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

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 with the support of the Leeds People's Voices Partnership. We have worked together (co-produced) with the key partners outlined in Appendix A. 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.

2. 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/

3. 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.

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.

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 people Represents 6% of deaths between Oct – Dec 2022 Demographics 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 people 7 carers/family 1 health professional	May 2022	• **Person-centred care** – all participants reported experiencing person-centred care • **Workforce** – all participants reported experiencing kind and compassionate staff

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
National Library of Medicine	**Patients receiving palliative care and their experiences of encounters with healthcare professionals** [https://pubmed.ncbi.nlm.nih.gov/35235482/)](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)](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

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
				• **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	**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 people Demographics 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.

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
				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. **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

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
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)]	31 carers of people at end-of-life. 15 case studies No 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	**Health needs data update end of life care services for adults in Leeds** [Health-Needs-Assessment-for-EoLC-2019-Final.pdf (leedspalliativecare.org.uk)]	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

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
				• **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%) • **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	**Frailty -** Engagement was to understand what matters to people living with frailty, those at end of life and their carers	134 people, of which 96 were people living with frailty, and 38 were carers.	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

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
	https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/	Demographics available in link		- **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 **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.

Source	Publication	No of participants and demographics	Date	Key themes relating to end-of-life experience
				• **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).

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.

a. **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.

b. **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

c. **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

End of Life Population Outcome Framework

Link to Healthy Leeds Plan Strategic Indicators

Health Outcome Ambitions	**System Activity Metrics**	**Quality Experience Measures**
Increase proportion of people who experience a 'good death'	Increase expenditure on the 3rd Sector Increase proportion of people being cared for in primary and community services Reduce rate of growth in non-elective bed days and A&E attendances	Improve the experience of those using: - Primary care services - Community services - Hospital services Person centred co-ordinated care experience P3C-EQ

	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 EOL with an advanced care plan (particular focus on inequity for this measure) % of people who die 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
2	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 & 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	
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	% people with 3 or more unplanned admissions in the last 90 days of life with an EPACCS % people with 3 or more unplanned admissions in the last 90 days of life without an EPACCS Add into the bereaved carers survey 'how well do you think the team caring for your relative worked together' Burden of Care score (OACC measures)	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
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.	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?	

End of Life population outcomes framework

Link to Healthy Leeds 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.
2. 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	
3. All people approaching the end of life receive high-quality, well-coordinated care at the right place	• % 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.	• Length of time getting from a request for a bed in the hospice to getting into the hospice.

Outcome	Outcome measure	Process measure
at the right time and with the right people.	- 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 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.
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.	- 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.	People report that their relative died in the place they wanted

	Respecting people’s choices, views and decisions	
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 links People 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).

6. **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.

7. **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.

8. **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.

9. **Sexual 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