

Insight Report: Waiting lists.

Understanding the experiences, needs and preferences of patients waiting for care and treatment.

May 2024 V1.0

1. What is the purpose of this report?

This paper summarises what we know about people waiting for treatment in Leeds. This includes the experiences, needs and preferences of:

- People waiting for treatment.
- Their carers, family, friends, and staff

Specifically, this report:

- Sets out sources of insight that relates to this population
- Summarises the key experience themes for this population

2. What do we mean by waiting lists?

An elective waiting list is a list of people waiting for pre-planned hospital treatment and outpatient appointments. This is what most people mean when they talk about NHS waiting lists.

What we want to know

The Networked Data Lab (NDL) is currently preparing to do some research (analysis) on the topic of people on waiting lists.

In January 2024, the Health Foundation held a workshop with patients and members of the public to understand their experiences and views of waiting lists. We wanted to understand these views to contribute to our topic selection process.

Following the workshop, we began to develop the topic of waiting lists into realistic research questions. We are at an early stage in agreeing the question(s) but have prepared a list below, which may change over time as more information becomes available.

1. Are certain demographic groups more likely to experience a longer waiting time?
2. Reasons for people waiting.
3. Do people have different experiences depending on time on a list, characteristic, and speciality?
4. Are people waiting more likely to experience a mental health condition?
5. What health risks are associated with diabetic patients waiting on a list?
6. What are the costs to the NHS for certain procedures?

3. What are the key themes identified in this insight report?

The insight review highlights several key themes:

- Waiting times are longer and it is harder to access GP services post-COVID-19.
- Staff not listening to issues especially to the elderly.
- Advocacy is so important to help and speak up for patients/carers.
- People are using other services whilst waiting, for example, physiotherapy, hospital admissions, and social prescribing activities.
- Waiting can have a financial impact on people resulting in being unable to work or funding private treatment.
- Impact on physical health with health deteriorating resulting in poorer outcomes.
- Impact on mental health often resulting in anxiety and depression whilst waiting and unable to undertake daily tasks which could result in social isolation: life on hold.
- Poor communication with people not being kept informed about where they are on the waiting list, people feeling “forgotten”.
- People want help to make a plan in order to manage their health better.

4. 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 three years and highlights key themes as identified in Appendix A.

| Source | Publication | Date | Key themes relating to waiting list experience |
|-----------------------------------|---|------------|--|
| National Voices | People’s Experiences of Diagnosis https://s42139.pcdn.co/wp-content/uploads/Peoples-Experiences-of-Diagnosis_Final-v7-1.pdf | June 2024 | <p>Stress and worry while waiting with no support or communication from professionals.</p> <p>People who are given a clear plan of what to expect can manage their health better: “help me make a plan”.</p> |
| Healthwatch West Yorkshire | Hospital Care March 2024 Briefing Paper https://www.healthwatchbradford.co.uk/sites/healthwatchbradford.co.uk/files/%27Focus%20on%27%20Hospital%20care-%20Briefing%20paper.%20ICB%20March%2024.pdf | March 2024 | <p>Waiting time for cancer care seems to be good.</p> <p>Better communication for how long people will be waiting generally needs to be better.</p> <p>Consequences of waiting can cause a deterioration especially around mental health</p> |

| Source | Publication | Date | Key themes relating to waiting list experience |
|-------------------|---|----------|--|
| Health Foundation | <p>Workshop on waiting lists.</p> <p>Not available online</p> | Feb 2024 | <p>General Comments</p> <ul style="list-style-type: none"> • Waiting times are longer and it is harder to access GP services post-COVID-19. • One person shared that their parent waited over two years for cataract surgery during COVID-19. When they were finally treated, it made a huge difference for their independence. • One person shared that whilst on a waiting list their appointment has been cancelled twice. • If you are looking for specific support (for example, from someone of the same background) this can be even harder to access. • Location played a large factor in whether you were able to get support or not. One person noted that there are more services offering the support that they need in southern England compared to the north where they are based. • Long waiting lists can sometimes mean that symptoms are no longer a problem by the time a patient is referred. This can waste time and resources and ultimately means that the patient did not receive the required support when needed. • “Bottom-up pressure is fantastic and necessary, but top-down commitment is required to change anything”. • “I’m lucky compared to some people but it is such a battle”. • “You have to be bloody fit and healthy to deal with the NHS”. <p>Advocacy</p> <ul style="list-style-type: none"> • Recognition that responsibility for self-care and advocacy for referrals or treatment is placed with the patient or carer. This can be scary, particularly when a patient is not able to communicate on their behalf. |

