Insight Report: Planned Care

Understanding the experiences, needs and preferences of people accessing planned care services, their carers / family / friends, and staff
August 2023 V2.2

1. What is the purpose of this report?

This paper summarises what we know about people's experiences of planned care services in Leeds. This includes the experiences, needs and preferences of:

- People using planned care services
- Their carers, family, and friends
- Staff working in planned care services

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. 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 using planned care services. The paper is a review of existing insight and is not an academic research study.

2. What do we mean by **planned care**?

Planned care is also known as 'elective' care. It is treatment that people decide to have to help manage a health problem, rather than emergency treatment for an urgent medical condition, or following a serious accident for example. People are usually referred for planned care by their GP or another healthcare professional.

Planned care refers to services for pre-arranged health appointments either in a community setting or in the hospital. Planned care can cover many different medical procedures including joint replacements and cataract surgery as well as the management of conditions in community settings. It also includes diagnostics, which are tests that are carried out to detect diseases such as cancer and other serious medical conditions. Most planned care procedures are done as day cases, where patients leave hospital on the day of the procedure. Sometimes patients have to stay in hospital overnight or a bit longer if necessary.

Planned care refers to the different stages of someone's medical journey which covers being referred, receiving treatment, having tests, and having an onward management plan (where appropriate).

3. Outcomes for planned care in Leeds

The Planned Care Delivery 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 services and make better use of public resources.

The ambition of our planned care work in Leeds is that we will improve the lives of people using planned care services, their carers, family, and friends. The outcomes listed below show how we will measure progress in relation to this ambition:

- Planned care services are accessible to all regardless of who they are.
- People are supported whilst waiting for planned care services.
- People agree appropriate and realistic shared health goals, and actively participate in their achievement.

These are our identified outcomes. By setting these clear goals, that are focused on how services impact the people they serve, the board is able to better track whether we're really doing the right thing for the people using these services.

Improving our planned care services is one of the West Yorkshire Health and Care Partnership's main priorities and we have an Improving Planned Care Programme that focuses just on this work. You can find out more about how the West Yorkshire Health and Care Partnership is working towards improving planned care in the region online here: https://www.wypartnership.co.uk/our-priorities/improving-planned-care. 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:

- People tell us they value being treated as an individual when they access planned care. They want to be treated with respect and dignity and where possible they want to have their care tailored to their needs and preferences (**person-centred**).
- People tell us they want to be involved in decisions about their care and want to be fully informed about their treatment through their care journey (**involvement in care / information**)
- People tell us that they sometimes feel ‘forgotten’ when they are on a long waiting list (**communications / information**)
- People tell us they want **information** about their treatment that allows them to plan for their appointment and stay well after their treatment.
- People tell us they want information about their treatment to be available in alternative formats such as videos and websites (**information / health inequalities**).
- People tell us that staff behaviours, attitudes and competence have a big impact on their experience and outcomes when using planned care services (**workforce**).
- People tell us that it is important that they have a **choice** as to how they access appointments and care (face to face or digital, for example).
- People from communities who experience the greatest health inequalities often tell us that services struggle to meet their specific needs. For example, people have reported that their needs around race, age, and sexuality, risk being overshadowed by a person’s learning disability or autism because staff lacked knowledge and understanding about equalities (**health inequality / person centred**).
- People using planned care services tell us they want to see health and care services working better together so that they feel well-informed, and their care is well coordinated (**joint working**)
- There are some potential **gaps** in our current insight including:
    - Patient’s experience of local providers who deliver planned care services (including LTHT and LCH).
    - People from diverse ethnic communities.
    - People from areas of deprivation.
    - Members of the LGBTQIA+ communities.
    - Carers.
    - Working age adults

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 planned care services.

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.

As planned care services are delivered across all populations in Leeds, the insight for this review has pulled information from across insight gathered for the other boards as well as insight specific to planned care services.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
Healthwatch Leeds	**How does it feel for me? – Emma and Adam's story** https://healthwatchleeds.co.uk/wp-content/uploads/2023/01/Emma-and-Adam-summary-report-FINAL-v2.pdf	2, one autistic female with identified mental health and physical health conditions and their carer	2023	Healthwatch Leeds' 'how does it feel for me?' work, follows the journeys of people receiving health and care services in Leeds and regularly captures their experiences through videos. At the end of a year's involvement, this is then written into a summary report. • **Communication –** consistent, clear information is important prior to appointments and throughout the care pathway. • **Communication** – the first contact, including the 'hello, my name is' principles, is important; people need to know who is calling, and why. • **Information / communication** – co-produced patient / service user notes mean everyone is clear on actions and progress, and people feel involved and listened to. • **Person-centred / workforce / involvement in care** - when someone is struggling and finding it difficult to articulate their needs, it is important that staff are considerate when acting on someone's care and listening to what is being said (or not), including any communications by a carer. • **Satisfaction / resources / health inequality –** knowledgeable, trained and kind staff are important to people's experience of care.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Joint working –** services across boundaries (e.g. Harrogate and Leeds) can have different access criteria, limited awareness of other services and sometimes no access to patient records. This can make an already complicated system even harder to navigate. • **Joint working / satisfaction –** more joined up and coordinated services make a very positive difference to people's care. • **Choice / satisfaction / person-centred –** offering a choice of appointments can help people to engage better with their care.

Care Opinion + NHS.UK	**Stories from Care Opinion with search team "Autism – Leeds", "Learning disability – Leeds" and ADHD – Leeds"**
	
	https://www.careopinion.org.uk/
		12 stories relating to 'autism' tag
		
		2 stories relating to 'ADHD' tag
		
		0 stories relating to 'learning disability' tag
			2016 - 2023	**"Autism – Leeds" – 12 stories across all Leeds services (GPs, LYPFT, LADS)**
				• **Satisfaction** - Fairly even split of positive and negative experiences.
				• **Workforce** – staff were mentioned in almost every story, notably in some having the biggest bearing on someone's experience, both positively and negatively. People noted:
				  ○ Negative – a lack of understanding / patience for people's individual needs and what their condition might mean in how they present.
				  ○ Negative – the feeling of not being listened to / believed by staff had an impact
				  ○ Positive – a positive, kind and caring attitude, focused on the person can make even very difficult situations more manageable.
				• **Clinical treatment** –some people reported that when in crisis, they were left without any help or understanding of where they would get help.
				• **Communication** – people told us they sometimes need extra time to process information or alternative ways to communicate, including written options due to some autistic people's 'mutism'.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				- **Communication** – some people mentioned note making, and inconsistencies between what was discussed and what was written in letters / notes.
				“ADHD – Leeds” – 2 stories across all Leeds services (GPs, LYPFT) **Satisfaction** – both stories reflected negative experiences, however, both noted positive experiences with staff. - **Resources –** difficulty in using the e-consult system was noted - it was hard to explain their difficulties using the categories in the system. - **Joint working / communication –** a poorly joined up experience with miscommunication and inconsistencies in reporting and planning was noted, leading to a feeling of being bounced between services.
West Yorkshire Health and Care Partnership	**Seeking patients’ views on delays to planned care caused by the pandemic** https://www.wypartnership.co.uk/application/files/3316/5596/5634/Seeking_patients_views_on_delays_to_planned_care_June_22.pdf	9 members of the planned care citizens panel were involved	2022	Members of the planned care citizens panel shared their experiences and ideas. - **Choice** – many patients would be happy to travel further afield (across West Yorkshire) if it meant that they could be treated soon. - **Communication** – health and care services must understand how delays to planned care are affecting people mentally and physically and the ‘not knowing, or ‘feeling forgotten’ only makes the situation worse. Regular contact and updates can help alleviate this. - **Information** – it was suggested that a letter or leaflet could be sent in the post, explaining what concerning signs of deterioration to look out for, including information about what to do and who to contact if they feel their condition is getting worse.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Communication** – it was suggested that occasional contact by phone to provide an opportunity for patients to speak to someone to explore any needs. • **Resource** – more GP appointments should be made available so that patients waiting for planned care can be assessed.
				• **Choice** - if a patient declines the option to be treated at an elective site, they should not be disadvantaged and removed from the list, after a specified number of refusals, for example. • **Transport and travel** - if people are given the option to travel further away from their home to be able to access treatment sooner, that service should include transport to and from the site because not everyone has a car or can use public transport. • **Information / joint working** – make sure people who are waiting know about support services such as social prescribing services, and mental health support services. • **Wider determinants** - for some people, the wait for treatment is causing massive money worries. People are worried that they're going to lose their jobs. If you can signpost effectively to people who might be able to help with things like benefits and claims, it could improve their wait. • **Information / resources** - primary care networks need to know about all the different community health and care services available in their local areas so they can recommend these services to patients if appropriate.
				• **Communication –** people want to be spoken with honestly and openly, be honest about lack of communication (if applicable) and waiting times. • **Communication –** patients should be told what to expect and when to expect it throughout the care pathway.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Communication** – if a longer wait is anticipated, regular communications with patients to let them know they haven't been forgotten with how to get in touch if they have questions / concerns. • **Information –** when people leave hospital, they need to have all relevant information, including: ○ Possible side-effects of medication / symptoms to look out for ○ Who to contact in the first instance if there are concerns ○ Advice on how to aid recovery • **Joint working** – people want to see better conversations between hospital staff and GPs to avoid incorrect or unnecessary referrals. • **Joint working / resource** – ensure that patient records are available at appointments with hospital consultants. • **Resource / transport and travel –** look at whether hospital-based things might be doable in the community to free up hospital capacity, this might make it easier for some people to access without a reliance on transportation / issues around parking etc. • **Involvement in service development –** we need to make sure that people with specific lived experience are involved in the work of developing healthcare services so that they really meet the needs of the people that access them.
Leeds Palliative Care Network and Healthwatch Leeds	**Bereaved Carers Survey about End-of-Life Care in Leeds** https://healthwatchleeds.co.uk/wp-	115 people Represents 6% of deaths between Oct – Dec 2022	2022	People's experience of end-of-life care and support for their friend / relative in hospices, hospitals, in their own homes and care homes • **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

