

Insight Report: Cancer

Understanding the experiences, needs and preferences of adults in primary or secondary health care with an active cancer diagnosis, their carers / families / friends, and staff.

August 2023 V2.4

1. What is the purpose of this report?

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

- Adults with a cancer diagnosis
- Their carers, families and friends
- Staff working with people with a cancer diagnosis.

Specifically, this report:

- Sets out sources of insight that relate 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 on it together 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 cancer. The paper is a review of existing insight and is not an academic research study.

2. What is cancer?

Cancer is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs. Cancer sometimes begins in one part of the body before spreading to other areas. This process is known as metastasis.

1 in 2 people will develop some form of cancer during their lifetime. In the UK, the four most common types of cancer are breast cancer, lung cancer, prostate cancer, and bowel cancer. There are more than 200 different types of cancer, and each is diagnosed and treated in a particular way.

Around 4,100 people are diagnosed with cancer each year in Leeds and 56% of cancers are diagnosed at stage one or stage two (as per National Disease Registration Service data 2019). Leeds is home to a Clinical Trials Unit (CTU), which delivers innovative and practice-changing clinical research that impacts the care of and outcomes for cancer patients in the UK and across the world (www.cancerresearchuk.org/our-research-in-leeds).

It's our ambition that we achieve the best in cancer care for the people of Leeds. We will work with all communities to ensure that everyone affected by cancer has access to the same high-quality care.

3. Outcomes for cancer care in Leeds

The Cancer Population Board brings together partners from across Leeds so that we can tailor better care and support for individuals and their carers, design more joined-up and sustainable health and care services and make better use of public resources for the benefit of people using cancer services.

Our ambition is that:

- More cancers will be prevented.
- People with cancer in Leeds will be diagnosed earlier.
- People will receive safe and effective cancer treatment.
- People with cancer will receive person-centred care.

These are our identified outcomes. By setting these clear goals, that are focused on how services impact the people they serve, the board is better able to track whether we're really doing the right thing for the people using these services. The full framework can be seen in [Appendix B](#).

4. What are the key themes identified by the review?

The insight review highlights a number of key themes:

- **Satisfaction** - Many people tell us about the excellent quality of care they received once referred for treatment.
- **Timely care** - Several people have told us that getting their initial diagnosis was difficult. This was sometimes due to “not being believed” or not being referred for screening because they were believed to be “too young to have bowel cancer”, for example.
- **Information** - People tell us they value regular contact and being kept informed about what’s happening about their treatment and care, and what to expect.
- **Information** - People tell us that receiving a diagnosis can feel overwhelming. They say that it can often be difficult to take in and remember information when they get a diagnosis.
- **Information / health inequality** - People tell us that accessible information is important in raising awareness of cancer. This is particularly important for diverse communities where people may not see their GP because of a lack of understanding about signs and symptoms of different types of cancer.
- **Information / communication / person-centred** - People tell us that information and communication about cancer needs to be given in a way that meets people’s individual needs. For example, translated into different languages or formats.
- **Communication** - People tell us that it is essential that they are kept informed about their diagnosis, waiting times and treatment options at all stages of their treatment.
- **Communication** - People tell us that it is important to continue receiving support after their hospital treatment has ended. This might be a referral to a support group or having someone they can contact if they have a question about their condition.
- **Communication / person-centred** - People tell us the way they were informed about their diagnosis was very important to them. They say it can be distressing to find out about their diagnosis by letter and they would prefer this to be done face-to-face.
- **Health inequality / person-centred** - People from diverse communities tell us that it is important for staff and services to consider a range of multi-cultural beliefs about cancer. For example, in some communities, just the word ‘cancer’ brings fear, and it can be seen as an ‘automatic death sentence’.
- **Person-centred care / resources** - People tell us they value connecting with, and hearing stories from, other people who have had cancer, especially people from their own community.

This insight should be considered alongside city-wide cross-cutting themes, and insight work relating to the other population boards, 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 may include relevant national and international data on people’s experience of cancer.

