Version 1.0

The Networked Data Lab: Statistical analysis plan for Topic 5: Waiting Lists

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Date 30/03/25

Version number 01

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1. Research rationale and objectives

As of May 2024, the waiting list for hospital treatment in England exceeds 7.6 million, commonly referred to as the "elective care" or "RTT" (referral to treatment) waiting list. This includes 6.4 million unique patients, indicating multiple procedures for some individuals (Kirk-Wade, Harker, & Stiebahl, 2024). The waiting list reached a peak of 7.8 million in September 2023, the highest since records began in 2007. Although it has since decreased by 2%, it remains higher than any point before summer 2023.

The NHS Constitution stipulates that patients referred for non-cancer pathway consultant-led treatment should begin treatment within 18 weeks, with the target being that 92% of those on the waiting list should wait less than 18 weeks, and a 'zero tolerance' policy for waits over 52 weeks (NHS England, 2022).

Between 2012 and 2019, the waiting list for treatment in England rose consistently, and this increase accelerated after the pandemic. The waiting times improved after the 18-week target was introduced, with the target met continuously from January 2012 to November 2015. However, from 2015 onwards, waiting times started to worsen, and by January 2020, the 92nd-percentile waiting time had increased to 25 weeks, seven weeks higher than the target (Kirk-Wade, Harker, & Stiebahl, 2024)

During the pandemic, waiting times rose significantly due to reduced treatment activity. There was a slight recovery in 2021 but waiting times have remained high. Historically, the number of patients waiting over 52 weeks fell sharply after RTT targets were introduced but saw a rise to over 3,000 in 2018. A successful drive reduced this to just over 1,000 by mid-2019. The pandemic caused a significant increase, peaking at 436,000 in March 2021. Numbers have been consistently falling since September 2023, with NHS England aiming to eliminate 52-week waits by March 2025. These trends highlight ongoing challenges and efforts in managing waiting times for treatment within the NHS.

Similarly on a local level the Elective Recovery and Planned Care program is working to meets the following objectives: no patient waiting 48 weeks or more by March 25, Reducing the Outpatient RTT waiting list by 10% and focusing on Ear, Nose, Throat (due to large numbers). The local partnership also working towards meeting the nationally set waiting list target of treating all patients waiting 65 weeks or more by the end of September 2024[1].

To address the objectives for Ear, Nose, Throat (ENT) the following action has been taken: developing a directory of GPs with Extended Roles (GPwER) and maximising their roles in ENT pathways, new planned pilot programme with the Tympa platform[2] to increase access and delivery of ear and hearing care in West Yorkshire, the new 'super clinic' at MidYorkshire Teaching NHS Trust to see, treat and discharge patients in a session.

Leeds Teaching Hospital Trust currently address a challenge to improve the number of cataract cases seen in theatre following GIRFT[3] guidance by planning new cataract pathways by reducing number of appointment and introducing (One Stop Clinic)[4].

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[1] Elective Recovery Programme: Issue 4 - April 2024 (cloud.microsoft)
[2] Tympa Platform - TympaHealth
[3] Further Faster Programme - Getting It Right First Time - GIRFT
[4] Cataract Pathways and One Stop Clinics (youtube.com)

The biggest local challenge is to reduce numbers for outpatients' appointments, Currently, in local trusts there are 82% of patients on RTT waiting for seeing consultant in outpatient clinic. The goal is to reduce the non-admitted waiting list by 10% overall (21,000 fewer patients this time next year). This will support the objective to ensure no patient waits more than a year for treatment by March 2025. Trusts will continue to work towards reducing the number of unnecessary follow-up appointments, whilst recognising that there is a backlog of follow-up patients who still need to be seen.

Additionally, the Leeds system Priorities included the following KPI to achieve by March 2025:

- The number of incomplete Referral to Treatment (RTT) pathways (patients yet to start treatment) of 65 weeks or more (especially around Gynaecology, Trauma and Orthopaedics, Paediatrics)
- Reduce a number of cancer patients waiting for over 62 days.
- Meet the cancer faster diagnosis standard by March 2024 so that 75% of patient who have been urgently referred by their GP for suspected cancer are diagnosed or have cancer rules out within 28 days.
- Increase the percentage of patients that receive a diagnostic test within 6 weeks in line with the March 2025 ambition of 95%.

To address the above priorities, a better understanding of patients' characteristics and their health conditions is required. This will help to understand who is waiting and what additional care is needed while waiting to support patients and to adequately plan strategies to reduce waiting times. The Leeds NDL team will contribute toward this to identify inequalities and consequences of waiting as main project aims.