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
	content/uploads/2022/09/Leeds-Bereaved-Carers-Survey-Report-2021-2-Final.pdf	Demographics available in report		
NHS ICB in Leeds	**Shakespeare Medical Practice Insight Report** https://www.healthandcareleeds.org/have-your-say/shape-the-future/insight-reviews/shakespeare-medical-practice/	Insight from a range of sources.	2022	An insight review into the primary care (GP) needs and preferences of people living in Lincoln Green and the surrounding area. • **Information** - Various groups report difficulties understanding basic health information and therefore struggle to make appropriate health decisions. • **Information / health inequality (health literacy)** - Some groups in particular struggle most with health literacy. These groups include but are not limited to; Non-English Speakers, people with learning disabilities, people from deprived backgrounds. • **Health inequality (digital)** - There is evidence that a rapid increase in the use of digital health could exacerbate existing health inequalities experienced by people who have lower levels of digital health literacy. • **Information** - Feedback has told us that understanding the health care system can be confusing for people and we are seeing people default to the GP practice in spite of other services being available. • **Choice / information** - People have also told us that they are unaware of health care options and the services that are available (such as Urgent Treatment Centres and mental health services). • **Choice / timely care** - There is evidence that people who cannot be seen in a quick enough time will visit alternative health care services, including the Emergency Department. • **Person-centred** - Feedback tells us that people are having a mixed experience when receiving person-centred and accessible care.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Health inequality (translation)** - Feedback suggests that for individuals for whom English isn't their first language, accessing translation or an interpreter is important but not always accessible. It also means they require longer appointment times to accommodate translation time when this is available. • **Person-centred / health inequality / workforce** - People fed back that interactions with staff can be mixed in terms of attitude and attentiveness to cultural / diverse needs. People reported negative / unhelpful attitudes and unfriendly tone, particularly from reception staff. We know that this can impact on people's relationship with the service and can lead people to disengage from services. • **Health inequality** - Certain communities require extra support in accessing health care and may not understand what is required or how the system works (for example, refugees and asylum seekers). • **Resources** - People fed back they want to see more support for communities in the area, with projects that might support wellbeing in different ways.
NHS England	**Supporting autistic people in primary care** https://soundcloud.com/nhsengland/supporting-autistic-people-in-primary-care?in=nhsengland/sets/primary-care-network	N/A	2022	An NHS England podcast that explores autism and reasonable adjustments to support autistic people in primary care: • **Person-centred / resources** – autistic people can get very anxious about attending health care appointments, needing help from a carer to attend. • **Communication / information** – providing clear and helpful information before and throughout an appointment can ease the anxiety of autistic people. For some, the fear of what might happen, and sensory overload might be enough to dissuade them from attending an appointment.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience

				- **Communication –** autistic people often struggle with a condition called ‘alexithymia’ meaning they can struggle to identify and describe emotions or what they are feeling, which can make communicating a problem difficult in appointments.
				- **Person centred / environment –** autistic people identified that a number of ‘reasonable adjustments’ can make attending GP appointments easier, including:
				  ○ Longer / double appointments
				  ○ A quiet space separate from main waiting room
				  ○ Appointments at the start or end of the day (quieter waiting room)
				  ○ Opportunities to alter the environment (turn off / down lights)
				- **Choice** – people want the option of attending appointments face to face or digitally.

NHS West Yorkshire Integrated Care Board (ICB) in Leeds	**Involving You 2021-2022** https://www.healthandcareleeds.org/publications/involving-you-2021-2022/	Total engaged with 37,222 Males: 9,612 Females: 14,241 Under 25: 2,859 Transgender: 85 Aged over 65: 3,438 LGBTQIA+ 470 Non-binary / other 81	2022	The Leeds Health and Care Partnership annual report on involvement activities in Leeds for the year 2021 / 2022. Key themes identified: - **Satisfaction** - People told us that generally their experience of using healthcare services in Leeds is positive. - **Joint working / communication / information** - People told us they want their care to be more joined up and to be communicated with regularly, in a compassionate and accessible way at all stages in their health and care journey. - **Communication / Timely care** - People told us they want faster access to joined-up mental health services and better information about what mental health support is available.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
		Carers: 2,147 Homeless people:37 Diverse ethnic backgrounds 2,798 People with disabilities 1,933		• **Choice** - People have told us how much they value their GP practice. However, patients have increasingly reported more difficulty in accessing their doctor. • **Information / communication** - People told us they want better quality and accessible information about health services, including while they wait for treatment. • **Choice** - People told us that they want the option to be able to access services both digitally and in-person. • **Health inequality / wider determinants / person-centred** - People reminded us that Leeds is a diverse city and we must support people in all our different communities to access our services.
Care Quality Commission (CQC)	**Experiences of being in hospital for people with learning disability and autistic people** https://www.cqc.org.uk/publication/experiences-being-hospital-people-learning-disability-and-autistic-people/report	N/A	2022	The CQC carried out a review focusing on what people experience when they need physical health care and treatment in hospital. • **Person centred / health inequality –** people said they found it difficult to access care because reasonable adjustments weren't always made. • **Communication / person centred / resources -** there is no 'one-size-fits-all' solution for communication. Providers need to make sure that staff have the tools and skills to enable them to communicate effectively to meet people's individual needs. • **Involvement in care -** people are not being fully involved in their care and treatment. In many cases, this is because there is not enough listening, communication, and involvement. Providers need to make sure that staff have enough time and skills to listen to people and their families so they understand and can meet people's individual needs.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				- **Health inequality -** equality characteristics, such as age, race and sexual orientation, risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about inequalities. - **Workforce / resources -** specialist practitioners and teams cannot hold sole responsibility for improving people's experiences of care. Providers must make sure that all staff have up-to-date training and the right skills to care for people with a learning disability and autistic people.
IPSOS	**Measuring Person Centred Outcomes -** Nicola Moss, Vicky Mullis (Report available on request)	Random sample of 9,358 addresses completed by 1,608 adults aged 18+ years People living with frailty – excluding end of life population	2022	Responses from people who are experiencing frailty showed higher levels of poor physical and mental health that people with long-term conditions and the healthy population. People living with frailty were also more likely to be dissatisfied with social activities and relationships. People living with frailty are high users of health and care service, often accessing three or more different services. - **Person-centred** - Compared with other populations, those living with frailty were less likely to receive person centred coordinated care - **Involvement in care** - Compared with other populations they were more likely to feel that they were only sometimes able to discuss what was important to them in managing their own health and wellbeing - **Person-centred** - The living with frailty population were also more likely to report that they were only sometimes considered as a whole person in relation to their care. - **Communication** - Focusing on communication, between health professionals and individuals as well as between services, those living with frailty were more likely to report instances where they were required to repeat information

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				- **Communication / information** - Communication, information and support was particularly important for this population as a significant proportion reported feeling less confident about managing their own health and wellbeing - **Information** - the data suggests that the living with frailty population currently does not receive enough support or information to help them manage their own health and wellbeing.
National Institute for Health Research (NIHR) – Yorkshire and Humberside Applied Research Collaboration	**What are the top 10 priorities of older people living with frailty?** https://www.arc-yh.nihr.ac.uk/news-events-and-media/blogs/priorities-of-older-people-living-with-frailty	The survey was sent to 141 participants with moderate or severe frailty. The response was very good - 87 surveys (62% of those sent) were completed and returned.	2022	Top priorities for people with moderate to severe frailty: - **Involvement in care -** Making decisions with family or friends, carers and health professionals about any care or support I might need in the future - so everyone, including me, is involved in decisions about my future care. - **Joint working -** Having more joined up care - so that all my health and care needs are considered together, and I can get the right help at the right time from the right person. - **Workforce -** Health and care professionals having a better understanding of the experiences and needs of older people - for example, GPs, hospital doctors, nurses having a better understanding of my health conditions(s) and symptoms - this might include physical or mental health conditions. - **Information -** Having more information about my health condition(s) and symptoms - this might include physical or mental health conditions. - **Information -** Having more information about what I can do to manage my health or symptoms - for example, having the right diet, staying active.
Leeds City Council Public Health +	**Weight Stigma in Leeds: The consequences of weight stigma and**	Survey responses from 169 tier 2 and tier 3 weight	2022	Findings underline the importance of **person-centred care** and **workforce**: - 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.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
University of Leeds	**implications for policy and practice.** https://observatory.leeds.gov.uk/wp-content/uploads/2022/02/2022_Weight-Stigma-in-Leeds.pdf	management service participants in Leeds		- 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.
NHS England	**Cancer patient experience survey results for Leeds Teaching Hospitals NHS Trust (LTHT)** https://www.ncpes.co.uk/wp-content/uploads/2022/06/CPES-2021-Trust-Leeds-Teaching-Hospitals-NHS-Trust-RR8.pdf	1,383 LTHT patients responded out of a total of 2,377 - a 58% response rate. People aged 16 years and over with a confirmed primary diagnosis of cancer and treated in hospital between April - June 2021.	2022	Almost 60,000 people responded to this NHS England annual survey, which was conducted between October 2021 and February 2022. Results are provided for local NHS Trusts. Areas where LTHT scored above the expected range: - **Communication** - Diagnostic test results were explained in a way patients could completely understand - **Communication** - Treatment options were explained in a way patients could completely understand - **Information** – Beforehand, patients said they had enough understandable information about surgery - **Information** – Beforehand, patients said they had had enough understandable information about chemotherapy - **Information** – Beforehand, patients said they had enough understandable information about radiotherapy - **Information** - Patients said they had enough understandable information about progress with chemotherapy