5. Insight review

We are committed to starting with what we already know about people's experiences, 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 people's experiences of cancer
Leeds Cancer Awareness Service and Public Health, Leeds City Council	Cancer: Removing Barriers and Improving Cancer Outcomes in Leeds (Webinar) Cancer - Removing barriers and Improving Cancer Outcomes in Leeds - YouTube	No participants - Overview of current situation in Leeds (including health inequalities, barriers to screening, improving outcomes, etc.)	2022	<p>In relation to how health inequalities are impacting on the uptake of cancer screening in Leeds, the webinar highlights the following:</p> <ul style="list-style-type: none"> Data shows that uptake of screening for bowel cancer in Leeds (74.1%) is higher than the national target of 60%, even in areas of highest deprivation (IMD 1) where take up is 66.7%. However, for breast and cervical screening, Leeds uptake is lower than the national target of 80% for both (breast 66.8%, cervical 70.3%) and lower still in IMD 1 areas (breast 60.2%, cervical 64.2%)
BMJ Journals	National Cancer Patient Experience Survey Cancer services patient experience in England: quantitative and qualitative analyses of the National Cancer Patient Experience Survey BMJ Supportive & Palliative Care	Analysis of 214,340 patient responses to National Cancer Patient Experience Surveys 2015-2018.	2022	<p>The English National Cancer Patient Experience Survey seeks to understand what proportions of patients give positive and negative feedback about their cancer care, and to identify themes in their responses. Patients were most likely to give the highest positive score of 10 (38.25%), while the overwhelming majority (87.12%) gave a score between 8 and 10.</p> <ul style="list-style-type: none"> Workforce - Analysis of 1000 positive comments found that most respondents (54%) praised staff's interpersonal skills. Workforce / Communication / Timely care - Other frequent themes of positive feedback included treatment standards, staff's communication skills, speed of diagnosis and treatment, and staff members' technical competence.

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
				<ul style="list-style-type: none"> • Communication / Timely care - The most prominent themes in the negative comments were communication skills, treatment standards and waiting times for appointments and test / scan results, and delays and cancellations to appointments and operations. <p>Main themes - Workforce, Communication and Timely care - Standards of treatment and staff communication skills are prominent themes of positive and negative feedback. Staff's interpersonal skills are more likely to be praised than criticised, while negative feedback is more likely to focus on issues around time (ie, delays and long waits). Clarity and honesty in communication about the lengths and causes of waits and delays are likely to increase patient satisfaction.</p>
<p>NHS England</p>	<p>Cancer patient experience survey results for Leeds Teaching Hospitals NHS Trust (LTHT)</p> <p>2021 National Cancer Patient Experience quantitative reports (ncpes.co.uk)</p>	<p>1,383 LTHT patients responded out of a total of 2,377 - a 58% response rate.</p>	<p>2022</p>	<p>Almost 60,000 people responded to this NHS England annual survey, which was conducted between October 2021 and February 2022. Respondents included people aged 16 years and over with a confirmed primary diagnosis of cancer and who had been treated in hospital between April and June 2021. Results are provided for local NHS Trusts. Areas where LTHT scored above the expected range:</p> <ul style="list-style-type: none"> • Communication - Diagnostic test results were explained in a way the patient could completely understand • Communication - Treatment options were explained in a way the patient could completely understand • Information - Beforehand patient completely had enough understandable information about surgery • Information - Beforehand patient completely had enough understandable information about chemotherapy

