalities Review**

We are committed to tacking health inequalities in Leeds. Understanding the experiences, needs and preferences of people with protected characteristics is essential in our work. This section of the report outlines our understanding of how end of life care is experienced by people with protected characteristics (as outlined in the Equality Act 2010 – [Appendix D](#AppendixD)).

Please note that we are aware that the terminology used in relation to the recognition of a person’s identity may depend on the context of its use. Some people may define some terms differently to us. We have tried to use terminology that is generally accepted. Please do get in touch if you would like to discuss this further.

|  |  |
| --- | --- |
| **Protected Characteristic** | **Insight** |
| Age | People aged under 65 are slightly less likely to have a preferred place of death recorded or die in their preferred place of death.**(Leeds Health Needs Assessment Update, 2019)** |
| Disability | No issues identified |
| Gender (sex) | Males are slightly less likely to have a preferred place of death recorded. Males are also less likely to die in their preferred place of death when compared to females (70% and 76% respectively). A higher proportion of males die in hospital when compared to females**(Leeds Health Needs Assessment Update, 2019)** |
| Gender reassignment | No issues identified |
| Marriage and civil partnership  | No issues identified |
| Pregnancy and maternity | No issues identified |
| Race  | Lower proportions of Mixed and Black ethnic groups have a preferred place of death recorded and die in their preferred place of death when compared to other ethnic groups.**(Leeds Health Needs Assessment Update, 2019)**Some issues identified relating to primary care access for older people:* it can be a struggle to book appointments with GP for people who do not speak English
* they would like for GP consultations to be longer for frail older people
* it is important to them to be able to speak in their own language.

**(NHS Leeds CCG Frailty Engagement, 2018)** |
| Religion or belief | No issues identified |
| Sexual orientation | No issues identified |
| Homelessness | No issues identified |
| Deprivation  | There is no correlation between deprivation and the percentage of those people who achieved their preferred place of death. However, data samples are small and it is worth noting that two of the three areas that recorded below 60% for the achievement of their preferred place of death were in the most deprived areas of the city.**(Leeds Health Needs Assessment Update, 2019)** |
| Carers | it is important to have a private space for clinical staff and people at end of life or relatives to communicate. **(Leeds CCG Frailty Engagement, 2018)**Insufficient communication (between services and with loved ones **(HealthWatch Leeds, End of Life Care in the Community, 2020)**Almost all respondents (99%) felt their relative/friend had died in the right place. **(HealthWatch Leeds, Bereaved Carers Survey, 2021)** |
| Access to digital | No issues identified |
| Served in the forces | No issues identified |

## **7. Gaps and considerations** – are there any gaps in our evidence or things we need to consider?

This section explores gaps in our insight and suggests areas that may require further investigation.

### **Gaps identified in the report:**

* Whilst the majority of respondents to the bereaved carers survey described high quality across settings, it has also identified variation and indicate areas for improvement. It is vital that we address, and demonstrate measurable improvement in, those inequalities impacting on people from:
	+ Ethnically diverse communities (in particular people whose first language is not English)
	+ some areas of deprivation,
	+ men,
	+ people under 65.
* Feedback from staff working with people at end of life

### **Additional gaps and considerations identified by stakeholders**

* It is important to recognise inequalities in death. (Carers Leeds)
* Do we understand the needs of carers/families/friends of people who die relatively unexpectedly? (Carers Leeds)
* Do we understand the practical support needs and preferences of people at the end of life, particularly if they want to die at home? (Carers Leeds)
* There are some themes arising around how we talk about death and dying as a community, compassionate communities and the practical support that people need when they wish to die at home (Local Care Partnerships Development Team)

## **8. Next steps** – What happens next?

We would like to outline our next steps to demonstrate how this insight report will be used to improve end of life care in Leeds.

* 1. **Add the report to the Leeds Health and Care Partnership website**

We will add the report to our website and use this platform to demonstrate how we are responding to the findings in the report.

* 1. **Hold a workshop with key partners in the autumn**

We will meet with key end of life stakeholders in the autumn to

* Describe our end of life work in Leeds
* Outline and agree the findings of this report
* Identify and agree additional gaps
* Plan involvement work to understand the gaps in our knowledge
* Coproduce an approach to involving the public in shaping end of life services in Leeds
	1. **Explore how we feedback our response to this report**

We will work with partners to feedback to the public on how this insight is helping to shape local services.