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				Areas where LTHT scored below the expected range: • **Person-centred** - Patients were not always able to get help from ward staff when needed. • **Person-centred** - Patient were not always able to discuss worries and fears with hospital staff. • **Clinical treatment** - Hospital staff did not always do everything they could to help the patient control pain • **Information** – Patients were not always given enough information about the possibility and signs of cancer coming back or spreading.
Care Quality Commission (CQC)	**NHS Community Mental Health Survey Benchmark Report 2022 – Leeds and York Partnership NHS Foundation Trust** https://nhssurveys.org/wp-content/surveys/05-community-mental-health/05-benchmarks-reports/2022/RGD_Leeds%20and%20York%20Partnership%20NHS%20Foundation%20Trust.pdf	282 people took part (1250 were invited) Full demographics included in report – majority of respondents (86%) were White.	2022	The survey collected feedback on community mental health services. The survey was available to people aged 18 and over who were receiving care or treatment for a mental health condition and were in contact with LYPFT between 1 Sept 2021 and 30 Nov 2021. **Where service user experience is best compared to other mental health trusts (scored out of 10, 10 being the highest satisfaction):** • **Person-centred –** people told us that members of staff understand how their mental health affects other areas of their life (7.6 out of 10). • **Communication / person-centred** – most people felt that they were given enough time to discuss their needs and treatment with a member of staff (7.8 out of 10). • **Wider determinants / person-centred** – people told us that decisions about their care took into account other areas of their life (7.6 out of 10).

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				Where service user experience could improve compared to other mental health trusts (scored out of 10, 10 being the highest satisfaction): • **Choice / involvement in care** – people told us that they wanted more choice in deciding what NHS talking therapies to use (6.7 out of 10). • **Involvement in service development** – people told us that they didn't feel involved in service development (1.6 out of 10). • **Communication** – some people told us that they sometimes found it difficult to understand what NHS talking therapies were available to them (8 out of 10). • **Involvement in care / wider determinants** – people told us that they would like their family / friends / carer to be more involved in their care (6.6 out of 10).
British Red Cross and Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance	**Barriers and opportunities: improving access to mental health support for refugees and people seeking asylum** https://migrantinfohub.org.uk/issue-based-resources-1/barriers-and-opportunities-improving-access-to-mental-health-support-for-refugees-and-people-seeking-asylum	32 people were involved, including: • 16 people with lived experience of migration 16 people who work in services that support people with experience of migration	2022	This report looks at how we can improve mental health support for people with experience of migration. The report findings include: • **Person centred** – people told us that a person-centred approach was important to them. • **Person centred** – people told us that a trauma-informed approach was important to them. • **Communication / person centred / health inequalities / information** – people told us that they would like longer appointment times to help them overcome language barriers, including written and translated communications. • **Communication / person-centred / health inequality / information –** some people told us that they had a preference for face-to-face appointments.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				- **Communication / person-centred / health inequality -** people told us that they wanted consistent access to professional interpreters. - **Communication / joint working** - Services need to coordinate better and communicate with each other. - **Involvement in service development** – people told us that there needed to be better and more opportunities to feedback and these should be accessible and easy to understand.
Alzheimer's Society	**Left to Cope Alone – The unmet needs after a dementia diagnosis** https://www.alzheimers.org.uk/sites/default/files/2022-07/left-to-cope-alone-after-diagnosis-report.pdf	Over 2,000 people affected by dementia contributed to this report. Services, members of staff were also involved. Demographics not available	2022	This national report sought the views of people affected by dementia (patients and carers / family and staff) to understand what support people needed after diagnosis. - **Resources –** people affected by dementia reported not receiving adequate mental health support, if at all. - **Timely care –** 57% of people who had been signposted to mental health services report having to wait up to 12 months or more to receive the support they needed. - **Workforce** – psychologists reported that, given local pressure to diagnose dementia, much of their clinical time and input was too focused on diagnosis, leaving little room for post-diagnosis support, such as counselling.
London South Bank University (LSBU) Institute of	**Waiting for treatment and self-management: Summary of the desk research**	N/A	2021	This desk research summary provides background information around waiting for treatment and self-management: - **Communication** – people are fearful that they will be forgotten, particularly when communication is lacking whilst people wait. - **Health inequality** – as people wait over the 'norm', anxiety as well as illness and disability may increase.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
Health and Social Care	https://www.lsbu.ac.uk/__data/assets/pdf_file/0016/332413/Key_Messages_Waiting_for_treatment_and_self_management.pdf			• **Wider determinants / health inequality -** people's ability to cope with waiting is correlated to their resilience. Resilience is correlated to life circumstances and factors such as poverty, insecure finances, caring responsibilities, or employment. Once on the waiting list, people from more deprived communities are more likely to cancel or postpone their care (NHS Confed, 2021). Training people to cope is not the answer. • **Resource -** supporting people who are waiting requires a care process and therefore resources. This may include providing; supportive physical care (e.g., physiotherapy or pain management), emotional care, information (resources to inform self-management; information about the waiting process) and access to services to support financial and employment security.
				The impact of waiting • **Health inequality / wider determinants -** Waiting places three types of burden on people: ○ Burden on quality of life: physical health, mental health and wellbeing. ○ Burden on their financial stability (impact on their job). ○ Burden on their social context, including caring responsibilities and relationships. • **Clinical treatment –** waiting has implications for recovery (e.g., surgical) and on other services. • **Person centred -** During waiting people can get worse, get better, or stay the same - and therefore the need for intervention can change whilst waiting.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				What people need People who are waiting need the following to help them manage their condition and anxiety: 1. Acknowledgement of concerns. 2. Periodic communication about wait-list position and anticipated procedure date. 3. Tailored prioritisation according to need and circumstances. 4. Advice on identification and management of 'red flags.' 5. Contact details for concerns and confidence that they will be responded to. 6. Information to help them manage their condition as they wait. 7. Access to and information about relevant supportive services (including non- medical services). 8. Peer support.
NHS Leeds Clinical Commissioning Group (CCG)	**Understanding Current System Demand on GP Practices and Emergency Departments (EDs) in Leeds** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102636/https://www.leedsccg.nhs.uk/get-involved/your-views/system-demand/	152 people in total: • 45 responses from primary care staff in GP practices, • 104 responses from patients attending ED in recent months, • 3 members of ED staff.	2021	GP practice staff **(workforce)** told us that: • **Health inequality -** There had been an increase in general health anxiety – most evident amongst young people • **Timely care** - Some patients were presenting late e.g., with cancer or complex care needs • **Resources / clinical treatment -** People appear to lack confidence to self-care (treat their own minor health needs) People using emergency departments (ED) told us: • **Clinical treatment / information / timely care** - 80% of people had contacted another NHS service before attending the ED. 38 had contacted NHS111 and 33 had tried to access their GP. Some people had contacted several different services prior to attending the ED.

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				• **Information / joint working** - They felt frustrated because they had tried to contact the right service as they understood the pressure that services are under and realised that ED was probably not the right place to go to.
NHS England	**Autism – My Story (a series of video case studies)** **Joe -** https://www.youtube.com/watch?v=MDkPO8VGMv8 **Rosalind -** https://www.youtube.com/watch?v=pUw2tq3F3Lc **Adrian -** https://www.youtube.com/watch?v=IO02QTF5eOw&t=117s **Amy -** https://www.youtube.com/watch?v=tpUY3ti9dJI&t=9s	Four autistic people involved	2021	NHS England case studies of autistic people, highlighting the difficulties they experience as well as what services / society can do to support autistic people. • **Communication / person-centred** - it can be hard to process information at a fast pace. • **Communication** – it is important to explain rules and why they exist, how things work and what to expect for autistic people. • **Transport and travel / resources** – some people cannot travel independently and need support from a carer. • **Person-centred** – autistic people need to work with people who will take the time to listen to and understand their needs. • **Health inequality / joint working** – other diagnoses (such as mental health conditions) should not overshadow someone’s autistic needs.
Leeds Voices – Voluntary	**Stroke Rehabilitation Engagement Report**	116 people from South Asian,	2021	Main findings: • **Information** - Information about the service should be widely available in different languages

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Action Leeds / NHS Leeds CCG	https://doinggoodleeds.org.uk/wp-content/uploads/2021/10/Leeds-Voices-Stroke-Rehabilitation-Report_Video-Removed.pdf	Black Caribbean, Black African and Eastern European communities		• **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. • **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 patent 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.

