Insight Report: **Long-term Conditions**

Understanding the experiences, needs and preferences of people with long-term conditions, their carers / families / friends, and staff.
August 2023 V3.7

1. What is the purpose of this report?

This paper summarises what we already know about the long-term conditions population in Leeds. This includes the experiences, needs and preferences of:

- People with long-term conditions
- Their carers, families, and friends
- Staff working with people with long-term conditions

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 together (co-produced) with the key partners outlined in Appendix A. The report is intended to support organisations in Leeds to put people's voice 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 care and support for long-term conditions. The report is a review of existing insight and is not an academic research study.

2. What do we mean by long-term conditions?

Long-term conditions (LTCs) are illnesses that cannot be cured. They are health conditions that can impact a person's life and may require ongoing care and support.

Long-term conditions are a major cause of poor quality of life in England. People in poorer areas are more likely to have long-term health conditions, and these conditions tend to be more severe than those experienced by people in less deprived areas. Deprivation also increases the likelihood of having more than one long-term condition at the same time. On average people in the most deprived areas of the population develop multiple long-term conditions ten years earlier than those in the least deprived areas.

People from diverse ethnic groups are more likely than White British people to report life limiting long-term illness and poor health, with those identifying as White Gypsy and Irish Traveller reporting the poorest health.

The Long-Term Conditions Population Board brings together partners from across Leeds to tackle long-term illness. This will help us tailor better care and support for individuals and

their families and carers, design more joined-up and sustainable services and make better use of public resources.

The long-term conditions population includes people aged 18 and over, not at end-of-life or frail, and with at least one diagnosed long-term condition (for example, heart disease, diabetes, arthritis, and asthma).

3. Outcomes for long-term conditions care in Leeds

The ambition of our long-term conditions work in Leeds is that we will improve support for people managing long-term conditions and for their families and carers. The following ambitions outline what we want to achieve as a board:

- I'm as healthy and as well as I can be with my long-term condition(s)
- People with a long-term condition return to and maintain their normal activities and lifestyle in ways that matter to them
- People with a long-term condition take an active role in managing their condition

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.

Each outcome has a number of measures - the 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 review?

The insight review has highlighted a number of key themes so far:

- People tell us how important it is to have **information** about what services are available to them in relation to their health and care, for example, NHS Health Checks.
- Many people who had attended NHS Health Checks tell us it was generally a positive experience – **satisfaction**.
- People with long-term conditions tell us they value regular contact with the service providing their care. They tell us it is important to be kept up to date with their care and what to expect at their appointments – **information / communication**.
- People tell us how important it is to note or flag people's individual communication needs to ensure they are getting the right support and information in the right way for them. For example, patients who are blind or hard-of-hearing may require additional support in busy waiting areas – **health inequality / person-centred care**.
- People tell us how important it is to know who to contact about their care, especially if they use a number of different services – **communication / information**.
- People tell us that **information** and guidance for families and carers to support people with long-term conditions coming home from hospital is important.

- People tell us that language can be important in how they feel about their care. For example, being 'discharged' when they are leaving hospital but continuing to receive care at home can make people feel they are being "abandoned" – **communication / person-centred care**.
- People tell us that expectations around self-management need to consider people with low health literacy, a lack of digital skills / access, and people who have different communication needs – **health inequality**.
- People tell us how important it is for staff to be culturally aware of the differing needs of diverse communities. For example, for some there is a 'cultural pressure' to care for loved ones at home rather than in a hospital or rehab setting – **health inequality**.

We will add further themes here as we collect them.

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 data on people's experiences of care for long-term conditions.