| Source | Publication | Date | Key themes relating to waiting list experience |
|--------|-------------|------|---|
| | | | <ul style="list-style-type: none"> • One-person shared advice received from their neighbour on getting their GP to take it seriously, “pretend you are dying!” This worked and they finally got a referral. • One person shared that as a patient and carer, getting people to listen and take them seriously before reaching a crisis point is an ongoing challenge. • Many in the group are carers as well as patients. This often requires advocating for the person being cared for with little energy left to advocate for yourself. • One person shared that an assessment for their spouse was riddled with errors highlighting the need for advocacy. • One person shared that their parents aren’t listened to because they’re elderly, so they try to be the best advocate they can on their behalf. • Community hubs and related initiatives have so much potential to be helpful. For example, Citizen’s Advice in Liverpool. <p>Using other services whilst waiting</p> <ul style="list-style-type: none"> • Existing conditions worsen and overall health declines leaving you vulnerable to new health problems. • One person described additional referrals for physiotherapy, nurses attending, and hospital admissions which may have been avoided if the waiting times had not been so long. • Self-care was a strongly recurring theme amongst all of the groups. People referenced tools such as Headspace or SILVERCLOUD, walking groups, massage, talking therapies and social prescribing. • It was also acknowledged that self-care did not always help as there may not be any appropriate services locally and that some of these services may not be affordable. |

| Source | Publication | Date | Key themes relating to waiting list experience |
|--------|-------------|------|---|
| | | | <ul style="list-style-type: none"> • Many people mentioned receiving support from charities whilst waiting but the ability to do so is often location dependent and charities themselves may also have waiting lists. • One person shared that they made use of employer support though this was quite limited. • One person shared that they attended an online workshop created to support those on the waiting list, but it was poorly run and did not have the patients in mind when designing the workshop. • One person shared that their parent was on a waiting list and unable to see for over two years, they were able to use their savings to access quality private healthcare (opticians, dietitians etc.). • One person shared that they had to modify the house, install extra smoke alarms and purchase a microwave as safety was a big concern for their parent who was on a waiting list. • Tools for navigating the process - one patient was given a 'staying well document' by the healthcare provider but noted that additional support is needed to help patients make proper use of this resource. • Some people had concerns about the ways that they had to treat themselves for the health issues that they were awaiting treatment for. For example, consistently taking antibiotics to fight repeated infections or privately purchasing blood sugar regulating medication. These concerns can create anxiety around the health impact of these medications, as well as the financial impact of funding your own care to bridge the gap whilst waiting. • One person shared that the ownership of patients and their deteriorating physical and / or mental health whilst on waiting lists is generally ignored by the service or specialism. A more proactive management of preparation for surgery as a focus would ensure better outcomes and recovery as well as a substantial cost reduction for services and costs to |

| Source | Publication | Date | Key themes relating to waiting list experience |
|--------|-------------|------|--|
| | | | <p>the individual / families / carers and the workforce / economic productivity.</p> <p>Impact on waiting on physical health</p> <ul style="list-style-type: none"> • Physical health can often deteriorate leading to changes in treatment options and poorer outcomes. • Often times people have multiple conditions with symptoms which have a knock-on effect on each other. • One person shared that they worked in the health service for 30 years and observed terrible knock-on consequences in orthopaedics'. Patients end up in a much worse state when they do finally have their operation. This then requires more input; a longer hospital stay and unfortunately worse outcomes. • Whilst waiting, physical symptoms can prevent people from engaging in activities that they would normally want to do, impacting their quality of life. <p>Impact on waiting on mental health</p> <ul style="list-style-type: none"> • Long waiting times negatively impact mental health for patients and carers. Examples of negative impact can include frustration, depression, and anxiety. • Long waiting times mean lengthy periods of time when patients aren't able to undertake everyday tasks (such as work or shopping) which can lead to social isolation, loss of independence, and feelings of hopelessness. This in turn impacts mental health and physical health in a vicious cycle. • Several people discussed feeling left behind compared to others, and that being on a waiting list prevents them from continuing with their lives. |