## **Appendix A: Key partners**

It is essential that we work with key partners when we produce insight reports. This helps us capture a true reflection of people’s experience and assures us that our approach to insight is robust. To create this insight report on end-of-life care, we are working with the following key stakeholders:

### **Board members**

|  |  |
| --- | --- |
| **Name** | **Organisation**  |
| Gill Pottinger | Clinical Lead for Palliative Care / GP |
| Steph Lawrence | Leeds Community Healthcare NHS Trust  |
| Caroline Mcnamara  | Leeds Community Healthcare NHS Trust  |
| Lindsay Charles | Leeds and York Partnership NHS Foundation Trust  |
| Elizabeth Rees | Leeds Teaching Hospital NHS Trust  |
| James Woodhead | Leeds City Council - Adults and Health |
| Tom Daniels | NHS Integrated Care Board in Leeds  |
| Kerry Jackson | St Gemma’s Hospice |
| Natalie Sanderson | Wheatfields Hospice  |
| Paul Musgrave | Wheatfields Hospice  |
| Elise Hoadley  | Wheatfields Hospice  |
| Adam Hurlow | Leeds Palliative Care Networ |
| Suzanne Kite  | LTHT  |
| Stuart Morrison | Healthwatch Leeds |
| Claire Turner  | Carers Leeds (Third sector rep) |
| Mark Phillott | Leeds City Council |
| Helen Smith  | Leeds ICB |
| Jenny Baines | Leeds ICB |
| Fazila Jumabhoy | Primary Care |
| Tim Fielding  | Public Health |

### **Third sector and public representatives**

|  |  |
| --- | --- |
| **Name** | **Organisations** |
| Sharon Brooks | Care & Repair Leeds |
| Iain Anderson | Age UK Leeds |
| Nicolas Allen | The Leeds Office of the ICB |
| Rachel Mooring | ICB project support |
| Karl Witty | Forum Central |
| Amy Rebane | NIHR Leeds Biomedical Research Centre |
| Rachel Ainscough | Local Care Partnerships Development Team |
| Stuart Emsley | Care homes |
| Geraldine Montgomerie  | Swan Song |
| Michelle Clarke | Cruse Bereavement Support |
| Katty Keyhani | Alzheimer’s Society |
| Barbara Stewart | Leeds Bereavement Forum |
| Ali Kaye | Leeds Older People’s Forum |
| Kath Newton | ICB Volunteer |
| Emma Clare | End of Life Doula |

### **Networks and partnerships**

|  |  |
| --- | --- |
| **Contact** | **Group** |
| Francesca Wood | Leeds Health and Care Partnership Third Sector Reference Group |
|  | Dying Matters Partnership |
| Diane Boyne | Leeds Palliative Care Network |

## **Appendix B: End of life Outcomes Framework**

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**End of Life population outcomes framework**

Link to HealthyLeeds Plan strategic indicators:

* **Health outcome ambitions**
	+ Increase the proportion of people who experience a ‘good death’
* **System activity metrics**
	+ Increase expenditure on the third sector
	+ Increase the proportion of people being cared for in primary and community services
	+ Reduce the rate of growth in non-elective bed days and A&E attendances.
* **Quality experiences measures**
	+ Improve the experience of those using:
		- Primary care services
		- Community services
		- Hospital services
	+ Person-centred co-ordinated experience.

| **Outcome** | **Outcome measure** | **Process measure** |
| --- | --- | --- |
| 1. People approaching the end of their life are recognised and supported on time.
 | * EPACCS and RESPECT – % of people at end of life with an advanced care plan (particular focus on inequity for this measure)
* % of people who with an EPACCS in place
* Length of time on the end-of-life register
* System-wide quality audit of EPACCS (aspirational)
 | % of people on the end of life register with a preferred place of death recorded. |
| 1. People approaching the end of life live and die well according to what matters to them
 | * Bereaved carers survey (patient section)
* % of people who achieve their preferred place of death
* % of people who die in each potential setting vs and of people who choose to die there – need to recognise potential challenges with this data.
* Change in IPOS score for psychological and physical symptoms (aspirational)
* % of people on end of life register completing a ‘what matters to me’ assessment / an advanced care plan (aspirational).
* Audit of the quality of what matters to me assessments
 |  |
| 1. All people approaching the end of life receive high-quality, well-coordinated care at the right place at the right time and with the right people.
 | * % of people with three or more unplanned admissions in the last 90 days of life with an EPACCS.
* % of people with three of more unplanned admissions in the last 90 days of life without an EPACCS.
* Add into the bereaved carers surveys ‘how well do you think the team caring for your relative worked together’
* Burden of care score (OACC measure)
 | * Length of time getting from a request for a bed in the hospice to getting into the hospice.
* Length of time it takes to move someone from hospital to the community once the request has been made.
* Numbers of people transferred from hospital with fast track funding in place.
* Number of issues reported with availability of anticipatory medicines in the community.
 |
| 1. People approaching the end of life and their carers are able to talk about death with those close to them and in their communities. They feel their loved ones are well supported during and after their care.
 | * Bereaved carers survey
* % of people asking to die at home who achieve this
* Something around the dying matters survey – need to speak to public health representative. Maybe number of contacts made during dying matters week? Number of new wills written?
 |  |