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	Participants	Date	Key themes relating to long-term conditions
Leeds City Council Public Health + University of Leeds	**Weight Stigma in Leeds: The consequences of weight stigma and implications for policy and practice.** 2022_Weight-Stigma-in-Leeds.pdf	Survey responses from 169 tier 2 and tier 3 weight management service participants in Leeds	2022	Findings underline the importance of **person-centred care** and **workforce**: • the survey has emphasised the prominence of weight related bias and discrimination. • individuals experience weight related bias and discrimination in early stages of life • the portrayal of weight stigma in the form of teasing, unfair treatment and verbal abuse can have a long-lasting impact causing preventable mental hardships such as anxiety and depression. • family members, teachers and healthcare professionals are responsible for most weight related bias and discrimination • individuals do not trust help from others as they believe that these figures believe their battle with weight and size is solely their fault. • healthcare professionals should acknowledge the emotional trauma caused by weight stigma throughout an individual's lifetime and empathise and support solutions when prescribing beneficial weight management pathways.
Leeds City Council	**NHS Health Check Review Insight Summary** (Report available on request)	Online survey was completed by 91 members of the public. 66% of respondents were female, 29% male. 19% of respondents were disabled. Minority ethnic	2022	A survey was conducted through the Citizen's Panel to assess people's awareness and expectations of NHS Health Checks. Main findings: • **Communication** - 70% of respondents had not seen the health check promoted anywhere. • **Satisfaction** – respondents who had attended a health check reported that it was an efficient process, staff were friendly, underlying issues were discovered and dealt with, it was generally a positive experience, informative, could talk to a professional about their health and positive feedback on the location of the health check.

		groups are underrepresented (9% in survey vs. 18% of Leeds population).		• **Timely care / information** – barriers to accessing the health check included inaccessible appointment times (especially for full-time workers), location, the expectation of a negative experience, the number of appointments, lack of awareness, feeling nervous about test results and not knowing what to expect, highlighting a need for clear communication about what health checks involve.
Leeds Office of the WYICB	**Atrial Fibrillation Voices** (Report available on request)	Survey responses from 44 atrial fibrillation (AF) patients	2022	Main themes relating to people's experience of care. Some respondents reported a good standard of care and positive experiences: 81% stated they knew who to contact if they had a concern or a query re medication. Several people reported common issues or concerns, including: • **Information** – a lack of information on their condition and / or treatment • **Communication** – a lack of contact from GPs and / or clinicians – 74% said No, when asked if their GP spoke to them regularly about their AF or their medication. Some people mentioned a lack of follow-up care. • **Covid-19 –** some people mentioned Covid-19 as having affected their treatment or waiting times. • **Satisfaction** – When asked to score their experience of care 43% said ok, 18% said good and 20% said very good.
Leeds Voices – Voluntary Action Leeds / NHS Leeds CCG	**Stroke Rehabilitation Engagement Report** Leeds-Voices-Stroke-Rehabilitation-Report_Video-Removed.pdf (doinggoodleeds.org.uk)	116 people from South Asian, Black Caribbean, Black African and Eastern European communities	2021	Main findings: • **Health Inequality** - The FAST campaign was unknown to many focus group participants. The imagery could be more powerful and language more accessible. • **Information** - Information about the service should be widely available in different languages • **Information** - The use of a video to give a visual representation of what the hospital (rehabilitation unit) was like alleviates the 'unknown'. Many participants suggested this should be shown to all patients and families before admission. • **Satisfaction** - People were happy with the hospital environment compared to LGI both inside and outside and valued the green surroundings.

				• **Person-centred care** - The provision of items to make people feel at home if they didn't have family support is really important. • **Workforce** - The importance of staff who can help the patient emotionally was emphasised, and the reassurance that staff will behave in a way that respects cultural diversity. • **Involvement in care** - Carers and family members wanted to receive more information and education around how to look after the patient once they had been discharged from the rehab unit. It was also important for them to be offered mental health support and regular updates on the state and progress of the patient; something that had not been accessible in the LGI. Key Points: **Health inequality** - There is a general lack of awareness amongst culturally diverse communities that stroke rehab services are available **Choice** - Those from South Asian and Black communities usually choose to have rehab in their home as it is a familiar environment with family members of multiple generations who can look after them **Wider determinants** - There is a 'cultural pressure' for families to be seen to care for their loved ones at home.
Brainbox Research / NHS Leeds CCG	**Review of insight research that informs changes to outpatient services** Microsoft Word - v5 Final report on current insight into outpatient	Review of 28 pieces of locally commissioned research considering: • More care provided in community locations and less in main hospitals • Greater use of	2020	• **Choice -** There is support for all the three proposed changes and, providing patients retain choice about how and where they access their care, there is no need for further patient consultation. • **Joint working -** Satellite clinics that involve collaborative working between GPs and consultants can increase GP confidence to manage care for longer in primary care. Patients have greater confidence in the care delivered by their GP. • **Person-centred care -** Patients have concerns that video consultations will mean they lose a personal connection with their clinician, and so a blended model is likely to work best, in which patients receive both face-to-face and video consultations.