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NHS Leeds CCG	**Leeds Community Neurological Rehabilitation Service Review** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102633/https://www.leedsccg.nhs.uk/get-involved/your-views/comm-neurology-2021/	66 people who took part with a range of conditions including: MS, lupus, stroke, Parkinson's and brain injury Demographics not available.	2021	The aim of the engagement was to understand people's experiences of using the community neurological rehabilitation service in Leeds in order to commission a service that meets the needs of local people: • **Choice** – people told us they prefer to be seen in local community hospitals rather than big general city hospitals. • **Health inequality / communication / information** – people from diverse communities need more assurance as to what to expect when arriving at a hospital setting. • **Choice** – people need to be given a range of options to access the service. • **Involvement in care** – carers, friends and families want to be more involved. • **Communication** – people want better communication whilst waiting to access the service.
Healthwatch Leeds	**Community Mental Health Transformation – What people told us was important to them when getting mental health support** https://healthwatchleeds.co.uk/reports-recommendations/2022/community-mental-health-transformation/	421 responses from people with lived experience, carers and others Demographics available in the report	2021	Healthwatch Leeds were asked to carry out engagement work in three pilot areas of the community mental health transformation work. They wanted to know what really mattered to people when accessing mental health care and support, and what would encourage them to get involved in the work. • **Person-centred** – people told us that mental health services should be flexible enough to meet the needs of different communities and individuals. • **Information** – people told us that mental health services should have simple and clear information about the service, who can and cannot get support and how it can be accessed. • **Joint working** – services need to work together in a way that ensures people can get support for all their needs.

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				• **Involvement in care** – people told us that carers are an important part of services, and they should be fully involved and supported. • **Person-centred / workforce** – people told us there should be key-workers in place to ensure consistency for people. • **Timely care / information** – people told us they wanted to see clear and honest communication about waiting times and said that there should be regular check-ins for people on waiting lists. • **Choice** – people told us that they want to have the choice of how their support is given, including face-to-face support, group sessions and remote appointments.
West Yorkshire and Harrogate Health and Care Partnership	**Making health services better with people who are neurodiverse** https://www.wypartnership.co.uk/application/files/1516/4736/4357/Making_health_services_better_with_people_who_are_neurodiverse_October_2021.pdf	Worked with a number of neurodivergent children and young people and adults as well as their family and carers	2021	The aim of this work was to explore and understand how to support the development of kinder, more compassionate, and effective health and care services with people who are neurodivergent. • **Communication –** neurodivergent people reported having anxiety about being 'ill enough' to access services (legitimacy anxiety). People said that when they are reassured, they could receive and relay information effectively about their condition. • **Person-centred / workforce –** kindness from clinicians is effective in helping someone who is neurodivergent and anxious when accessing health and care services. This relates to communication, actions, and behaviours. • **Resources –** people said they wanted to be known and flagged on records as neurodivergent so that all staff (for example, reception team and doctors) know that additional support maybe needed.

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				• **Choice –** face to face appointments were preferred to telephone appointments. • **Communication / information –** additional information that explains the appointment experience and how to make the most of appointments (including pre-appointment preparation) are useful. These can be done via videos or other visual aids. • **Workforce –** people spoke of anxiety with reception staff; that they were unsure that staff would be welcoming and friendly, and not feeling confident that any additional needs would be picked up and then catered to. • **Wider determinants / COVID-19 –** people noted the impact the COVID-19 pandemic has had on people's understanding of the hidden disabilities' lanyard, noting that some people only take it to mean exemption from mask wearing.
				• **Environment / information –** waiting areas can generate a lot of anxiety for neurodivergent people. ○ Clear information and knowledge about what to expect can help with this. ○ Have clear updates on waiting times and instructions on when to check to ensure you haven't been forgotten and other things (e.g. ask for the key if you need the toilet). ○ Many people liked the electronic check-in screens. ○ Suggestion for use of electronic call pads (like in restaurants). ○ Access to distractions (including details on using Wi-Fi, access to fidget toys / books etc.). ○ Where possible, facilitate a quiet room / more private waiting area.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Timely care –** a suggestion was that neurodivergent people could be given priority in a waiting room to assist with anxiety and help the person be at their best to engage in their care. • **Person-centred / communication / workforce** – people said that they often need 'processing time' to think about a question or conversation and answer, clinicians need to ensure they are not rushing neurodivergent people. Staff may need additional training / awareness for the best ways to communicate with neurodivergent people.
Healthwatch Leeds and Forum central	**Leeds Health and Care Tackling Health Inequalities Toolkit: Qualitative Data Pack** https://docs.google.com/presentation/d/1456gDM0qCjNEpTVVzULi8cwqawvtG32x/edit#slide=id.p6	Details of demographics are not available	2021	This data pack brings together written information and analysis to provide the health and care system with a simple, unified view of health inequalities in Leeds. The document outlines ten key actions to address health inequalities in Leeds based on feedback from local people and communities. • **Information / choice / timely care / health inequality** – People told us that they see their General practice as their central point of information, their key access point to healthcare, the co-ordinator of their care, as a trusted partner in their health and care, of the central part of someone's health and care journey. Actual or perceived difficulties in accessing GP care has a significant impact on health inequalities and general health and wellbeing. • **Person-centred** – people told us that front-of-house services, such as the receptionists, have a significant impact on their experience of using services. • **Information / Health inequality (general)** – People told us that to stay well they need to be communicated with in a suitable way. This includes accessing translation and digital services. People also told us they have difficulties in accessing documents in plain English, jargon free.

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				- **Joint working** – people told us that they have to repeat their stories as services often do not appear talk to each other. - **Wider determinants (poverty) / health inequality (deprivation)** – people told us that to stay healthy and well they need affordable health care. People reported not being able to access the same services or services as quickly as people who could afford private care such as dentistry. - **Health inequality / choice (digital inclusion, deprivation)** – people told us that the move to digital services during Covid had left behind many people and communities who struggled to access care digitally. - **Person-centred / workforce** – To stay healthy and well people told us that they need to be able to access services that support different cultures and needs such as those for people whose first language was not English.
Leeds Palliative Care Network	**Leeds Adult Palliative and End of Life Care Strategy 2021-2026** https://leedspalliativecare.org.uk/wp-content/uploads/2021/06/PEOLC-Strategy-Document-2021-2026-FINAL.pdf)	60 people from 21 health and care organisations	2021	To support the strategy development, the Leeds Palliative Care Network (LPCN) organised and facilitated two events in November 2018 that engaged more than 60 people from 21 health and social care organisations, including statutory and third sectors. **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 planned care 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 / resources -** Have their care provided by people who are well trained to do so and who have access to the necessary resources. • **Communication / 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.
Healthwatch Leeds	**What can health and care providers do to play their part in addressing health inequalities?** https://healthwatchleeds.co.uk/wp-content/uploads/2021/07/Health-inequalities-report_FINAL.pdf	Spoke with Leeds Autism AIM and People in Action	2021	Healthwatch Leeds spoke with a number of third sector organisations on what services can do to improve their offer for the people they work for. **Autism** • **Person centred** – people said that continuity of care is important, and that for autistic people, retaining information can be difficult. It was queried if it could be standard practice for GPs to put advice in writing so that people with autism can take it away. Also queried if priority access to the same GP be given to people with autism • **Health inequality** - not all people with autism are flagged or asked about autism when talking about reasonable adjustments on service's systems – autistic people might not know whether to tell someone about it. • **Person centred** – for autistic people, processing time can be slower. It was queried as to whether their appointment times be extended as a matter of practice, instead of leaving it up to the patient to book extended sessions.