| Source | Publication | Date | Key themes relating to waiting list experience |
|---|---|-------------|---|
| | | | <ul style="list-style-type: none"> • Mental health and physical health are inextricably linked but there does not seem to be a link between mental and physical health care. However, if better questions are asked at an earlier stage, needs could be better assessed and potentially supported. • Mental health support that is provided is often unhelpful as each session is with a different doctor and there is no continuity of care. • Being on a waiting list can have financial implications (one person shared that money spent on private care cuts into the family budget) which in turn can increase anxiety and continue to negatively affect mental health. • Despite mental health challenges whilst waiting, patients still have to juggle other aspects of their life (e.g., elderly parents and kids) which can add additional burden. • If the waiting list a patient is on involves mental health alongside physical health, it can be harder for a patient to get staff to listen to them properly. • One person shared about their experience of caring for someone with dementia, this condition can lead to people isolating themselves which leads to faster deterioration. However, accessing support services is so difficult as it takes a long time without a guarantee of success. |
| Cancer insight report (ICB Leeds) | https://www.healthandcareleeds.org/have-your-say/get-involved/populations/cancer/ | August 2023 | Essential that people are kept informed about diagnosis, waiting times and treatment |
| Planned care insight report (ICB Leeds) | https://www.healthandcareleeds.org/have-your-say/get-involved/populations/planned-care/ | August 2023 | People tell us that they sometimes feel “forgotten” about why they are on a long waiting list |

| Source | Publication | Date | Key themes relating to waiting list experience |
|--|---|----------|---|
| Mental Health insight report (ICB Leeds) | https://www.healthandcareleeds.org/have-your-say/get-involved/populations/mental-health/ | Jan 2023 | People told us that waiting times to access both crisis mental health care and waiting lists for therapy were too long |
| Healthwatch Leeds Check in | | 2022 | <p>How's waiting had an impact?</p> <ul style="list-style-type: none"> • It's not had an impact: 3 people • Condition has got worse, but found ways to cope: 19 people • Condition has got worse, and have struggled to cope: 36 people • The condition has become untreatable or terminal: 1 person • Have been unable to work and lost job: 6 people • Financial impact: 7 people • Emotional wellbeing: 36 people • Affected my family/friends: 9 people <p>Information about how long they would be waiting.</p> <ul style="list-style-type: none"> • "Any communication would be helpful and reassuring". • "To know my treatment hasn't been forgotten about even if I had simply to wait in the queue." • Information about how they can look after themselves or what they should do while they waited. • Reasons why their treatment was delayed and what to do in a medical emergency. <p>Not kept informed about delays</p> <ul style="list-style-type: none"> • 55 people out of 69 said they were not kept informed by the service about how long they can expect to wait. |

| Source | Publication | Date | Key themes relating to waiting list experience |
|---|---|----------|---|
| | | | <p>What people have done to try and manage their wait</p> <ul style="list-style-type: none"> • “I paid £1 per minute for physiotherapy at home. • I could not afford to carry on with the treatment.” • Others considered going private, "the cost is estimated £1350 [dentistry]. Where is the NHS here?" |
| Primary care insight report (ICB Leeds) | https://www.healthandcareleeds.org/have-your-say/get-involved/populations/primary-care/ | Dec 2022 | <ul style="list-style-type: none"> • People raised concerns about timely care often struggling to get through on the phone to make an appointment and they wait too long. • People with mental health difficulties find it particularly difficult to access their GP. • Evidence suggests people can struggle to access appointments with a GP, noting that waiting times to be seen can be long. • Feedback also notes the difficulty with calling at certain times to book for an appointment and it taking a long time to get through. • There is evidence that people who cannot be seen in a quick enough time will visit alternative health care services, including the Emergency Department. |

5. Inequalities Review

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

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 | Elderly people are more likely not to be listened to when they have a medical issue |
| Disability | We have been unable to source any local evidence relating to the experience of disability |
| Gender (sex) | We have been unable to source any local evidence relating to the experience of gender |
| Gender reassignment | We have been unable to source any local evidence relating to the experience of the Trans community |
| Marriage and civil partnership | We have been unable to source any local evidence relating to the experience of marriage and civil partnership (Marriage and civil partnership in relation to the Equality Act is only relevant to employment – not service provision) |
| Pregnancy and maternity | We have been unable to source any local evidence relating to the experience of pregnancy and maternity |
| Race | We have been unable to source any local evidence relating to race |
| Religion or belief | We have been unable to source any local evidence relating to the experience of religion or belief |
| Sexual orientation | We have been unable to source any local evidence relating to the experience of sexual orientation |
| Homelessness | We have been unable to source any local evidence relating to the experience of homelessness |
| Deprivation | People from more deprived areas are more likely not to be able to access alternative treatment due to financial implications of paying for treatment |
| Carers | Carer's find it difficult getting people to listen and take them seriously before reaching a crisis point is an ongoing challenge. This often leaves them with little energy left to advocate for themselves. |
| Access to digital | We have been unable to source any local evidence relating to the experience of accessing digital |
| Served in the forces | We have been unable to source any local evidence relating to the experience of people who have served in the forces |