	services.docx (leedsccg.nhs.uk)	technology (including a Health app) • Patient-driven and patient-managed care, enabled by more empowered patients		• **Workforce -** Data sharing and providing sufficient IT and administrative support for satellite clinics and video consultations, present challenges. • **Health Inequality -** There is mixed evidence of age being a barrier. With help to set up their technology, and with the option of a face-to-face appointment, older people can find a move to technology-based clinics acceptable. • **Workforce -** The changes require staff who are motivated to break down traditional barriers and to develop new processes. It is helpful if these new processes have a clinical lead and clear support from leaders and commissioners.
NHS Leeds CCG	**Developing Cardiac and Pulmonary Rehabilitation Programmes in Leeds** 2020_06_Cardio_Pulmonary_Rehab_Programmes_FINAL_Report-1.pdf (rackcdn.com)	106 respondents including: 61 patients 16 staff 21 members of the public	2020	• **Satisfaction -** Positive experiences – people who attended either the cardiac or the pulmonary rehabilitation programmes were positive about the service they had received and highlighted the benefit of the programmes. Attendees were very positive about the staff supporting the programmes. • **Satisfaction -** Benefits of attending - people were keen to tell us about the positive benefits of attending, including boosting their confidence, socialising with peers and learning more about staying fit and healthy in spite of a cardiac or pulmonary event or disease. • **Person-centred care –** people told us that accessing the rehabilitation programmes could be difficult due to location, venue, time of session and concerns regarding accessing and paying for public transportation. • **Person-centred care -** Other commitments – people told us that caring, work and other commitments meant that they might not be able to get involved in a rehabilitation programme, even if they wanted to.
				• **Information –** people told us that having information about the rehabilitation programmes and what they can offer ahead of time would be useful and may encourage better uptake. Translation of these leaflets into required languages would be of benefit. • **Timely care -** Waiting times – people told us that the waiting lists to join a rehabilitation programme were too long and some people decided not to attend as their life had to carry on.

				• **Health inequality -** Technology – people told us that if they were to access digital support elsewhere, it would be primarily from websites in order to seek out information. Though uptake of technology was low. • **Workforce –** staff members told us that there was a lack of dedicated staff to help support the rehabilitation programmes. • **Person-centred care -** Ability levels – people told us that the programmes would benefit from sessions that are tailored to patient's different ability levels.
Qa Research / NHS Leeds CCG	**Patient Choice Deliberative Event: Report** Client name (rackcdn.com)	70 Leeds residents	2020	Cross cutting themes across three listed scenarios: • **Person-centred care -** The longer the term of the episode of care, the greater the extent to which consistency and continuity of care were valued. • **Person-centred care -** The greater the severity of the condition or the higher the level of clinical expertise required to manage the condition, the more patients were prepared to trade off the convenience of local provision, or appointments out of hours for having access to the best possible service. • **Choice -** There was a very high level of trust in the quality of NHS services, and consequently a general lack of priority assigned to having a choice of provider. • **Choice -** There is a significant cohort of patients who do not feel comfortable exercising choice, feeling that they are ill equipped to make such choices, and that they would prefer for the choice to be made for them by the referring GP or other qualified clinician. • **Environment** - Other issues raised concern about facilities, (particularly in relation to barriers to access), and potential lack of privacy, and security of data where it needs to be shared across providers.
				A clear finding is that if there is to be greater uptake / enthusiasm for patients to use community services, patients need to be reassured that such services are able to demonstrate that the standard of quality is entirely appropriate to deliver the high standard of service that they have been commissioned to provide. The key point for emphasis is that services are commissioned to be delivered by community healthcare services, because that is the best and most appropriate place for them to be delivered.

Leeds City Council	**The State of Women's Health in Leeds (Chpt 9)** 9_Long_term_conditions_frailty_and_end_of_life.pdf (leeds.gov.uk)	N/A	2019	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. There are 151,435 females living in Leeds who have one or more long-term condition, which is 36.2% of the female population. **Health inequality** - There is a strong relationship between long term conditions and deprivation, with the Yorkshire Health Study showing that 46% of those living in deprived areas experienced multiple morbidity as compared to 27% of those in non-deprived areas (Li et al. 2016).
Asthma UK	**On the edge: How inequality affects people with asthma** auk-health-inequalities-final.pdf (asthma.org.uk)	N/A The paper collates the evidence on health inequalities and asthma	2018	Key findings – all of which relate to **health inequality**: • Asthma is more prevalent within more deprived communities, and those living in more deprived areas of England are more likely to go to hospital for their asthma. • Those from disadvantaged socio-economic groups are more likely to be exposed to the causes and triggers of asthma, such as smoking and air pollution. • There is significant variation in access to basic care for asthma across geography, age group and ethnicity. • Asthma requires self-management, which is harder to embed in groups with lower health literacy. • To reduce health inequality in asthma and enable people to better adhere to self-managed treatment, there must be preventative action on causes and triggers, improved access to basic care, and digital innovation to improve engagement in healthcare and health literacy.