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				- **Workforce** / **resources** – it was noted that there is a variation in receptionists' awareness of autism. - **Environment –** it was fed back that a quiet waiting room would be preferable for autistic people due to sensory sensitivities. - **Workforce / health inequalities / resource –** it was fed back that doctors' understanding of autism varies widely (with some people thinking doctors "don't believe" in autism). Autism awareness training (including information on how some people respond to questions) would be beneficial. - **Choice / information** – people told us that e-Consult can be useful, as people don't need to speak to the receptionist. However, a lot of the questions can be confusing. For example, it might ask what the problem is, then ask what the symptoms are. This can result in people with autism giving up. It would help if there was some guidance for each question.
				Learning disabilities - **Joint working -** people told us that there needs to be more of a joined-up approach between health, individual, families, and support organisations. - **Information** – people fed back that accessible information should be readily available as needed.
Healthwatch Leeds	**Supporting people to be more involved in their health and care** https://healthwatchleeds.co.uk/reports-recommendations/2021/su	79 people – Survey via focus groups with people who experience disproportionately	2021	Healthwatch Leeds worked in partnership with Leeds City Council (Public Health) and partners to find better ways to support individuals and their carers to understand the health information they receive about their care and treatment:

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	pporting-people-to-be-involved-in-their-health-report/	low or inadequate health literacy including people with disabilities.		- **Person centred / communication** - a number of people told us they were not asked about their communication needs or that their preferred communication needs were not met. - **Involvement in care** - some people felt they could not ask questions at their appointment. - **Information** – people fed back on the tools provided as options, there was support for them, the most popular being 'It's OK to ask' (page 17).
Cancer Wise Leeds	**Barriers to Cervical Screening for 'First Timers' (patients aged 25-29)** https://bit.ly/3S11VE9 (slide presentation)	9 people (6 White British, 3 Pakistani) with an average age of 25 attended focus groups in East Leeds.	2021	Focus groups were held in East Leeds where there was a high non-attendance rate of cervical screening 'first-timers' in postcodes LS8, LS9, LS14, and LS15. Attendees discussed ideas that may encourage more people to attend: - **Communication** - The use of jargon and some of the language in leaflets 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.
Healthwatch Leeds	**Bereaved carers survey about end-of-life care in Leeds** https://healthwatchleeds.co.uk/wp-content/uploads/2020/11/Fi	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 - **Satisfaction** - Every respondent expressed satisfaction with the care provided. - **Workforce**

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
	nal-Report-Bereaved-Carers.pdf)			○ 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.
				Hospitals - 104 responses were received from the hospital setting • **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 • **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

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Healthwatch Leeds	**Big Leeds Chat 2021** https://healthwatchleeds.co.uk/wp-content/uploads/2022/06/big-chat-leeds-2022-RevC.pdf	Approx. 548+ Details of demographics are not available – but the chats were held in various wards and with community groups	2021	The chats were held in Local Care Partnerships areas, as well as at Community of Interest groups and young people's organisations. 43 chats took place and a number of themes emerged that relate to 'staying healthy': • **Wider determinants (cost-of living) / health inequality (deprivation)** – People told us that they often struggled to access health activities due to high costs. • **Transport and travel / health inequality (age / deprivation)** – Some people told us that travelling around the city for appointments and activities was difficult due to infrequent, expensive, and unreliable public transport. This was particularly the experience of older people and people from deprived backgrounds. • **Involvement in service development** - Children and young people told us that want more opportunities to share their voice. • **Choice**- Young people told us that want to interact with professionals in person, rather than remotely. • **Timely care** - Children and young people told us they want easier access to mental health support services • **Wider determinants (cost-of living) / health inequality (deprivation)** – People told us that they often struggled to access health activities due to high costs.
Brainbox Research / NHS Leeds CCG	**Review of insight research that informs changes to outpatient services**	Review of 28 pieces of locally commissioned research considering:	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

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	https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102556/https://www.leedsccg.nhs.uk/get-involved/have-your-say/insight-reviews/outpatient-services/	• More care provided in community locations and less in main hospitals • Greater use of technology (including a Health app) • Patient-driven and patient-managed care, enabled by more empowered patients		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. • **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** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102631/https://www.l	106 respondents including: 61 patients 16 staff 21 members of the public	2020	• **Satisfaction -** 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 -** people were keen to tell us about the positive benefits of attending, including boosting their confidence, socialising with peers and

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
	eedsccg.nhs.uk/get-involved/your-views/developing-cardiac-and-pulmonary-rehabilitation/			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 -** 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 alternative languages would be of benefit. • **Timely care -** 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 -** 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 -** 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**	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.

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	https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102630/https://www.leedsccg.nhs.uk/get-involved/your-views/patient-choice/			• **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 can 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.
Friends, Families and Travellers	**Reducing Health Inequalities for People Living with Frailty:** A	International scoping exercise and	2020	The conditions in which we work and live, known as the "social determinants of health", affect our health outcomes and life expectancy. All of the groups included in this project experience exclusion or inequalities across the social determinants of health. Summary of feedback:

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	resource for commissioners, service providers and health, care and support staff https://www.collectivevoice.org.uk/wp-content/uploads/2020/10/HWA-frailty-Report-FINAL.pdf	eight focus groups.		• **Health inequality / resources / wider determinants** - A significant number of people from disadvantaged groups report feeling that a lack of support for non-clinical needs makes it difficult to recover when unwell. • **Health inequality / workforce** - Participants described being turned away from health and care services, feeling stigmatised, or not being taken seriously, leading to low expectations and a lack of trust in services. • **Health inequality / communication / information** - Participants stated that issues around communication, including a lack of accessible information or access to interpreting services, made it difficult to engage with care. • **Health inequality / transport and travel** - Many of the project participants reported practical difficulties in accessing services, including lack of transport and long travel times to services. • **Health inequality / joint working** - Participants report that they may have to re-explain their story to multiple professionals and that their needs can fall through gaps between services due to a lack of clear accountability. • **Health inequalities / person centred** - People experiencing multimorbidity report that limited time with GPs means they have to prioritise between issues and are left unsure of how to manage conditions long-term.
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	31 carers of people at end-of-life. 15 case studies	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

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
	Healthwatch-EOLC-Report-Final-.doc.pdf (leedspalliativecare.org.uk)	No data on demographics		- **Workforce -** pressures on services and staff due to COVID-19
Youthwatch - Healthwatch Leeds	**How to improve young women's mental health Event** https://healthwatchleeds.co.uk/youthwatch-news-events/2020/young-womens-mental-health-event/	120 individuals, made up of 51 young people, 10 parents and 59 Demographics aren't available	2020	Youthwatch volunteers chaired and facilitated table discussions about improving young women's mental health: - **Joint working** - A joined up approach between services was seen as essential and information for families on how to successfully navigate transition. - **Choice** - Children and young people told they would like options of an online offer rather than just face-to-face.
Healthwatch and National Voices	**The doctor will zoom you now: getting the most out of the virtual health and care experience** https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/The_Dr_Will_Zoom_You_Now_-_Insights_Report_0.pdf	Spoke with 49 people who had experienced a remote consultation	2020	The Doctor Will Zoom You Now was a rapid, qualitative research study designed to understand the patient experience of remote and virtual consultations. - **Choice / transport and travel** – remote consultations can offer patients a convenient option for some people as they take less time out of their day and can avoid travelling, but people said that appointments need to fit in with their lives and respect people's time. - **Communication** – people need to be told when they can expect call - **Communication** – people always wanted high quality personal communication. - **Information** – provide the correct guidance and setting expectations was important.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Involvement in service development** – patients and carers want to take part in designing the remote experience. • **Person centred** – it's important to meet the needs of people for whom remote is not possible or appropriate. • **Joint working** – use existing patient groups to provide local support networks to increase confidence and access to using digital, including opportunities to develop training. • **Satisfaction / joint working** - people were frustrated when they had to 'tell their story' multiple times or fill in lengthy forms with information that seemed to be irrelevant or repetitive. The role of the receptionist was key, with people wanting a no intrusive experience (polite and not asking for too much information.
NHS Leeds CCG	**Developing community mental health services for Harrogate and rural districts, Wetherby and its surrounding areas** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102640/https://www.leedsccg.nhs.uk/get-involved/your-views/tewvmh2019/	89 people contributed to the engagement 30 service users 42 carers / family members 11 workers / volunteers 8 health and care staff 26 without direct experience of	2019	This engagement heard from people in the Wetherby area about proposals to develop community mental health services in the area. People were generally supportive of the proposals: • **Joint working / resource -** people told us that due to the boundary differences between Leeds and Harrogate they were not always getting a 'full package of care'. • **Communication –** people told us that services should be clear about what people should be getting and where from (Leeds or Harrogate) as it is confusing for people. • **Communication / workforce –** people also told us that staff need to be trained in what services people can and cannot access in Wetherby given the geographical boundary between services.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
		mental health services		- **Information / resource -** people told us that it isn't clear what services are available to people in Wetherby and there should be better promotion and help from services to access what is available. - **Choice -** people in the Wetherby area told us that they would like to see more services delivered within the Wetherby area. - **Transport and travel -** people told us that the Wetherby area is poorly served by public transportation and accessing services outside of the area can be time consuming, costly, and stressful. - **Workforce / resources -** people told us they would like to see investment in staff so they are supported enough to carry out their job as well as there being enough staff to meet the needs of the service.
Healthtalk	**Learning disability and health stories** https://healthtalk.org/Learning-disability-and-health/overview	Nine people with learning disabilities	2019	Nine people with learning disabilities told their story about accessing health and care services through videos. Locations of care services are not identified. - **Person centred / resources / environment** – one person (Gabrielle) spoke about safety and how a stay in hospital led her to be injured. This was due to the bath / shower not having the same safety features that she has at home (such as non-slip bathmats). - **Travel and transport / timely care / resources** – one person (Kristian) spoke about losing an appointment and having to wait four months for another one due to a lack of transportation to get to the appointment. The person's mother had not been contacted so didn't know about the issue with transportation, as they could have driven. - **Wider determinants / resource / timely care / health inequality** – one person (Nigel) spoke about the four months wait for special mobility shoes