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
				<ul style="list-style-type: none"> • Information - Beforehand patient completely had enough understandable information about radiotherapy • Information - Patient completely had enough understandable information about progress with chemotherapy <p>Areas where LTHT scored below the expected range:</p> <ul style="list-style-type: none"> • Person-centred - Patient was always able to get help from ward staff when needed • Person-centred - Patient was always able to discuss worries and fears with hospital staff • Clinical treatment - Hospital staff always did everything they could to help the patient control pain • Information - Patient was given enough information about the possibility and signs of cancer coming back or spreading
Cancer Wise Leeds	<p>Barriers to Cervical Screening for 'First Timers' (patients aged 25-29)</p> <p>1. Barriers to Cervical Screening for First Timers Younger Cohort - Nov. 21 Event Presentation.pptx (live.com) (slide presentation)</p>	9 people (6 White British, 3 Pakistani) with an average age of 25 attended focus groups in East Leeds.	2021	<p>Focus groups were held in East Leeds where there was a high non-attendance rate of cervical screening 'first-timers' in postcodes LS8, 9, 14 and 15. Attendees discussed ideas that may encourage more people to attend:</p> <ul style="list-style-type: none"> • Communication - The use of jargon and some of the language in leaflets, etc. can be a barrier • Communication – The use of videos or other ways of communicating may work better for this age group • Timely care – A lack of appointment availability at certain times can be a barrier to attending • Information – raising awareness of what to expect by using real life stories and experiences may help reassure people.

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
Leeds Cancer Programme	Community Cancer Support End of Engagement Summary 021219-CCS-End-of-Eng-summary.pdf leedsccg.nhs.uk	202 people responded, including patients, staff, carers and 68 people from diverse communities	2019	<p>The engagement aimed to find out what people with a cancer diagnosis (and their carers) would find helpful from a community cancer support (CCS) service. Main themes:</p> <ul style="list-style-type: none"> • Choice - 86% of respondents said they would use a CCS service, with most people stating a preference for it to be based at their GP practice, whilst also providing home visits. Opening times were seen as a potential barrier with people citing work or transport issues as maybe hindering their ability to attend. • Health inequality – diverse community members fed back through focus groups and highlighted several potential barriers to attendance at a CSS service, including: <ul style="list-style-type: none"> ○ Information – Cancer, for some communities, invokes fear, e.g. it can be seen as an ‘automatic death sentence’. In some communities even the word itself is taboo and not to be spoken. ○ Information – Many people stated they didn’t know much about the different types, or common signs or symptoms. Sometimes they may have access to leaflets but too often they are in English. ○ Wider determinants (belief) – Some people reported a mistrust in health services, leading to a reliance on for example, prayer or herbalist approaches to treatment. • Information – staff and stakeholders highlighted a lack of awareness and clarity on what support already exists, and how to signpost. They also mentioned the need to provide support other than just for clinical needs, and also psychological and emotional support, not just for patients but for their carers too.

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
Leeds Cancer Programme	Accelerate, Coordinate, Evaluate (ACE) Engagement Report https://webarchive.nationalarchives.gov.uk/ukgwa/2020902102610/https://www.leedsccg.nhs.uk/get-involved/your-views/ace-pathway/	55 respondents	2019	<p>Engagement report providing detail of people's feedback on the Clinical Nurse Specialist (CNS) assessment and route to diagnosis aspect of the ACE pathway:</p> <ul style="list-style-type: none"> • Timely care - 31% (most) of people were referred after seeing their GP 2-3 times. • Communication – 61% of people who responded did not receive an explanation about the referral in enough detail, leading people to think they were being referred for something non-cancer related. The same number also did not receive an explanation as to what ACE was. • Information – the majority of people (65%) did not receive information in a leaflet form explaining ACE. • Timely care – the majority of people felt that the wait time from seeing the GP to the CNS was completely reasonable. • Person-centred – just over half of people reported being told they could bring someone to their CNS appointment for support. • Communication – most people said instructions about the CNS appointment were clear and simple, and that they received a text message reminder with the correct details (a small percentage received the wrong details). • Choice – the majority of people reported having a choice as to where they wanted to attend their appointment. • Satisfaction – nearly all those who responded reported confidence in their CNS appointment and had a positive experience. • Communication – nearly all respondents reported that next steps were clearly explained and they had received contact details of a named CNS if they had any questions.