Additional Reading

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 care and treatment for long-term conditions 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	There is some evidence that age may be a barrier in relation to some older patients finding the introduction of more technology-based interventions more challenging - With help to set up their technology, and with the option of a face-to-face appointment, older people may find a move to technology-based clinics acceptable. Microsoft Word - v5 Final report on current insight into outpatient services.docx (leedsccg.nhs.uk)
Disability	Ability levels – people told us that the programmes would benefit from sessions that are tailored to patient's different ability levels. 2020_06_Cardio_Pulmonary_Rehab_Programmes_FINAL_Report-1.pdf (rackcdn.com)
Gender (sex)	We have been unable to source any local evidence relating to people of different genders and their experiences of care for long-term conditions.
Gender reassignment	We have been unable to source any local evidence relating to people experiencing gender reassignment, and their experiences of care for long-term conditions.
Marriage and civil partnership	At present, we have been unable to source any local evidence relating to marriage and civil partnership.
Pregnancy and maternity	We have been unable to source any local evidence relating to pregnancy and maternity in regard to people's experiences of long-term conditions.
Race	There was a general lack of awareness amongst culturally diverse communities that Stroke Rehab services are available, and the FAST campaign was unknown to many focus group participants. The imagery could be more powerful and language more accessible. Information about the service should be widely available in different languages. Leeds-Voices-Stroke-Rehabilitation-Report_Video-Removed.pdf (doinggoodleeds.org.uk)

	Translation of these leaflets into required languages would be of benefit. 2020_06_Cardio_Pulmonary_Rehab_Programmes_FINAL_Report-1.pdf (rackcdn.com)
Religion or belief	We have been unable to source any local evidence relating to religion or belief in regard to people's experiences of care for long-term conditions.
Sexual orientation	We have been unable to source any local evidence relating to sexual orientation in regard to people's experiences of care for long-term conditions.
Homelessness	We have been unable to source any local evidence relating to homelessness in regard to people's experiences of care for long-term conditions.
Deprivation	There is a strong relationship between long term conditions and deprivation, with the Yorkshire Health Study showing that 46% of those living in deprived areas experienced multiple morbidity as compared to 27% of those in non-deprived areas. 9_Long_term_conditions_frailty_and_end_of_life.pdf (leeds.gov.uk)
Carers	Other commitments, including caring for others, can prevent people from enrolling on rehabilitation programmes. 2020_06_Cardio_Pulmonary_Rehab_Programmes_FINAL_Report-1.pdf (rackcdn.com) Carers and family members wanted to receive more information and education around how to look after the patient once they had been discharged from the rehab unit. It was also important for them to be offered mental health support and regular updates on the state and progress of the patient; something that had not been accessible in the LGI. Leeds-Voices-Stroke-Rehabilitation-Report_Video-Removed.pdf (doinggoodleeds.org.uk)
Access to digital	Technology – people told us that if they were to access digital support elsewhere, it would be primarily from websites in order to seek out information. Though uptake of technology was low. 2020_06_Cardio_Pulmonary_Rehab_Programmes_FINAL_Report-1.pdf (rackcdn.com)
Served in the forces	We have been unable to source any local evidence relating to those who served in the forces and their experiences of care for long-term conditions.
Covid-19	Some people mentioned Covid-19 as having affected their treatment or waiting times. Atrial Fibrillation Voices Survey – Leeds ICB

7. Gaps and considerations

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

Gaps identified in the report:

- There is a lack of insight available relating to the experiences of staff delivering services and care for people with long-term conditions.

Once we have received and reviewed more insight on this topic, we will be able to identify further gaps in our understanding.