## **Appendix C: Involvement themes**

The table below outlines key themes used in our involvement and insight work. The list is not exhaustive and additional themes may be identified in specific populations.

|  |  |  |
| --- | --- | --- |
| **Theme** | **Description** | **Examples** |
| **Choice** | Being able to choose how, where and when people access care. Being able to choose whether to access services in person or digitally | People report wanting to access the service as a walk-in patient.People report not being able to see the GP of their choice |
| **Clinical treatment** | Services provide high quality clinical care | People told us their pain was managed well |
| **Communication** | Clear communication and discussion between professionals and patients/ carers about services, conditions and treatment. Two-way communication | People report that their treatment was explained in a way that they understood and they could ask questions about the information they were given |
| **Covid-19** | Services that are mindful of the impact of Covid-19 | People report the service not being accessible during the pandemic |
| **Environment** | Services are provided in a place that is easy to access, private, clean and safe and is a way that is environmentally friendly and reduces pollution | People report that the waiting area was dirty |
| **Health inequality** | Services are provided in a way that meet the needs of communities who experience the greatest health inequalities. | Older people report not being able to access the service digitally |
| **Information** | Provision of accessible information about conditions and services (leaflets, posters, digital). One-way communication. | People report that the leaflet about their service was complicated and used terms they did not understand. |
| **Involvement in care** | Involvement of people in individual care planning and decision-making. | People told us they were not asked about their needs and preferences |
| **Involvement in service development** | Involvement of people in service development. Having the opportunity to share views about services and staff. | People told us that they were given an opportunity to feedback about the service using the friends and family test |
| **Joint working** | Care is coordinated and delivered within and between services in a seamless and integrated way | People report that their GP was not aware that they had been admitted to hospital |
| **Person centred** | Receiving individual care that doesn’t make assumptions about people’s needs. Being treated with dignity, respect, care, empathy and compassion. Respecting people’s choices, views and decisions | People report that their relative died in the place they wanted |
| **Resources** | Staff, patients and their carers/family/friends have the resources and support they need | Family reported that adaptions to the house took a long time to be made |
| **Satisfaction** | Services are generally satisfactory | Most people told us that they were very happy with the service. |
| **Timely care** | Provision of care and appointments in a timely manner | People report waiting a long time to get an appointment |
| **Workforce** | Confidence that there are enough of the right staff to deliver high quality, timely care | People raised concerns that the ward was busy because there were not enough staff |
| **Transport and travel** | Services are provided in a place that is easy to access by car and public transport. Services are located in a place where it is easy to park. | People report poor local transport linksPeople report good access to parking |
| **Wider determinants** | Services and professionals are sensitive to the wider determinants of health such as housing | People told us that their housing had a negative impact on their breathing |

## **Appendix D: Protected characteristics (Equality and Human Rights Commission 2016)**

1. **Age -** Where this is referred to, it refers to a person belonging to a particular age (for example 32 year olds) or range of ages (for example 18 to 30 year olds).
2. **Disability -** A person has a disability if she or he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.
3. **Gender (Sex) -** A man or a woman.
4. **Gender reassignment -** The process of transitioning from one gender to another.
5. **Marriage and civil partnership -** Marriage is no longer restricted to a union between a man and a woman but now includes a marriage between a same-sex couple. [1]

Same-sex couples can also have their relationships legally recognised as 'civil partnerships'. Civil partners must not be treated less favourably than married couples (except where permitted by the Equality Act).

1. **Pregnancy and maternity -** Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.
2. **Race -** Refers to the protected characteristic of Race. It refers to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.
3. **Religion or belief -** Religion has the meaning usually given to it but belief includes religious and philosophical beliefs including lack of belief (such as Atheism). Generally, a belief should affect your life choices or the way you live for it to be included in the definition.
4. **Sexua****l orientation -** Whether a person's sexual attraction is towards their own sex, the opposite sex or to both sexes.

### **Other characteristics**

Other protected characteristics identified by the ICB in Leeds include:

* **Homelessness** – anyone without their own home
* **Deprivation** – anyone lacking material benefits considered to be basic necessities in a society
* **Carers** - anyone who cares, unpaid, for a family member or friend who due to illness, disability, a mental health problem or an addiction
* **Access to digital** – anyone lacking the digital access and skills which are essential to enabling people to fully participate in an increasingly digital society
* **Served in the forces** – anyone who has served in the UK armed forces