The Networked Data Lab

Topic 5: Waiting List Highlights

NDL [Leeds Network Data Lab]

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Glossary

Diagnostic test: A test used to help figure out what disease or condition a person has based on their signs and symptoms.

Ear, Nose, and Throat (ENT): A medical specialty dealing with that part of the body.

Emergency Department (ED): A hospital department which gives immediate treatment to people who are seriously injured in an accident or who are suddenly taken seriously ill.

General medicine: A medical specialty that involves diagnosing, treating and preventing a wide range of diseases in patients of all ages.

Gynaecology: A medical specialty dealing with the treatment of women's diseases, especially those of the female reproductive organs.

Healthwatch: An independent organisation that listens to people's experiences of health and social care services and ensures their feedback shapes and improves those services.

Mental health conditions: A health issue that impacts a person's thinking, feelings or behaviour.

NHS 111 or '111': Is a free telephone and online service in England that provides medical advice and guidance when it's not a life-threatening situation.

Orthopaedics: A medical specialty dealing with injuries and diseases affecting bones, muscles, joints and soft tissue.

Paediatrics: A medical specialty dealing with children and their diseases.

Pandemic: The coronavirus disease 2019 global pandemic.

Waiting list: A list of people waiting for treatment or admission to hospital.

Data sources

- WLMDS - The Waiting List Minimum Dataset (WLMDS) is a weekly data collection relating to demand, activity and waiting lists for elective care. The data flow started on January 2024 to the WYIC warehouse and covers data from April 2021 when providers began submitting these data on a weekly basis. It includes: RTT open (incomplete) pathways, RTT clock starts (new RTT periods), RTT clock stops (completed pathways) and RTT Diagnostics (waiters for diagnostic tests).
- Secondary Uses Service (SUS), containing inpatient attendances, outpatient appointments, and A&E visits. The extract of these data is available for Leeds NDL team via LDM, including information related to the service provision and where available RTT period.
- LDM (Leeds Data Model) Cohort table – Leeds GP registered patients record with the demographic information and long-term condition flags. These were retrieved from Primary Care Systems (TPP/EMIS)
- LDM GP data – including information about patients' appointments.
- LDM GP Events - GP patients' appointments.
- LDM Prescription - GP-issued prescriptions.
- Death Records

1. Introduction

NHS Waiting Lists and Plans for Improvement

As of December 2024, more than **7.5 million people** in England were waiting for hospital treatment. This is called the elective care or referral to treatment (RTT) waiting list. Some patients are waiting for multiple treatments, so the actual number of unique individuals is around **6.2 million**.

Current Waiting Times:

- Most patients (about 70%) are treated within the target **18-week** timeframe.
- **200,375 patients** have waited more than a year.
- **15,568 patients** have waited over **65 weeks**.
- **2,059 patients** have waited over **78 weeks**.
- **155 patients** have waited more than **two years**.
- Only **58.9%** of patients received treatment within **18 weeks**, far below the NHS target of **92%**.

In **December 2024**, over **1.5 million** new treatment cases were added, and over **1.3 million** treatments were completed. However, the median waiting time for patients still waiting was **14.2 weeks**, with the **longest waiting patients** waiting up to **42.7 weeks**.

NHS Plans to Reduce Waiting Times

The NHS Constitution says that **92% of patients** should get treatment within **18 weeks**, and no one should wait more than **52 weeks**. However, the current performance is far behind these targets.

The Labour Party's Plan to improve the NHS includes:

- **40,000** additional appointments per week, adding up to **2 million** extra treatments per year.
- Doubling the number of cancer scanners for earlier diagnosis.
- Hiring 8,500 more mental health professionals.

In January 2025, the NHS set new priorities for 2025/26:

1. Reduce elective waiting times – **65%** of patients should be treated within **18 weeks**.
2. Improve emergency care – Ensure **78% of ED patients** are seen within **4 hours**.
3. Better GP and dental care – Add **700,000** urgent dental appointments.
4. Improve mental health services – Speed up crisis and outpatient care.