Additional gaps and considerations identified by stakeholders

- As above - To be added

8. Next steps – What happens next?

This insight report will contribute to work to improve people's experiences of treatment and care for long-term conditions in Leeds. We will:

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. The link to the page for the Long-term Conditions Population Board is Long-Term Conditions - Leeds Health and Care Partnership (healthandcareleeds.org)

b. Hold a workshop with key partners

We will meet with people with long-term conditions, their families and carers, and key stakeholders to:

- Describe our work on long-term conditions in Leeds
- Outline and agree the findings of this report
- Sense-check the draft outcomes
- Identify and agree additional gaps
- Plan involvement work to understand the gaps in our knowledge
- Coproduce an approach to involving, and representing, the public in shaping long-term conditions care and 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 and improve local services and support for people with long-term conditions, their families and carers.

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 long-term conditions, we are working with the following key stakeholders:

Board members

Name	Organisation
David Wardman (Chair)	NHS West Yorkshire Integrated Care Board (Leeds)
Mandy Young	Leeds Community Healthcare NHS Trust
Ankush Vidyarthi	Leeds and York Partnership NHS Foundation Trust
John Adams	Leeds Teaching Hospitals NHS Trust
Shona McFarlane	Public Health, Leeds City Council
Carl Mackie	Public Health, Leeds City Council
Lindsay McFarlane	West Yorkshire Integrated Care Board (Leeds)
Marcus Julier	Leeds GP Confederation
Iain Anderson	Age UK
Ruth Buchan	Community Pharmacy
Hannah Davies	Healthwatch Leeds
Stephen Bush	Leeds Community Healthcare NHS Trust
Sam Prince	Leeds Community Healthcare NHS Trust
Stephanie Lawrence	Leeds Teaching Hospitals NHS Trust
Ian McDermott	Leeds Teaching Hospitals NHS Trust

Third sector and public representatives

Name	Organisations
Lydia Robson	Adults and Health Directorate, Leeds City Council
LCH Community Cardiac Service	lchcardiac.service@nhs.net
LCH Community Respiratory Team	lchdiabetes.service@nhs.net
LCH Diabetes Service	lchdiabetes.service@nhs.net
Active Leeds Health Conditions Support Services	health.programmes@leeds.gov.uk
Linking Leeds Social Prescribing Service	linking.leeds@nhs.net
Leeds Stroke Recovery Service	Niamh.Andrews@stroke.org.uk

Wharfedale Hospital in Otley, the Cardiac Club	Dave - wghcardiacclub@gmail.com
West Leeds Breathe Easy Group	derek.hawkhead@ntlworld.com / pudseygeoff@gmail.com
East Leeds Breathe Easy Group	pat.goodacre@talktalk.net
Leeds United Foundation – Fit Fans (Weight Management)	Rachel.Newman@leedsunited.com
Leeds Older People's Forum	Jo Volpe (CEO) - jo@opforum.org.uk
Cardiomyopathy – Leeds + York support group	Community Peer Support Manager christie.jones@cardiomyopathy.org
Pulsations Leeds (Heart Support Group)	Pulsations Leeds - Call Richard
Leeds Congenital Heart Unit Facebook page	Leeds Congenital Heart Unit | Facebook
Leeds pulmonary fibrosis support group	jane.slough@nhs.net
Leeds Diabetes UK Support	diabetesleeds@hotmail.co.uk
ABA Enhance (Leeds)	aishwaryav@abaleeds.org.uk