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
Observatory. leeds.gov.uk	The State of Women's Health in Leeds report – 12. Use of Health Services 12_Use-of-health-services.pdf (leeds.gov.uk)	N/A	2019	<p>Commissioned by Women's Lives Leeds and Leeds City Council, the report provides a comprehensive picture of life, health and wellbeing for women and girls in Leeds. Section 12.2 explores the issues facing women in Leeds with regard to health screening:</p> <ul style="list-style-type: none"> • Health inequality - For some groups within society, the take up of screening is more problematic than for others, with specific attention required to help address their needs. These include: <ul style="list-style-type: none"> ○ Individuals who have hearing problems or are deaf. ○ Individuals with a visual impairment. ○ Individuals who have a physical disability. ○ People from ethnic minority backgrounds who have no or poor understanding of the English language. ○ Travelling communities. ○ Lesbian and bisexual individuals. ○ Transgender individuals.
West Yorkshire & Harrogate Cancer Alliance	Recovery Package Patient Survey Report Final Patient RP Survey Report.pdf (leedsccg.nhs.uk)	86 people completed the survey – 75% women, 20% men, with the majority (37%) having received treatment in Leeds.	2018	<p>The survey asked for patient's experiences and views of the different elements of the cancer Recovery Package. People told us that:</p> <ul style="list-style-type: none"> • Resources - Implementation of the different elements of the Recovery Package were patchy across the region. People who had not received it had many ideas of how it could have helped them. • Information – Patients who did receive it were positive about it and found the information helpful. • Person-centred – Some patients reported how the support just ended at the end of their treatment, and noted how links to peer support and other options to check in about their health would have made a big difference, especially in relation to their mental wellbeing.

Source	Publication	No of participants and demographics	Date	Key themes relating to people's experiences of cancer
Macmillan Cancer Support and NHS Leeds CCG	Leeds Cancer Strategy - engagement event report https://www.leedsccg.nhs.uk/content/uploads/2017/06/Engagement-report-FINAL-2017-08-04.pdf	47 people attended the event	2017	<p>The event brought together members of the public, the voluntary sector and staff to help develop the Leeds strategy. Main themes from people's priorities groupwork were:</p> <ul style="list-style-type: none"> • Information - There needs to be more and better awareness in the community about cancer. • Communication - Jargon should be avoided at all costs. • Information - Education in schools is important if we are to involve young people in the strategy. • Health inequality - The Leeds Cancer Strategy needs to recognise 'hidden' communities in Leeds. • Health inequality - There should be good education for community-specific cancers, information available in alternative formats and advocacy to support vulnerable groups in treatment. • Person-centred - Patients need to be empowered and confident to manage their own care. • Clinical treatment / Joint-working - GPs need to be knowledgeable about cancers and pathways into treatment. • Joint-working - Statutory and voluntary organisations need to work in Partnership, including all stakeholders e.g. pharmacists, and patients. • Person-centred - There needs to be more emotional support for people living with and beyond cancer and their carers. • Timely care - Access to test results quickly is important.

Additional Reading

6. Inequalities Review

We are committed to tackling 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	We have been unable to source any local evidence relating to age.
Disability	<p>The Million Women study (Floud et al. 2017) found women with disabilities were 36% less likely to attend breast screening and 25% less likely to participate in bowel screening than women who were disability free.</p> <p>12 Use-of-health-services.pdf (leeds.gov.uk)</p>
Gender (sex)	<p>In some diverse communities men's and women's needs were different when it came to accessing health related support. In a number of the groups it was suggested that men wouldn't willingly come forward and ask for help and information. However, women were viewed as key players in disseminating important messages to the men in their life. Some groups highlighted that men don't seek medical advice / go to the GP because it is 'shameful' and embarrassing.</p> <p>021219-CCS-End-of-Eng-summary.pdf (leedscclg.nhs.uk)</p>
Gender reassignment	<p>The transgender community have specific issues relating to their screening needs, specifically trans men and their risk of cervical cancer. For instance, the invitation system used for cervical screening is set up automatically to only invite the correct eligible patients, which may exclude male trans people who still have a cervix. In addition, women with a male history, or men with a female history that have developed breast tissue, still need breast screening.</p> <p>12 Use-of-health-services.pdf (leeds.gov.uk)</p>
Marriage and civil partnership	N/A - The Equality Act provides protection in the area of employment only.
Pregnancy and maternity	We have been unable to source any local evidence relating to pregnancy and maternity.
Race	Ethnic minorities have been found to have lower uptake of screening opportunities, leading to later presentations and poorer outcomes. The sex of the practitioner for cervical cancer tests, language barriers, health literacy, lack of awareness of religious requirements can all be significant factors in accessing screening opportunities. Women from the Romany,