The current scoping phase showed that there is a limited usability of the national Waiting List Minimum Dataset (WLMDS) dataset. The Leeds Office of Data Analytics (ODA) created a dashboard for monthly RTT reports for year 2023- 2024 showing numbers for incomplete pathways. North of England Care System Support (NECS) our commissioning support service with South Yorkshire ICB have developed an enhanced dashboard RAIDR National Elective Waiting List Dashboard Development[5]. The main use of this dashboard is to report the current waiting cohort, determine health inequality, and analyse patients moving through the system on selected pathways.

The RAIDR System uses WLMDS dataset, a weekly data collection. This national dataset has been recently flow to West Yorkshire ICB warehouse, and it will be the main data source for this analysis. The pre analysis showed a problem with the patients flow between different waiting lists as well as data quality issues, which has not been addressed in the RAIDR documentation. Thus, quantifying data quality and proposing preprocessing methods will be one of the objectives of this project.

Discussion with local stakeholders has helped to identify the following area of interest to understanding impact of waiting for: Endometriosis laparoscopy, gall bladder removal and stoma reversal as a procedure that impact patients' quality of life. These characterise with the increased return to health care services for prescription, GP visits and AE and non-elective admission. Also, the areas of orthopaedics related to hip replacement is one of the local interest due to large numbers of waiting patients.

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5 RAIDR NEWL

In 2023 HealthWatch interviewed over a thousand patients who have their NHS care cancelled or postponed (HealthWatch, 2023). They found 39% of surveyed patients, have had their NHS care cancelled or postponed two or more times this year. This has included hospital operations, tests, scans, outpatient appointments, and community health service appointments. 18% of the respondents have had their care cancelled or postponed at the last minute, and 45%, experienced a cancellation with between one- and seven-days' notice. 66%, said cancellations had impacted their lives, reporting ongoing pain, worsening mental health, worsening symptoms, and disrupted sleep, among many other problems. Around 40% of respondents were told or believed their cancellation was due to the industrial action in the NHS. Additionally, other 40% of responders said their care was cancelled for another reason; and 20% didn't know why. Local stakeholders also suggested analysing missed appointments (DNA) and cancelations as they have significant impact on the waiting lists.

The proposed NDL analyses aim to explore elective waiting list by defining elective patients' pathways with the activities on referral to treatment (RTT) periods, together with non-RTT events by linking this data to primary and secondary care data. To achieve this, a set of research questions have been identified and grouped into three general themes. These include:

1. Identifying Patient Pathways and RTT activities
2. Who is waiting?
3. What are the consequences of waiting?

The research questions related to each analysis theme are summarised in Tables 1,2, and 3, The questions in Table 1 support the subsequent analysis generating a data quality report and dashboard would supplement this work but are not proposed as part of the central analysis.

Table 1: Identifying Patient Pathways and RTT activities.

Research Questions	**Report/Analytical Output**
1.1. What are the quality issues with WLMDS?	Data Quality Report. Procedures to work with missing information. Using Open Pathway list to fill the gaps
1.2. How to identify activities with RTT period on patient pathway	RTT activities extraction procedures, conversion to sequence of events, extracting events from open pathways. Dashboard

Table 2: Who is waiting?	
Research Questions	**Analytical Output**
2.1. What are the demographic characteristics of patients waiting <18 weeks, >18 weeks, >36 weeks and >52 weeks?	Descriptive statistics and visualisation of patient population with breakdown by demographic variables. Following HF central analysis

2.1 What is the health profile of the patient population patients waiting <18 weeks, >18 weeks, >36 weeks and >52 weeks?	Descriptive statistics and visualisation of patient population, breakdown by health metrics (Frailty, LTC, other Health conditions: GP Contact, AE contacts, Non-Elective Admission, Adult Social Care, Community Services). Following HF central analysis
Satellite Analysis	
2.3. Which specialities meet the national target of seeing patients by 52 weeks?	Descriptive statistics and visualisation of patient population for each speciality and weeks of waiting:<18 weeks, >18 weeks, >36 weeks and >52 weeks.
2.4 What are the rates for DNA, cancellation, or death per Speciality?	Descriptive statistics and visualisation speciality to understand rates of missed appointments (DNA), cancellation and deaths while waiting?