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				that he needed; he was told they would take four weeks. Had to wear slippers everywhere, including going out and on the bus. He reports being subject to bullying and getting weird looks and feeling silly and upset. • **Communication** – one person (Neal) spoke about when he was diagnosed with Type 1 diabetes and how the doctor didn't explain what diabetes was or where it came from to help him understand. • **Health inequality / person centred / resources** – one person (Kevin) spoke about an experience whilst he was staying in hospital and his dad was admitted to the same hospital. Kevin wanted to visit his dad on the ward, but the staff didn't believe that he was his father's son so wouldn't let him see his dad until his brother's wife told them. Kevin said that the staff need training on working with people with learning disabilities.
Leeds Cancer Programme	**Community Cancer Support End of Engagement Summary** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102643/https://www.leedsccg.nhs.uk/get-involved/your-views/community-cancer-support-project/	202 people responded, including patients, staff, carers and 68 people from diverse communities	2019	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: • **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: ○ **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.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				○ **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.
				• **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 in their CNS appointment and had a positive experience in their appointments. • **Communication –** nearly all respondents reported that the next steps were clearly explained and received contact details of a named CNS if they had any questions. • **Choice –** the majority of people were seen at St. James Hospital with the next most popular venue being Seacroft. Nearly all people said that the venues met their needs. • **Resources –** people told us that they felt able to speak more freely at a hospital appointment compared to a GP appointment as GP surgeries are busy.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
Observatory. leeds.gov.uk	**The State of Women's Health in Leeds report – 12. Use of Health Services** https://observatory.leeds.gov.uk/wp-content/uploads/2019/07/12_Use-of-health-services.pdf	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. Section 12.2 explores the issues facing women in Leeds with regard to health screening: • **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: ○ 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.
NHS Leeds CCG	**Non-Obstetric Ultrasound (NOUS) engagement** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102610/https://www.leedsccg.nhs.uk/get-involved/your-views/nous/	76 people contributed to this engagement 75 patients 1 carer / family member	2019	• **Satisfaction** – people's current experiences of NOUS appointments is very positive. • **Environment** – people said that being able to park nearby was very important • **Timely care** – getting appointments quickly was very important for a majority of people.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
Leeds Cancer Programme	**Accelerate, Coordinate, Evaluate (ACE) Patient Feedback** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102610/https://www.leedsccg.nhs.uk/get-involved/your-views/ace-pathway/	55 people contributed to this engagement	2019	**GP feedback** • **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 did not receive information in a leaflet form explaining ACE. **CNS feedback** • **Timely care** – the majority of people felt that the wait times from seeing the GP to the CNS was reasonable. • **Person-centred** – just over half of people reported being told they could bring someone to their CNS appointment for support. • **Communication** – most people felt that the instructions about their CNS appointment was 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 in their CNS appointment and had a positive experience in their appointments. • **Communication –** nearly all respondents reported that the next steps were clearly explained and received contact details of a named CNS if they had any questions.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Choice –** the majority of people were seen at St. James Hospital with the next most popular venue being Seacroft. Nearly all people said that the venues met their needs. • **Resources –** people told us that they felt able to speak more freely at a hospital appointment compared to a GP appointment as GP surgeries are busy.
West Yorkshire & Harrogate Cancer Alliance	**Recovery Package Patient Survey Report** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102644/https://www.leedsccg.nhs.uk/get-involved/your-views/cancer-recovery-package-patient-survey/	86 people completed the survey – 75% women, 20% men, with the majority (37%) having received treatment in Leeds.	2018	The survey asked for patient's experiences and views of the different elements of the cancer Recovery Package. People told us that: • **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.
NHS Leeds CCG	**Support needs of parents / carers of children and young people dealing with mental health issues** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902110406mp_/https://w	277 contributed to this engagement	2018	This engagement sought the views of parents and carers around services and support for children and young people with mental health issues, and aimed to find out what parents and carers in general would like should they have concerns about the mental health of a child / young person within their care: • **Timely care / communication -** parents and carers reported waiting long periods of time to access support for their children / young person, without advice or information during this time.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
	ww.leedsccg.nhs.uk/content/uploads/2018/10/PMH_final_-report.pdf			• **Person-centred** - parents and carers felt that there was a lack of acknowledgment of the effects of certain conditions, such as Autism, on a child's or young person's mental health. • **Involvement in care** - parents and carers reported that they were not always listened to regarding their child's or young person's symptoms and behaviour. • **Communication** – people told us they had difficulty in obtaining a referral with parents and carers feeling the criteria for support was too high. • **Information** - lack of clarity around what services are available and the pathways to accessing that support. • **Information** – people told us about a lack of guidance, support and advice for parents and carers. • **Communication / joint working** – people told us that communication between services could be better.
NHS Leeds CCG	**Frailty** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102538/https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/	134 people, of which 96 were people living with frailty, and 38 were carers. Demographics available in link	2018	Engagement was to understand what matters to people living with frailty, those at end of life and their carers. • **Wider determinants** – people told us it was important to socially connected and maintain hobbies and interests. People living with frailty told us that being physically active and healthy was important to them. Being mobile and being able to go for a walk, play golf and go dancing was very important to people. Both people living with frailty and their carers told us that access to transport was important to them. People said that poor access to transport had a big impact on other areas of their life that mattered to them. • **Person centred** – people told us it was important to them to be treated with dignity and respect and that they had a good relationship with people

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				delivering their care. People living with frailty told us that independence was very important for them. They told us that being able to do everyday activities such as maintaining their personal care, going to the shops, and looking after their home was very important to them.
				• **Information -** Another important aspect of good healthcare for both people living with frailty and their carers was receiving good quality, up-to-date and accurate health information. • **Involvement in care -** Carers told us that it was very important to them to be recognised as caregivers by professionals and to be involved in the planning of care. People living with frailty told us that feeling rushed during consultations made them feel less respected, listened to and less involved in their care. • **Resources -** Carers also talked about the importance of independence. They told us that independence for them meant being in control of their life. People told us that this included having flexibility and freedom and being able to meet the needs of their pets and family while fulfilling their role as a carer. Carers also told us that it was important that they had time to look after their own needs. Access to respite care was seen as important my many of the carers we spoke to.
				Feedback from people with protected characteristics: • **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

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				○ 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	**Changing the way we prescribe** https://webarchive.nationalarchives.gov.uk/ukgwa/20220902102630/https://www.leedsccg.nhs.uk/get-involved/your-views/prescribing-changes-across-leeds/	3,259 people were involved Demographics available in report	2017	This engagement sought the views of people on proposed changes to the way that Leeds prescribed gluten-free products, over-the-counter medicines, and branded medicines. **Gluten-free products** • **Healthy inequality / person-centred –** the majority of people (65%) who fed back were in support of not routinely prescribing gluten-free products providing that people who cannot afford to purchase them should still be able to access them to stay healthy. • **Healthy inequality –** people told us about their concerns of creating a “false economy” by the risk of people needing to access more NHS services in the future due to the implications of not receiving gluten-free items. • **Person-centred / health inequality –** people with co-morbid conditions or other impairments (such as a learning disability) could be greatly impacted. • **Health inequality –** people raised concerns about those with visual impairments or difficulties in reading labels may struggle to identify gluten-free products. • **Information –** people identified a need to provide education on how to maintain a gluten-free diet / lifestyle.

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				• **Health inequality –** people raised concerns about "postcode lotteries" where there were inconsistencies in what services / medicines are provided.
				Over the Counter (OTC) medicines • **Healthy inequality / person centred –** the majority of people (82%) who fed back were in support of not routinely prescribing over the counter medicines providing that people who cannot afford to purchase them should still be able to access them to stay healthy. • **Person-centred** – people's individual circumstances (such as long-term conditions) need to be taken into consideration when deciding whether or not to prescribe OTC medicines. • **Healthy inequality –** people told us about their concerns of creating a "false economy" by the risk of people needing to access more NHS services in the future due to the implications of not receiving gluten-free items. • **Information** – people told us that better education and information is needed to help people make informed choices. • **Person-centred / resource** – people identified an issue with limitations on the number of certain medications a person can buy.
				Branded medicines • **Person-centred / clinical treatment –** the majority of people (84%) were in favour of switching prescribing to non-branded medicines providing the medicines perform in the same way as the branded medicine and that progress was monitored. • **Communication / information –** people told us that there needed to be better communication and information to patients about changes to their

Source	Publication	No of participants and demographics	Date	Key themes relating to planned care experience
				medicines to help them better understand and make informed decisions. This includes information about potential changes in packaging / suppliers regularly. - **Person-centred –** people told us that each prescription needs to be done on an individual basis and people should receive branded medicine if they needed it.