Protected Characteristic	Insight
	<p>Gypsy and Traveller community also have access issues with regard to health care in terms of structural factors, such as not being registered with a GP, cultural factors in relation to perceptions of health, language issues and the ability to understand messages.</p> <p>12 Use-of-health-services.pdf (leeds.gov.uk)</p> <p>Language was cited time and again as being a huge barrier to accessing services. In communities that already have to overcome stigma associated with cancer, not being able to understand the information around cancer compounds issues further.</p> <p>021219-CCS-End-of-Eng-summary.pdf (leedsccg.nhs.uk)</p>
Religion or belief	<p>Some groups highlighted that there were perceptions that by having cancer a person or their family could be ostracised by the community; that cancer was a punishment for past sins, or a way of being ‘washed clean’ of past sins. It was mentioned in some groups that the process of even seeking medical treatment showed a lack of faith, meaning people are reluctant to seek help.</p> <p>People discussed varying stigmas associated with cancer; from being able to ‘catch it’ by saying the word, to seeing it as a form of punishment for something, to questioning a person’s faith if they seek help.</p> <p>021219-CCS-End-of-Eng-summary.pdf (leedsccg.nhs.uk)</p>
Sexual orientation	<p>Uptake of cervical screening has been much lower for lesbian women than for heterosexual women in part due to a belief that they are at a lower risk as they are not engaging in heterosexual sex, but also due to a fear of discrimination and other anxieties relating to the procedure. Routine screeners felt more welcome in the health care setting, but for others who did not attend there was a fear of discrimination based on their sexual orientation and gender expression.</p> <p>12 Use-of-health-services.pdf (leeds.gov.uk)</p>
Homelessness	<p>We have been unable to source any local evidence relating to the experience of people who are homeless.</p>
Deprivation	<p>Data shows the uptake of cancer screening is the poorest in Leeds’ areas of highest deprivation (IMD 1).</p> <p>Cancer - Removing barriers and Improving Cancer Outcomes in Leeds - YouTube</p>
Carers	<p>Staff also mentioned the need to provide support other than just for clinical needs, and also psychological and emotional support, not just for patients but for their carers too.</p> <p>021219-CCS-End-of-Eng-summary.pdf (leedsccg.nhs.uk)</p>
Access to digital	<p>We have been unable to source any local evidence relating to access to digital resources.</p>
Served in the forces	<p>We have been unable to source any local evidence relating to the experience of people who have served in the forces.</p>

7. Gaps and considerations

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

Gaps identified in the report:

We will add detail here once this report has been shared for comment and feedback.

Additional gaps and considerations identified by stakeholders

We will add detail here once this report has been shared for comment and feedback.

8. Next steps – What happens next?

The findings of this insight report will be used to improve cancer treatment and care in Leeds as follows:

a. We will add the report to the Leeds Health and Care Partnership website

The insight report will be added to our website page for the Cancer Population Health Board here: [Cancer - Leeds Health and Care Partnership \(healthandcareleeds.org\)](https://healthandcareleeds.org)

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

b. We will hold a workshop with members of the public and key partners

We will meet with interested people and stakeholders at the end of March 2023 to:

- Describe our cancer 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
- Co-produce an approach to involving the public in shaping cancer services in Leeds

c. We will explore how we can best feed back our response to this report

We will work with our partners to feed back 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 cancer care, we are working with the following key stakeholders:

Board members

Name	Organisation
Stephen Bradley (Chair)	GP
Ruth Burnett	Leeds Community Healthcare NHS Trust
Stuart Murdoch (on behalf of Ruth Burnett)	Leeds Community Healthcare NHS Trust
Kevin Peters	NHS England
Beth Barron	Leeds Teaching Hospitals NHS Trust
Leigh Hawkins (Deputy for Beth Barron)	Leeds Teaching Hospitals NHS Trust
Andrew Robinson	GP – Lead for cancer prevention
Fiona Stephenson	West Yorkshire and Harrogate Cancer Alliance
Peter Lodge	Leeds Teaching Hospitals NHS Trust
Karen Henry (on behalf of Peter Lodge)	Leeds Teaching Hospitals NHS Trust
Carl Mackie	Public Health, Leeds City Council
Louise Cresswell (on behalf of Carl Mackie)	Public Health, Leeds City Council
Amanda Procter	Maggie's Yorkshire (Third sector)
Tom Daniels	NHS West Yorkshire Integrated Care Board (Leeds)
Stacey Taylor	NHS West Yorkshire Integrated Care Board (Leeds)
Mitul Patel	General Practice
Ross Lavery	People's voice
Forum Central	Third sector

Third sector and public representatives

Name	Organisations
Heather Nelson	Black Health Initiative + @BMECancerVoice
	Community Cancer Support Service (LCH)
Megan Arundel	Leeds Cancer Awareness
Darren Meade	Leeds Cancer Awareness
	Leeds Cancer Programme
	Leeds Cancer Support (LTHT)
Tracy Holmes	Macmillan Comms and Engagement Lead West Yorkshire and Harrogate Cancer Alliance
	Maggie's Yorkshire
Jill Long	Yorkshire Cancer Community
Stewart Manning	Yorkshire Cancer Community

Lisa Trickett	Yorkshire Cancer Research
Amber Lewis	Yorkshire Cancer Research
Muhammad Sohail	Primary Care Team Coordinator

Networks and partnerships

Contact	Group

Appendix B: Cancer Outcome Framework

Link to Healthy Leeds Plan Strategic Indicators		
Health Outcome Ambitions	System Activity Metrics	Quality Experience Measures
Reduce rate of early death under 75 from cancer Reduce potential years life lost avoidable causes and rates of early deaths Increase the proportion of people who experience a good death	Reduce rate of growth in non-elective bed days and A&E attendances Increase the proportion of people being cared for in Primary and Community services Reduce the rate of growth in non-elective bed days Reduce the rate of growth in A&E attendances	Improve the experience of those using: <ul style="list-style-type: none"> - Primary care services - Community services - Hospital services Person centred co-ordinated care experience P3C-EQ
Outcome	Outcome Measure	Process Measure
1 More cancers will be prevented	% of people diagnosed with all cancers by age % of people in Leeds who are smokers % of people who are overweight, obese, morbidly obese	% of smokers receiving effective smoking cessation % of people engaging with weight management services JSNA data- self reported activity levels
2 People with cancer in Leeds will be diagnosed earlier, when evidence shows this to be beneficial	% of people with cancer who are diagnosed at an early stage (stage one or two) Reducing the level of 'health inequality' in the stage of diagnosis data; linked to postcode, age, gender, ethnicity and other risk factors	% of people accessing cancer screening programmes Cervical screening 3.5/5.5 year coverage (age 25-64yrs) (national target 80%) <ul style="list-style-type: none"> • Bowel: percentage uptake ages 60-74yrs (national standard 60%) • Breast: Percentage 3 year coverage (ages 50-70) (national standard 80%) • Uptake of Lung Health Checks % of patients who have had a cancer/non-cancer diagnosis within 28 days Increase in the uptake of cancer screening in 10% most deprived and 'plus' populations.
3 People will receive the safest and most effective cancer treatments that are available	% of people each year who survive their cancer for five years or more <ul style="list-style-type: none"> • One year survival index (%) for breast, colorectal, and lung cancer combined (all ages) • One year survival from all cancers (all ages) • Five year survival index (%) for breast, colorectal, and lung cancer combined (all ages) • Five year survival from all cancers (all ages) People receive good quality cancer care as evidenced by Leeds decile position on the NCPES feedback	% of patients who have had a cancer/non-cancer diagnosis within 28 days Reduced number of emergency presentations of cancer Reduced number of emergency readmissions following discharge for people with cancer Psychological/psychosocial support offered to people living with cancer: Increased proportion of people feel supported to manage their condition and symptoms Reduced time spent in hospital. Increased cancer care delivered in the community with good access to Primary care
4 People with cancer will receive person centred care	Cancer Quality of Life Survey People receive good quality cancer care as evidenced by Leeds decile position on the NCPES feedback % of people who die in their place of choice PROMS	Completion of advanced care plans