Table 3: What are the consequences of waiting?	
Research Questions	**Analytical Output**
3.1. What is the health utilisation for each week group of waiting before treatment?	Descriptive statistics and visualisation of health utilisation (GP, AE, ASC, CN) for each speciality/selected procedures and weeks of waiting:<18 weeks, >18 weeks, >36 weeks and >52 weeks.
3.2. What is the health utilisation after treatment?	Descriptive statistics and visualisation of health utilisation (GP, AE, ASC, CNfor each speciality/selected procedures 6 month after treatment
3.3. What is the effect of waiting for treatment for an additional [x] weeks for [y] procedure on total healthcare A for [z] point of delivery, from referral to [follow up period]?	Causal Model DID – This can be expanded on various outcome (Non-elective Admission, Death, readmission after treatment). We will follow HF methodology for DAG. This also may include analysis defining health seeking behaviour profiles in relation to waiting time.

2. Data and data linkages

The Leeds Data Model is pseudonymised, personal level linked data set bringing together data from the range of a partner organisation delivering health and care to the people of Leeds. The model enables to identify specific cohorts through our population segments model to which we can compare service utilisation, priorities service and help to plan existing or new services.
These data are restricted to Leeds GP registered patients who have not opted out of data sharing for secondary use. Data is linkable via anonymised patient id.

These data are hosted by North England Commission Support (NECS) and accessed through secure connection to a virtual data warehousing environment, and the cloud services. Datasets for this study are listed below.

Data sets

- WLMDS - The Waiting List Minimum Dataset (WLMDS) is a weekly data collection relating to demand, activity and waiting lists for elective care. The data started to be flown on January 2024 to the WYIC warehouse and covers data from April 2021 when providers began submitting data to WLMDS on a weekly basis. It contains collections of: RTT open (incomplete) pathways, RTT clock starts (new RTT periods), RTT clock stops (completed pathways) and RTT Diagnostics.

- Secondary Uses Service (SUS), containing inpatient attendances, outpatient appointments, and A&E visits. The extract of the data is available for Leeds NDL team via LDM, including information related to the service provision and where available RTT period.

- LDM 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 - Read/SNOMED for GP patient's appointments.

- Death Records

3. Statistical methods

3.1 Study design

The proposed study will use a retrospective analysis t design to investigate the inequalities while waiting for speciality and investigate consequences of waiting.

3.2 Study period

The patients being referred to a speciality between 1st of April 2022 and 31st of March 2024 will be used to construct the study population. The follow up period will be 6 months after treatment for patients being treated by March 2024 The outcome variables (see **Section 3.4**) will be obtained based on primary, secondary, and waiting list data.

A patient may have multiple RTT periods along one pathway. Where a patient has more than one referral for unrelated clinical reasons, each referral will have its own patient pathway. The

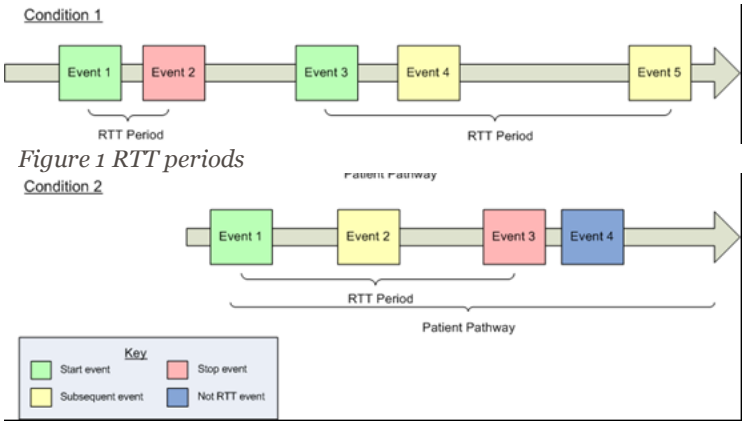

Figure 1 RTT periods

start of the patient pathway may start the first RTT period and there may be a number of subsequent RTT periods along the same patient pathway. Figure 1 illustrates how one patient could have multiple concurrent pathways and each pathway can have multiple RTT periods along it, but that the RTT periods in a pathway cannot be concurrent.

Each of RTT period on the pathway can be identified by patient pathway identified, organisation code issuing pathway id, RTT period start date and RTT period status. The start date for the second (or subsequent) RTT period should not be associated with the original referral date for the first RTT period (as this would produce an incorrect elongated RTT time).

There are several waiting lists where reporting has been made:

- New RTT periods (new referrals)
- Incomplete - Non-Admitted pathways are waiting times for patients with no decision to admit.
- Incomplete - Admitted pathways with a decision to admit for treatment are waiting times for patients waiting to be admitted for a treatment.
- Admitted pathways are waiting times (time waited) for patients whose treatment started and involved admission to hospital.
- Non-admitted pathways are waiting times (time waited) for patients whose treatment started and did not involve admission to hospital.