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 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	Some people told us that travelling around the city for appointments and activities was difficult due to infrequent, expensive and unreliable public transport. This was particularly the experience of older people and people from deprived backgrounds. (**Big Leeds Chat, 2022**) People's age risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about equalities. **(Experience of being in hospital for people with learning disability and autistic people, 2022)** Older people who experience depression are at an increased risk of frailty, functional decline, cognitive decline and reduce quality of life. (**Left to Cope Alone – The unmet needs after a dementia diagnosis, 2022**). 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. (**Review of insight research that informs changes to outpatient services, 2020**)
Disability	Autistic people have fed back about liking the option to have online or telephone type appointments as it saves from extra stressors such as travel. (**How does it feel for me? – Emma and Adam's story, 2023**)

Protected Characteristic	Insight
	Autistic people often experience ‘alexithymia’ which can make it difficult to identify and describe emotions, which can make communication in health and care settings difficult (**Supporting autistic people in primary care, 2022**). Depression and anxiety are highly prevalent in people with dementia; 38% of people with mild dementia have depression and or anxiety, as do 41% of people with moderate dementia and 37% of people with severe dementia. The 2021 community mental health survey found that people with dementia were less likely to have seen an NHS mental health service often enough for their needs compared to the general population. (**Left to Cope Alone – The unmet needs after a dementia diagnosis, 2022**). Some people from some communities prefer face-to-face appointments. This is particularly the case for people who are deaf or hard of hearing. Some people report that they are not confident that all primary care professionals understand the diverse needs of local communities, in particular the accessible information standard. The experience of people who are deaf or hard of hearing was worse than that of the general population. People with learning disabilities were amongst the groups who said that available health information was difficult to understand and did not help them make the right choices. People with hearing and sight difficulties want to be offered a choice between digital and face-to-face appointments. Parking close to the practice, reliable and frequent public transport and opening times outside traditional working hours are particularly important to people with disabilities. Longer opening times are important to people with disabilities **(Shakespeare Medical Practice Insight Report, 2022)** Waiting list management should factor in the impact of waiting on other circumstances such as poverty, employment, caring responsibilities, learning disabilities and mental health.

Protected Characteristic	Insight
	(**Waiting for treatment and self-management: Summary of the desk research, 2021**) People with learning disabilities, autism and some mental health conditions have raised concerns about the suitability of remote treatment for their needs. (**The doctor will zoom you now: getting the most out of the virtual health and care experience, 2020**) Ability levels – people told us that the programmes would benefit from sessions that are tailored to patient's different ability levels. (**Developing Cardiac and Pulmonary Rehabilitation Programmes in Leeds, 2020**) 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. (**The State of Women's Health in Leeds report – 12. Use of Health Services, 2019**) People with mental health difficulties noted that accessing mental health services can be difficult depending on their location, particularly if they are not in their local area as transportation can be difficult to navigate, particularly if someone is feeling unwell (physically or mentally). People highlighted the importance of the impact of their mental health on their ability to carry out tasks, such as navigating transportation and attending appointments. (**Developing community mental health services for Harrogate, and rural districts, Wetherby and its surrounding areas, 2019**).
Gender (sex)	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. (**Community Cancer Support End of Engagement Summary, 2019**)
Gender reassignment	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

Protected Characteristic	Insight
	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. (**The State of Women's Health in Leeds report – 12. Use of Health Services, 2019**)
Marriage and civil partnership	We have been unable to source any local evidence relating to marriage and civil partnership in regard to people's experiences of planned care services.
Pregnancy and maternity	We have been unable to source any local evidence relating to pregnancy and maternity in regard to people's experiences of planned care services.
Race	People's race risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about equalities. (**Experience of being in hospital for people with learning disability and autistic people, 2022**) People who need language interpreting services find appointments difficult when this is being done over the phone. Non-English speakers were amongst the groups who said that available health information was difficult to understand and did not help them make the right choices. People whose first language is not English want information in a range of languages and formats (**ICB in Leeds, 2022**) To stay healthy and well people told us that they need to be able to access services that support different cultures and needs such as those for people whose first language was not English. (**Leeds Health and Care Tackling Health Inequalities Toolkit: Qualitative Data Pack, 2021**) 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. (**Stroke Rehabilitation Engagement Report, 2021**) Language was cited time and again as being a huge barrier to accessing services. In communities that already have to overcome stigma

Protected Characteristic	Insight
	associated with cancer, not being able to understand the information around cancer compounds issues further. (**Community Cancer Support End of Engagement Summary, 2019**) 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, 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. (**The State of Women's Health in Leeds report – 12. Use of Health Services, 2019**) Some people whose first language is not English 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. **(Frailty, NHS Leeds CCG, 2018)**
Religion or belief	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. 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. (**Community Cancer Support End of Engagement Summary, 2019**)
Sexual orientation	People's sexual orientation risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about equalities. (**Experience of being in hospital for people with learning disability and autistic people, 2022**)

Protected Characteristic	Insight
	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 (**The State of Women's Health in Leeds report – 12. Use of Health Services, 2019**)
Homelessness	We have been unable to source any local evidence relating to homelessness in regard to people's experiences of planned care services.
Deprivation	Some people told us that travelling around the city for appointments and activities was difficult due to infrequent, expensive and unreliable public transport. This was particularly the experience of older people and people from deprived backgrounds. (**Big Leeds Chat, 2022**) People from deprived backgrounds were amongst the groups who said that available health information was difficult to understand and did not help them make the right choices **(ICB in Leeds, 2022)** People told us that to stay healthy and well they need affordable health care. People reported not being able to access the same services or services as quickly as people who could afford private care such as dentistry. (**Leeds Health and Care Tackling Health Inequalities Toolkit: Qualitative Data Pack, 2021**) Once on the waiting list, people from more deprived communities are more likely to cancel or postpone their care (**Waiting for treatment and self-management: Summary of the desk research, 2021**) Data shows the uptake of cancer screening is the poorest in Leeds' areas of highest deprivation (IMD 1). Cancer - Removing barriers and Improving Cancer Outcomes in Leeds - YouTube
Carers	Carers have sometimes felt unheard or not involved in care or decisions. They have also reported feeling instances of feeling excluded. (**How does it feel for me? – Emma and Adam's story, 2023**)

Protected Characteristic	Insight
	Waiting list management should factor in the impact of waiting on other circumstances such as poverty, employment, caring responsibilities, learning disabilities and mental health. (**Waiting for treatment and self-management: Summary of the desk research, 2021**) 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. (**Stroke Rehabilitation Engagement Report, 2021**) 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. (**Community Cancer Support End of Engagement Summary, 2019**) If services are not easily accessible, or local, then many carers will struggle to regularly visit and be a part of a service users ongoing care should they be admitted to an out of area inpatient service. (**Developing community mental health services for Harrogate and Rural districts, Wetherby and its surrounding areas, 2019**)**.** Carers told us that it was very important to them to be recognised as caregivers by professionals and to be involved in the planning of care. Another important aspect of good healthcare for both people living with frailty and their carers was receiving good quality, up-to-date and accurate health information. Carers also talked about the importance of independence. They told us that independence for them meant being in control of their life. People told us that this included having flexibility and freedom and being able to meet the needs of their pets and family while fulfilling their role as a carer. Carers also told us that it was important that they had time to look after their own needs. Access to respite care was seen as important my many of the carers we spoke to. Both people living with frailty and their carers told us that access to transport was important to them. People said that poor access to

Protected Characteristic	Insight
	transport had a big impact on other areas of their life that mattered to them. Carers also talked about the importance of independence. They told us that independence for them meant being in control of their life. People told us that this included having flexibility and freedom and being able to meet the needs of their pets and family while fulfilling their role as a carer. Carers also told us that it was important that they had time to look after their own needs. Access to respite care was seen as important my many of the carers we spoke to. **(Frailty, NHS Leeds CCG, 2018)**
Access to digital	Some neurodivergent people have found using online services, such as e-consult, difficult to use as the categories felt restrictive to what someone was trying to detail. (**Care Opinion feedback, 2016-2023**) People have fed back about liking the option to have online or telephone type appointments as it saves from extra stressors such as travel. (**How does it feel for me? – Emma and Adam's story, 2023**) There is evidence that rapid increase in the use of digital health could exacerbate existing health inequalities experienced by people who have lower levels of digital health literacy. (**ICB in Leeds, 2022**) People told us that the move to digital services during Covid had left behind many people and communities who struggled to access care digitally. (**Leeds Health and Care Tackling Health Inequalities Toolkit: Qualitative Data Pack, 2021**)
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 planned care services.

7. Gaps and considerations

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

Gaps identified in the report:

- Local patient experience feedback from services that deliver planned care activities, including:
  - Leeds Teaching Hospitals NHS Trust
  - Leeds Community Healthcare NHS Trust
- People from diverse ethnic communities (told us we need to do more to work with them to develop services, in particular people whose first language is not English).
- People from areas of deprivation in the city.
- People from Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual (LGBTQIA) communities.
- We know that people who are considered homeless. We need to ensure we hear from them to make sure services are accessible and approachable.
- We know that there are some people who do not believe services are for them and are disengaged from services (for example not registered with a GP practice).
- Experience from previous engagement work has identified working age people as one of the more difficult groups to involve due to being at work when engagement activities are often held, during the day, on weekdays.
- Experience from previous engagement work has identified that carers can find it difficult to be actively involved due to their caring responsibilities.
- Considerations need to be made around ensuring offline stakeholders (people who do not / can’t access the internet or technology) are engaged and effort is made to reach out locally, to where people are.
- Feedback from people who have served in the armed forces.

Additional gaps and considerations identified by stakeholders

- To be added here once identified.