Local Efforts to Cut Waiting Times

The West Yorkshire NHS Trust has its own goals:

- No patient should wait **48 weeks or more** by **March 2025**.

- Reduce outpatient waiting lists by **10%**, especially for Ear, Nose, and Throat (ENT) cases.
- Open a ‘Super Clinic’ for faster ENT treatments.
- New cataract treatment pathways to speed up surgery.

The biggest local challenge is reducing outpatient waiting times. Currently, **82% of patients** are waiting to see a consultant. The goal is to cut the waiting list by **21,000 patients** in the next year to ensure no one waits **over a year**.

Other key targets for March 2025 include:

- Treating all patients waiting **65+ weeks**.
- Reducing cancer patient wait times (aiming for **75% of urgent cancer cases diagnosed in 28 days**).
- Ensuring **95%** of patients get diagnostic tests within **6 weeks**.

Understanding the Impact of Long Waiting Times

Delays in treatment affect patients’ health and quality of life. A study found:

- **39% of patients** had treatments postponed **twice or more**.
- **18%** had last-minute cancellations.
- **66%** said delays caused worsening health (pain, mental health issues, poor sleep).
- **40%** of cancellations were linked to NHS strikes.

To better understand the problem, local health teams are:

- Tracking waiting times and their impact.
- Investigating why patients are removed from waiting lists.
- Studying how delays affect healthcare costs.

The NHS is struggling with record-high waiting lists, but national and local efforts are underway to reduce delays and improve patient care. Key priorities include cutting waiting times, expanding access to services, and using data to understand and solve delays.

2. The Networked Data Lab project wanted to find out:

- Are certain demographic groups more likely to experience longer waiting times?
- Reasons for people waiting.
- Differences in experiences based on time on the list, characteristics, and specialties.
- Mental health conditions associated with waiting.
- Costs to the NHS for certain procedures.

Key Findings on Specific Conditions

The key findings below are indicative of differences between groups. It should be noted that further analysis is required to quantify these differences and determine if they are statistically significant.

Gall Bladder Treatment – who waits the longest?

- Women (higher proportion waiting over 42 weeks).
- Middle-aged adults (35-64 years old).
- People living in more deprived areas of Leeds.
- People with unknown ethnicity or unknown long-term condition status.

Healthcare trends related to longer waits:

- No big increase in GP visits.
- No major impact on hospital admissions (elective or emergency).
- Urgent care (111 & ED) use decreased for those waiting 19-30 weeks.
- Medication prescriptions remained stable.

Hip Surgery - Who waits the longest?

- Older adults (65+).
- People living in more deprived areas of Leeds.
- People living with multiple long-term conditions.
- Women (wait longer than men).
- Healthier patients (fitter individuals wait longer).

Healthcare trends related to longer waits:

- More GP, ED, and emergency care visits, though not always statistically significant.
- Painkiller use increases for those waiting longer.
- Elective procedure costs decrease, meaning some treatments may be deferred.
- Emergency admissions costs increase, suggesting delays lead to worsening health.

Hysteroscopy (Womb Examination Procedure) - Who waits the longest?

- Middle-aged, relatively healthy women living in more deprived areas of Leeds.

Who gets treated sooner?

- Patients living with multiple long-term conditions or frailty get treated sooner.

Healthcare trends related to longer waits:

- A significant increase in GP visits and GP-related costs after waiting over 42 weeks.
- A reduced use of urgent care services (111 helpline).
- An increase in prescriptions for pain and depression, though the rise isn't always statistically significant.

Who is Dying?

- More deaths among younger people (50-60 years old) for patients that have waited less than 12 weeks.
- Longer waiters (70+) have a higher death rate, possibly due to their age, complex health conditions, or prioritisation factors.
- Women have a higher death rate than men, regardless of waiting time.