Additional Reading / understanding

National

Additional resources

For more general information on waiting lists, please see these resources:

<https://www.kingsfund.org.uk/insight-and-analysis/reports/health-inequalities-nhs-waiting-lists>

NHS England (via Healthwatch Leeds)

In January 2024, the total elective waiting list fell to 7.58 million, down from 7.60 million in December (this covers all planned appointments, tests or operations. This marks the fourth consecutive month in which wait lists have been falling. However, the number of patients waiting more than 18 months for treatment increased from 13,164 to 14,013 in this period.

In January, only 62.3% of people started their first treatment within 2 months (62 days) of an urgent cancer referral. The target is 85%.

70.9% of A&E patients were seen within four hours in February, up from 70;3% in January. Despite this improvement, this falls well short of the government's target to hit 76% by the end of March 2024. NHS England has announced measures to improve performance against this target.

Healthwatch England chief executive Louise Ansari was quoted in an Evening Standard story on wait times, arguing that alongside efforts to improve performance in A&E, trusts should focus on measuring and acting on the things that matter most to patients such as how quickly they are initially triaged, their access to food, water, and pain relief, and the quality of communication while waiting for care.”

The hospitals with the worst waits revealed

<https://www.bbc.co.uk/news/health-68479414>

Appendix A: Involvement themes

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

| Theme | Description | Examples |
|---|---|--|
| Choice | Being able to choose how, where and when people access care. Being able to choose whether to access services in person or digitally | People report wanting to access the service as a walk-in patient. People report not being able to see the GP of their choice |
| Clinical treatment | Services provide high quality clinical care | People told us their pain was managed well |
| Communication | Clear communication and explanation from professionals about services, conditions and treatment. | People report that they're treatment was explained in a way that they understood |
| Covid-19 | Services that are mindful of the impact of Covid-19 | People report the service not being accessible during the pandemic |
| Environment | Services are provided in a place that is easy to access, private, clean and safe and is a way that is environmentally friendly and reduces pollution | People report that the waiting area was dirty |
| Health inequality | Services are provided in a way that meet the needs of communities who experience the greatest health inequalities. | Older people report not being able to access the service digitally |
| Information | Provision of accessible information about conditions and services (leaflets, posters, digital) | People report that the leaflet about their service was complicated and used terms they did not understand |
| Involvement in care | Involvement of people in individual care planning and decision-making. | People told us they were not asked about their needs and preferences |
| Involvement in service development | Involvement of people in service development. Having the opportunity to share views about services and staff. | People told us that they were given an opportunity to feedback about the service using the friends and family test |
| Joint working | Care is coordinated and delivered within and between services in a seamless and integrated way | People report that their GP was not aware that they had been admitted to hospital |
| Person centred | Receiving individual care that doesn't make assumptions about people's needs. Being treated with dignity, respect, care, empathy and compassion. Respecting people's choices, views and decisions | People report that their relative died in the place they wanted |

| | | |
|-----------------------------|--|---|
| Resources | Staff, patients and their carers / family / friends have the resources and support they need | Family reported that adaptations to the house took a long time to be made |
| Satisfaction | Services are generally satisfactory | Most people told us that they were very happy with the service. |
| Timely care | Provision of care and appointments in a timely manner | People report waiting a long time to get an appointment |
| Workforce | Confidence that there are enough of the right staff to deliver high quality, timely care | People raised concerns that the ward was busy because there were not enough staff |
| Transport and travel | Services are provided in a place that is easy to access by car and public transport. Services are located in a place where it is easy to park. | People report poor local transport links People report good access to parking |
| Wider determinants | Services and professionals are sensitive to the wider determinants of health such as housing | People told us that their housing had a negative impact on their breathing |

Appendix B: 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