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

The following outlines our next steps in demonstrating how this insight report will be used to improve planned 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 planned care stakeholders in the spring to
   - Describe our planned care 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 planned care 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 planned care, we are working with the following key stakeholders:

Board members

Name	Organisation
Dean Matheson	Calm and Centred
Cath Roff	Leeds City Council - Adults and Health
Ruth Burnett	Leeds Community Healthcare NHS Trust
Stuart Murdoch	Leeds Community Healthcare NHS Trust
Joanna Bayton-Smith	NHS West Yorkshire ICB in Leeds
Rob Eastham	NHS West Yorkshire ICB in Leeds
Jamie O'Shea	Primary Care
Mark Liddington	Provider Clinician 1
Lucy Jackson	Public Health

Third sector and public representatives

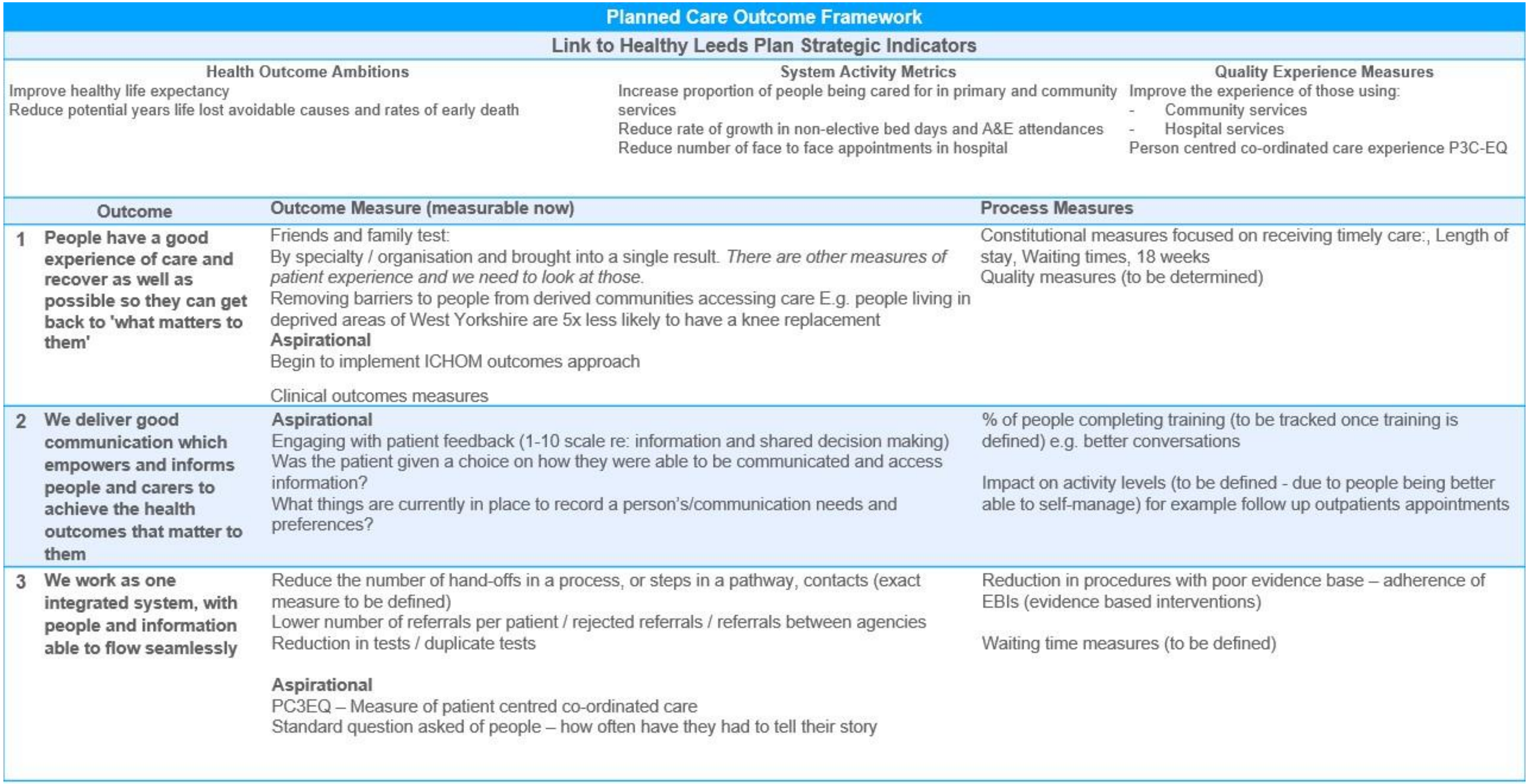
Name	Organisations
	Advonet
Iain Anderson	Age UK Leeds
	BARCA
	Basis Yorkshire
	Barnados
	Big Issue North
	Black Health Initiative
Claire Turner	Carers Leeds
Sharon Brooks	Care & Repair Leeds
	Community Links
	Feel Good Factor
Karl Witty Pip Goff	Forum Central
	GATE
	GIPSIL
	Hamara Centre
	Health for All
Hannah Davies	Healthwatch Leeds
Lesley Newlove	ICB project support
	ICB Volunteer
	Leeds Citizens
Elizabeth Messenger	Leeds City Council (Public Health)
James Woodhead	Leeds Neighbourhood Networks Scheme
	Leeds Involving People
	Leeds Islamic Centre

	Leeds Jewish Welfare Board
Ali Kaye	Leeds Older People’s Forum
Ellie Maciver	Leeds Teaching Hospitals NHS Trust
Lyndsey Charles	Leeds and York Partnership NHS Foundation Trust
Louise Bergin	Leeds and York Partnership NHS Foundation Trust
Rachel Ainscough	Local Care Partnerships Development Team
Kim Adams	Local Care Partnerships Development Team
Nicolas Allen	NHS West Yorkshire ICB in Leeds

Networks and partnerships

Contact	Group
	Alliance of Experts by Experience
	Leeds Asylum Seekers Support Network
Francesca Wood	Leeds Health and Care Partnership Third Sector Reference Group
Hannah Davies	People’s Voices Partnership

Appendix B: **Planned Care** Outcomes Framework



Planned Care Outcome Framework

Link to Healthy Leeds Plan Strategic Indicators

Health Outcome Ambitions	**System Activity Metrics**	**Quality Experience Measures**
Improve healthy life expectancy Reduce potential years life lost avoidable causes and rates of early death	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	Improve the experience of those using: - Community services - Hospital services Person centred co-ordinated care experience P3C-EQ

	Outcome	**Outcome Measure (measurable now)**	**Process Measures**
1	**People have a good experience of care and recover as well as possible so they can get back to 'what matters to them'**	Friends and family test: By specialty / organisation and brought into a single result. *There are other measures of patient experience and we need to look at those.* Removing barriers to people from derived communities accessing care E.g. people living in deprived areas of West Yorkshire are 5x less likely to have a knee replacement **Aspirational** Begin to implement ICHOM outcomes approach Clinical outcomes measures	Constitutional measures focused on receiving timely care:, Length of stay, Waiting times, 18 weeks Quality measures (to be determined)
2	**We deliver good communication which empowers and informs people and carers to achieve the health outcomes that matter to them**	**Aspirational** Engaging with patient feedback (1-10 scale re: information and shared decision making) Was the patient given a choice on how they were able to be communicated and access information? What things are currently in place to record a person's/communication needs and preferences?	% of people completing training (to be tracked once training is defined) e.g. better conversations Impact on activity levels (to be defined - due to people being better able to self-manage) for example follow up outpatients appointments
3	**We work as one integrated system, with people and information able to flow seamlessly**	Reduce the number of hand-offs in a process, or steps in a pathway, contacts (exact measure to be defined) Lower number of referrals per patient / rejected referrals / referrals between agencies Reduction in tests / duplicate tests **Aspirational** PC3EQ – Measure of patient centred co-ordinated care Standard question asked of people – how often have they had to tell their story	Reduction in procedures with poor evidence base – adherence of EBIs (evidence based interventions) Waiting time measures (to be defined)

Planned care outcomes 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
- **System activity metrics**
  - 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 experience.

Outcome	Outcome measure	Process measure
1. People have a good experience of care and recover as well as possible so they can get back to 'what matters to them'	• Friends and family test: • By specialty / organisation and brought into a single result. There are other measures of patient experience and we need to look at those. • Removing barriers to people from derived communities accessing care E.g. people living in deprived areas of West Yorkshire are 5x less likely to have a knee replacement • Aspirational • Begin to implement ICHOM outcomes approach • Clinical outcomes measures	• Constitutional measures focused on receiving timely care:, Length of stay, Waiting times, 18 weeks • Quality measures (to be determined)
2. We deliver good communication which empowers and informs people and carers to achieve the health outcomes that matter to them	• Aspirational • Engaging with patient feedback (1-10 scale re: information and shared decision making) • Was the patient given a choice on how they were able to be communicated and access information? • What things are currently in place to record a person’s/communication needs and preferences?	• % of people completing training (to be tracked once training is defined) e.g. better conversations • Impact on activity levels (to be defined - due to people being better able to self-manage) for example follow up outpatients appointments

Outcome	Outcome measure	Process measure
3. We work as one integrated system, with people and information able to flow seamlessly	• Reduce the number of hand-offs in a process, or steps in a pathway, contacts (exact measure to be defined) • Lower number of referrals per patient / rejected referrals / referrals between agencies • Reduction in tests / duplicate tests Aspirational • PC3EQ – Measure of patient centred co-ordinated care • Standard question asked of people – how often they have had to tell their story	• Reduction in procedures with poor evidence base – adherence of EBIs (evidence based interventions) • Waiting time measures (to be defined)

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 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