Who is Waiting the Longest? Summary

- The worst delays are in Gynaecology, Neurology, Paediatrics, and Trauma & Orthopaedics, with less than 60% of patients getting treated within the target time.
- Young children (especially under 10 years old) wait significantly longer than adults. As you get older you wait less. Paediatric services are some of the most affected pathways for long waits.
- Older adults (65+) face longer wait times for hip surgery.
- Women experience longer waits than men for gall bladder treatment, and hip surgery
- People from deprived areas (low-income neighbourhoods) have longer waits for gall bladder treatment and hip surgery
- Patients with multiple long-term conditions (LTCs) or severe frailty tend to get treated sooner.
- Fit and healthy patients may have waited longer for hip surgery, as sicker patients are treated first.

Overall Impact of Waiting Times

Positive Aspects

 Most patients (about 70%) are treated within the target 18-week timeframe.

 The NHS in Leeds seems to prioritise high-need patients well and those with severe conditions get seen faster.

✅ There’s almost no difference in healthcare outcomes across most delivery points, meaning prioritisation is working well.

Concerns & Inequalities

⚠️ Women consistently wait longer for some treatments, particularly in gynaecology and surgery.

⚠️ First study of this kind at an ICB (Integrated Care Board) level focusing on women's health, suggesting a need for more research.

3. How did we embed Patient and Public Involvement and Experience in the project and what did people say? (PPIE)

Firstly, we pulled together an insight report gathering what we already knew mattered to people about waiting for treatment. This information influenced the analysts’ areas of interest.

Healthwatch Leeds worked with us to facilitate the participation of local Leeds residents in focus groups. We intentionally picked patients who had been waiting over 52 weeks for treatment. As well as engaging regularly with the group, we also developed a survey to get a wider experience of patients waiting for treatment.

Analysing feedback from the 11 people who completed the survey (see Appendix B), the following themes are below:

1. Improve Coordination and Communication

Integrated Care Pathways: Establish clear, integrated care pathways to ensure seamless communication between different departments (e.g., rheumatology and orthopaedics). This can help prevent delays and confusion.

Consistent Follow-Up: Implement consistent follow-up procedures to ensure patients are not left to relay messages between departments or follow up on their own.

Effective Communication About Waiting: Utilise care coordinators and communicate regularly to manage patients' waiting journeys, especially for those on multiple waiting lists. This ensures that all necessary information is communicated effectively and in a timely manner.

2. Enhance Patient Support Systems

Carer Support: Provide additional support for carers, recognising the mental and physical toll of caring for patients with long waits for treatment.

Family Involvement: Encourage and facilitate family involvement in patient care, especially for those with memory loss or difficulty managing appointments.

3. Address Digital Exclusion

Alternative Communication Methods: Offer alternative communication methods for patients who struggle with technology, such as phone calls or letters, to ensure they receive important information.

4. Improve Mental Health Support

Mental Health Services: Provide access to mental health services for patients experiencing emotional distress due to long waits and fragmented care, as seen in multiple cases.

5. Streamline Referral and Appointment Processes

Efficient Referral Systems: Ensure referrals are actioned promptly and patients are kept informed about their waiting status.

Transparent Waiting List Management: Improve transparency in waiting list management, providing patients with clear timelines and expectations.

Waiting list Patients and Carers' Panel

The panel members were a good mix of both male and female participants and people from British and Indian backgrounds. Panel members spoke about their own experience (see Appendix A) and helped the analysts with gaps in data and recommendations for improvement. The analytical report was translated into plain English and shared with the group. Leeds analysts met with the Panel for a final time on 7 February to talk through the findings, and together, recommendations from the study were agreed. We asked the panel to discuss the following questions:

1. What matters most from the findings?
2. Were there any surprises in the results?
3. What is one change that should be prioritised?