Cancer population outcome framework

Link to Healthy Leeds Plan strategic indicators:

- **Health outcome ambitions**
 - Reduce rate of early death under 75 from cancer
 - Reduce potential years life lost avoidable causes and rates of early deaths
 - Increase the proportion of people who experience a good death
- **System activity metrics**
 - Reduce rate of growth in non-elective bed days and A&E attendances
 - Increase the proportion of people being cared for in Primary and Community services
 - Reduce the rate of growth in non-elective bed days
 - Reduce the rate of growth in 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 living with cancer will receive person centred care	<ul style="list-style-type: none"> • Cancer Quality of Life Survey • People receive good quality cancer care as evidenced by Leeds decile position on the NCPES feedback • % of people who die in their place of choice • PROMS 	<ul style="list-style-type: none"> • Completion of cancer care reviews • End of Treatment summaries
2. More cancers will be prevented	<ul style="list-style-type: none"> • % of people diagnosed with all cancers by age • % of people in Leeds who are smokers • % of people who with BMI over 25 	<ul style="list-style-type: none"> • % of smokers receiving effective smoking cessation • % of people engaging with weight management services • self reported activity levels

Outcome	Outcome measure	Process measure
<p>3. People with cancer in Leeds will be diagnosed earlier, when evidence shows this to be beneficial</p>	<ul style="list-style-type: none"> • % of people with cancer who are diagnosed at an early stage (stage one or two) • Reducing the level of 'health inequality' in the stage of diagnosis data; linked to postcode, age, gender, ethnicity and other risk factors • Reduced number of emergency presentations of cancer - % diagnosed via 2ww referral vs proportion diagnosed via emergency presentation 	<ul style="list-style-type: none"> • % of people accessing cancer screening programmes • Cervical screening 3.5/5.5 year coverage (age 25-64yrs) (national target 80%) • Bowel: percentage uptake ages 60-74yrs (national standard 60%) • Breast: Percentage 3 year coverage (ages 50-70) (national standard 80%) • Uptake of Lung Health Checks • % of patients who have had a cancer/non-cancer diagnosis within 28 days • Increase in the uptake of cancer screening in 10% most deprived and 'plus' populations.
<p>4. People will receive the safest and most effective cancer treatments that are available</p>	<ul style="list-style-type: none"> • % of people each year who survive their cancer for five years or more • One year survival index (%) for breast, colorectal, and lung cancer combined (all ages) • One year survival from all cancers (all ages) • Five year survival index (%) for breast, colorectal, and lung cancer combined (all ages) • Five year survival from all cancers (all ages) 	<ul style="list-style-type: none"> • % of patients who have had a cancer/non-cancer diagnosis within 28 days • Reduced number of emergency readmissions following discharge for people with cancer • Psychological/psychosocial support offered to people living with cancer: • Increased proportion of people feel supported to manage their condition and symptoms • Reduced time spent in hospital. • Increased cancer care delivered in the community with good access to Primary care • Time between first symptomatic presentation at GP and referral to specialist care

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 explanation from professionals about services, conditions and treatment.	People report that they're treatment was explained in a way that they understood
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)	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 adaptations 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