Networks and partnerships

Contact	Group

Appendix B: Long-term conditions Draft Outcome Framework

Long Term Conditions Population Outcome Framework				
Link to Healthy Leeds Plan Strategic Indicators				
Health Outcome Ambitions Improve healthy life expectancy Reduce potential years life lost avoidable causes and rates of early death Reduce rate of early death under 75 from Respiratory disease, alcoholic liver disease, CVD Reduce premature mortality for those with LD and SMI Reduce suicide rate		**System Activity Metrics** Reduce the proportion of adults: - With a BMI over 30 - Who smoke 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 Reduce number of face to face appointments in hospital	**Quality Experience Measures** Improve the experience of those using: - Primary care services - Community services - Hospital services Person centred co-ordinated care experience P3C-EQ	
	Outcome	**Outcome Measure – Operational**	**Outcome measure - Aspirational**	**Process Measure**
1	I'm as healthy and as well as I can be with my Long Term Condition(s)	Improved ratio in higher deprivation deciles of planned care to unplanned care Increased average age of LTC diagnosis in poorest IMD deciles (EQ5D) Length of time increasing in LTC segment Secondary prevention -	Proportion of patients with forward care plans, inc. crisis escalation plans P3CEQ Listening to the person and understanding what their aspirations are – personalised care plans (CCSP)	A&E attendance rates for this population Number of New Medicines Service (NMS) delivered. NMS supports patients when they are first prescribed new medicine (not all meds included but a large number) Same day primary care attendances Same day mental health requests Pain scores? Is this collected and how?
2	People with a LTC return to and maintain their normal activities and lifestyle in ways that matter to them	Rate of patients leaving segment for Healthy segment Individual service metrics of successful intervention outcomes – e.g. diabetes weight loss Days of work missed	Burden of disease measures? P3CEQ	Rate of delays for appointments/waiting times for services - stratified by deprivation and ethnicity as poorer and minority patients wait longer on average - work with Planned Care Board around this? Specific metrics – inhaler technique etc Rate of referral to rehabilitation services 'Well managed' metrics [will need to be split between conditions] Referral rates/completion rates
3	People with a LTC take an active role in managing their condition	Other programme attendance – eg smoking cessation, alcohol Disease management goals – rate of setting and achieving Improved rate of patient adherence to medicines	Psychological wellbeing - PROMs measure? Patient recorded outcomes need to strengthen - QOL surveys etc/ measure linked to what people want and need in terms of care; i.e. some won't want to be empowered and want/need to conserve energy to achieve optimal quality of	Inappropriate referrals to A&E - how would we measure this - A&E attendances not resulting in admission? Number of health checks Advice and guidance requests Attendance at education programmes Rate of unplanned admission

Long-term Conditions Population Outcomes Framework

Link to Healthy Leeds Plan strategic indicators:

- **Health outcome ambitions**
  - Improve healthy life expectancy
  - Reduce potential years lost to avoidable causes and rates of early death
  - Reduce rate of early death under 75 from respiratory disease, alcoholic liver disease, CVD
  - Reduce premature mortality for those with LD and SMI
  - Reduce suicide rate
- **System activity metrics**
  - Reduce the proportion of adults:
    - With a BMI over 30
    - Who smoke
  - 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
  - Reduce number of face-to-face appointments in hospital
- **Quality experiences measures**
  - Improve the experience of those using:
    - Primary care services
    - Community services
    - Hospital services
  - Person-centred co-ordinated care experience P3C-EQ

Outcome	Outcome measure - Operational	Outcome measure - Aspirational	Process measure
1. I'm as healthy and well as I can be with my long-term condition.	• Improved ratio in higher deprivation deciles of planned care to unplanned care	• Proportion of patients with forward care plans inc. crisis escalation plans (P3CEQ) • Listening to the person and understanding what their	A&E attendance rates for this population Number of New Medicines Service (NMS) delivered. NMS supports patients when they are first

Outcome	Outcome measure - Operational	Outcome measure - Aspirational	Process measure
	• Increased average age of LTC diagnosis in poorest IMD deciles (EQ5D) • Length of time increasing in LTC segment • Secondary prevention	aspirations are – personalised care plans (CCSP)	prescribed new medicine (not all meds included but a large number). Same day primary care attendances Same day mental health requests Pain scores?
2. People with a LTC return to and maintain their normal activities and lifestyle in ways that matter to them	• Rate of patients leaving segment for Healthy segment • Individual service metrics of successful intervention outcomes e.g. diabetes weight loss • Days of work missed	• Burden of disease measures? (P3CEQ)	• Rate of delays for appointments / waiting times for services – stratified by deprivation and ethnicity as poorer and minority patients wait longer on average – work with Planned Care on this? • Specific metrics – inhaler technique, etc. • Rate of referral to rehabilitation services • 'Well-managed' metrics (will need to be split between conditions) • Referral rates / completion rates
3. People with a LTC take an active role in managing their condition	• Other programme attendance e.g. smoking cessation, alcohol • Disease management goals – rate of setting and achieving • Improved rate of patient adherence to medicines	• Psychological wellbeing – PROMs measure? • Patient recorded outcomes need to strengthen – QOL surveys, etc. / measure linked to what people want and need in terms of care i.e. some won't want to be empowered and want / need to conserve energy to achieve optimal quality of life	• Inappropriate referrals to A&E – measure? • Number of health checks • Advice and guidance requests • Attendance at education programmes • Rate of unplanned admission

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 their 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 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