Main recommendations important to the group:

Improve Communication

- Ensure clarity in NHS messaging, especially for those who are digitally excluded.
- Strengthen communication between GPs and hospitals to reduce referral delays.

Ensure 18-Week Referral-to-Treatment Compliance

- Hold NHS services accountable for meeting targets.
- Address barriers causing delays, particularly for marginalised groups.

Enhance Public Awareness of Patient Rights

- Increase efforts to inform people about their rights and options while waiting for treatment.
- Improve visibility of the ICB's role and responsibilities.

Address Inequalities in Waiting Times

- Investigate socioeconomic disparities in access to treatment.
- Explore solutions to ensure fairer access across different patient demographics.

The findings and recommendations will be discussed with local decision makers over the next few months with actions which we will monitor. We have engaged with the relevant commissioners in this area at the Leeds ICB throughout the project. An external and internal media release will be drafted to publicise the findings.

Appendix A

Waiting List Panel Patient and Carer's Stories

Summary of Patient Cases (names have been changed)

Case 1

Claire was waiting for multiple treatments, including hip replacement, spinal surgery, and knee replacement. The major issue during her waiting was the lack of coordination and communication between rheumatology and orthopaedics, leading to significant delays and confusion. This fragmented care left her feeling physically and mentally overwhelmed.

Case 2

Rohan was waiting for knee surgery and hand surgery. The major issue was the perception that consultants prioritised private work over NHS pathways, leading to long waits and the need to seek private care. Automated waiting list systems added to his frustration, as they seemed to be delaying tactics.

Case 3

Cheryl's father was waiting for knee surgery. The major issue was his struggle with technology and memory loss, which led to missed appointments communicated via text. The lack of communication and delays, especially during the pandemic, worsened his condition and caused significant frustration.

Case 4

Reeha had to call the gynaecology team herself to follow up on her referral she faced a long waiting list and was eventually offered NHS care (Initial appointment following her referral) after waiting 13 months on the waiting list. She was offered alternative options of NHS gynaecological Care which could have been anywhere across the country which she declined as it could have been as far as 100+ miles and preferred to stay in Leeds.

Case 5

Sally 's brother-in-law, Peter, was waiting for hernia surgery. The major issue was the repeated cancellations and lack of communication from the hospital, leading to increased anxiety and worsening of his condition. Despite multiple attempts to follow up from the family, Peter's condition deteriorated significantly and passed away at home.

Case 6

Helen was waiting for a hip replacement. The major issue was the poor communication and delays in actioning her referral, which was initially not processed. This situation was exacerbated by her role as a carer and her own health issues, leading to significant stress. Case 7 Richard was waiting for hand surgery. The major issue was being dropped from the NHS waiting list due to miscommunication, which delayed his treatment. He had to follow up personally to rectify the mistake, highlighting the inequities of relying on private consultations to expedite NHS care.

1. Health Seeking Behaviour

- Case 1: Claire frequently visited multiple consultants and had to manage various pathways. She had to relay messages between departments due to poor communication.
- Case 2: Rohan used the NHS "Choose and Book" system but faced long waits and had to seek a second opinion privately. Automated waiting list systems were seen as delaying tactics.
- Case 3: Cheryl's father struggled with technology and memory loss, missing appointments communicated via text. Cheryl had to set up a system for the hospital to call the landline instead.
- Case 4: Reeha had to call the gynaecology team herself to follow up on her referral she faced a long waiting list and was eventually offered NHS care (Initial appointment following her referral) after waiting 13 months on the waiting list. She was offered alternative options of NHS gynaecological Care which could have been anywhere across the country which she declined as it could have been as far as 100+ miles and preferred to stay in Leeds.
- Case 5: Sally had to repeatedly contact the GP and hospital on behalf of her brother-in-law, Peter, who faced significant delays and poor communication.
- Case 6: Helen had to chase her GP and hospital for updates on her referral, which was initially not actioned.
- Case 7: Richard had to follow up with the consultant’s secretary after being dropped from the NHS waiting list due to miscommunication.

2. Mental Health – Emotional Impact on Patients

- Case 1: Claire felt overwhelmed and on a "slippery slope" physically and mentally due to the fragmented care and multiple surgeries.
- Case 2: Rohan experienced disappointment and distrust towards consultants, feeling that private work was prioritised over NHS care.
- Case 3: Cheryl’s father felt frustrated and anxious due to the lack of communication and delays, especially during the pandemic.
- Case 4: Reeha experienced significant distress due to worsening symptoms and long waits for treatment, compounded by a cancer scare.
- Case 5: Sally felt frustration and helplessness as she navigated the healthcare system on behalf of her brother-in-law, who suffered severe pain and ultimately passed away.

- Case 6: Helen felt the mental toll of being a carer without additional support, exacerbated by her own health issues and delays in treatment.
- Case 7: Richard acknowledged the stress of being dropped from the waiting list and the inequities of relying on private consultations.

3. Support Other Than NHS

- Case 3: Cheryl provided significant support to her father, managing his appointments and care due to his memory loss and difficulty with technology.
- Case 4: Reeha continued working with the support of her manager and used painkillers and other pain relief remedies to manage her symptoms.
- Case 5: Sally supported her brother-in-law, Peter, by managing his healthcare interactions and advocating for his care.
- Case 6: Helen highlighted the lack of support for her as a carer.
- Case 7: Richard acknowledged the privilege of being able to afford private consultations.

4. Digital Exclusion

- Case 3: Cheryl's father struggled with technology and memory loss, missing appointments communicated via text. Cheryl had to set up a system for the hospital to call the landline instead.
- Case 5: Sally did not receive communication from the hospital, leading to missed appointments and delays in care.

Appendix B

Summary Based on the Data from the Waiting Time Survey and Panel Case Studies January 2025

1. What we want to know

The Networked Data Lab (NDL) is conducting research on waiting lists to understand:

- Are certain demographic groups more likely to experience longer waiting times?
- Reasons for people waiting.
- Differences in experiences based on time on the list, characteristics, and specialties.
- Mental health conditions associated with waiting.
- Health risks for diabetic patients on waiting lists.
- Costs to the NHS for certain procedures.

To assist with this analysis, we conducted a survey and established a people's panel to gather detailed experiences.

2. Research Questions:

To help us with the analysis we devised a survey asked people with experience of being on a waiting list the following questions:

- What treatment were people waiting for?
- How long have people been waiting?
- Their stage on the waiting list.
- What they had done whilst waiting.
- Impact of waiting on your condition.

3. Survey Correspondents and Case Studies

3.1 Survey Responses:

We received 11 responses for the survey, summarised below:

Response	Treatment Waiting For	Waiting Duration	Stage	Contacted GP whilst waiting	Impact of waiting
1	Neurology.	7 to 12 months.	Waiting for treatment after the first hospital appointment.	Yes, more than 5 times.	Severe pain requiring new medication.
2	Repeat Colonoscopy and CT scan.	7 to 12 months.	Waiting for treatment after the first hospital appointment.	Yes, 3 to 5 times.	Minor worsening of symptoms.
3	Not specified.	Less than one month.	Waiting for the first hospital appointment.	Yes, 3 to 5 times.	Minor worsening of symptoms.
4	Pain management.	Over a year.	Waiting for the first hospital appointment.	Yes, more than 5 times.	Significant worsening of symptoms.
5	Paediatric pain consultation.	1 to 3 months.	Waiting for treatment after the first hospital appointment.	Yes, 3 to 5 times.	Minor worsening of symptoms.
6	Hand contraction treatment.	Over 2 years.	Waiting for the first hospital appointment.	Yes, 3 to 5 times.	Significant worsening of symptoms.
7	Hand surgery.	7 to 12 months.	Waiting for the first hospital appointment.	Yes, 1 to 2 times.	Significant worsening of symptoms.
8	Cardiology.	7 to 12 months.	Waiting for treatment after the first hospital appointment.	Yes, 1 to 2 times.	Minor worsening of symptoms.
9	Knee replacement.	1 to 3 months.	Waiting for the first hospital appointment.	No contact.	
10	Gynaecology.	Over a year.	Waiting for the first hospital appointment.	No contact.	

Response	Treatment Waiting For	Waiting Duration	Stage	Contacted GP whilst waiting	Impact of waiting
11	Musculoskeletal (MSK)	7 to 12 months.	Waiting for the first hospital appointment.	Yes, 3 to 5 times.	

Part 2: Findings

3.1 Health Seeking Behaviours:

- Most respondents contacted their GP multiple times.
- Many used medications to manage pain.
- Some sought alternative treatments like physical therapy and support groups.
- A few investigated private healthcare options.
- Nearly half of the respondents did not take any action and relied on self-care.

3.2 Mental Health Impact:

- Several respondents reported severe stress and anxiety due to waiting.
- Emotional impacts included feelings of desperation and negative outlooks.
- Carers expressed distress over seeing loved ones in pain.
- Carers of younger patients expressed more distress over their child's condition.

3.3 Support During Waiting:

- Experiences varied, with some reporting supportive GPs and others feeling neglected.
- Many relied on support from family, friends, and carers.

3.4 Updates on Expected Wait Time:

- Many respondents did not receive updates about their expected wait time or changes to their treatment date.

3.5 Cancellations During Waiting:

- Nearly half of the survey respondents experienced cancellations by healthcare providers. Reasons included consultant follow-up, unspecified reasons, and nurse illness.
- Only one person had to cancel their appointment due to a holiday.
- More than half the respondents did not experience any missed or cancelled appointments.

3.6 Digital Exclusion:

- Some struggled with technology, leading to missed appointments.

3.7 Overall Waiting Experience:

- Based on the survey responses, experiences ranged from negative to mixed with common complaints about lack of communication and long waiting times.

3.8 Differences in Waiting Experiences Between Young and Old; Different Areas of Leeds; Those from Minority Ethnic Communities:

- No significant differences noted in these areas based on the data provided.

4. Suggestions for Improvement from Patients and Carers:

- Regular updates on waiting times and treatment plans.
- More healthcare professionals to reduce waiting times.
- Interim support for pain management and mental health.

5. Recommendations

1. Improve Coordination and Communication

Integrated Care Pathways: Establish clear, integrated care pathways to ensure seamless communication between different departments (e.g., rheumatology and orthopaedics). This can help prevent delays and confusion.

Consistent Follow-Up: Implement consistent follow-up procedures to ensure patients are not left to relay messages between departments or follow up on their own.

Effective Communication About Waiting: Utilise care coordinators or implement effective communication strategies to manage patients' waiting journeys, especially for those on multiple waiting lists. This ensures that all necessary information is communicated effectively and in a timely manner.

2. Enhance Patient Support Systems

Carer Support: Provide additional support for carers, recognising the mental and physical toll of caring for patients with long waits for treatment.

Family Involvement: Encourage and facilitate family involvement in patient care, especially for those with memory loss or difficulty managing appointments.

3. Address Digital Exclusion

Alternative Communication Methods: Offer alternative communication methods for patients who struggle with technology, such as phone calls or letters, to ensure they receive important information.

4. Improve Mental Health Support

Mental Health Services: Provide access to mental health services for patients experiencing emotional distress due to long waits and fragmented care, as seen in multiple cases.

5. Streamline Referral and Appointment Processes

Efficient Referral Systems: Ensure referrals are actioned promptly and patients are kept informed about their waiting status, preventing situations like a delayed referral.

Transparent Waiting List Management: Improve transparency in waiting list management, providing patients with clear timelines and expectations.