This new clock will often start at the point the subsequent decision to treat is made and communicated to the patient. However, where a patient is referred for diagnostics or specialist opinion with a view to treatment it may be more appropriate to start the new clock at this point (onward referral date). Where the patient will be remaining under the care of the same consultant or under the care of a different consultant within the same provider, then the date of the decision to refer and the referral being received will be the same. This has to be considered by defining the referral date for activity RTT period and clock start dates for both admitted and not admitted patients.

Patients with more than one referral to different specialities will be treated separately, in case of multiple referrals to the same speciality we will define a clock start as the first referral date and the clock stop as latest close.

3.3 Study population

There will be three cohorts considered for the analysis:

Cohort 1: All new referrals onto the elective waiting list (i.e., unique pathways with a patient pathway ID and clock start) between 1 April 2022 and 31 March 2024. This will include some patients without a clock stop (incomplete pathways).

Cohort 2: If cohort 1, all pathways appearing at least once on the clock stop list (i.e., completed pathways) by 31 March 2024.

Cohort 3: Of cohort 2, all pathways ending in a definitive treatment (treatment status = 30, to filter out patients on active monitoring) and a wait length of at least 18 weeks (127 days elapsed since clock start) and with patient-level linkage to local electronic health records.

3.4 Definitions of outcomes and exposures

Type of variable (outcome or exposure)	Definition criteria	Dataset(s) from which the variable is derived	Other comments (including external references)
Outcome variable	A&E Visits	SUS	
	GP Visits	GP	
	Death	Death Record	
	Emergency Admission	SUS	
	LOS	SUS	Length of stay
	Hospital readmission (30 days)	SUS	Hospital readmission
	Death after treatment 30 days	Death Record	
Exposure variable	Age	LDM Cohort	
	Age Band	LDM Cohort	
	Gender	LDM Cohort	
	Ethnicity	LDM Cohort	
	IMD 2019	LDM Cohort	Area deprivation of patient residence
	PCN	LDM Cohort	Primary Care Networks based on registered GP practice of patient
	Frailty index (eFI)	LDM Cohort	Electronic Frailty Index, a measure of patient frailty, incorporates 36 deficits constructed using 2,171 CTV3 codes
	LTC Count	LDM Cohort	Recorded as “Single LTC”, “Comorbidity”, “Multimorbidity”, and “NA” for no record of LTC
	LTC	LDM Cohort	The presence of a set of long-term conditions flagged in existing LTC table.
	RF_Alcohol_use	LDM Cohort	Heavy drinker (finding) Moderate drinker - 3-6u/day (finding) Heavy drinker - 7-9u/day (finding) Very heavy drinker - greater than 9 units/day (finding) Alcohol intake above recommended sensible limits (finding) Binge drinker (finding)
	Speciality	WLMDS	
	Referral date	WLMDS	

	First Outpatient date	WLMDS	
	RTT Clock Start date	WLMDS	
	Decision to Admit date	WLMDS	
	RTT Clock End date	WLMDS	
	Cancelation date	WLMDS	
	DNA data	WLMDS	
	Priority	WLMDS	

3.5 Statistical approaches

The study will utilise two modelling techniques, namely:

- Descriptive Statistics
- Causal Inference
- Machine Learning

Descriptive Statistics:
To analyse variation in length of wait for all specialities, the number and percentage of pathways will be reported for the following categories a) > 18 weeks b) >18 weeks c) >36 weeks and c) >52 weeks for Cohort 1

Patient characteristics	*Total*		*<=18 weeks*		*>18 weeks*		*>36 weeks*		*>52 weeks*	
	n	%	n	%	n	%	n	%	n	%
Total										
Specialty (one per row)										
Male										
Female										
Age band (one per row)										
Ethnicity (one per row)										
IMD (One per row)										
PCN (one per row)										
RF_Alcohol_Use										
	mean	sd	mean	sd	mean	sd	mean	sd	mean	sd
Frailty index (eFI)										
LTC Count										

To analyse the reason for completion for Cohort 2 the following statistics will be reported. The RTT period status is described by following defined in Appendix.

Patient characteristics	*Treatment – admitted (30)*		*Treatment – non-admitted (34)*		*…*		*Death (36)*	
	n	%	n	%	n	%	n	%
Total								
Specialty (one per row)								
Male								
Female								
Age band (one per row)								
Ethnicity (one per row)								
IMD (One per row)								

PCN (one per row)								
RF_Alcohol_Use								
	mean	sd	mean	sd	mean	sd	mean	sd
Frailty index (eFI)								
LTC Count								

To analyse variation of waiting time for completed pathways, the following times will be considered a) total time b) referral to first outpatient c) first outpatient to treatment decision d) treatment decision to treatment date separately for admitted and not admitted patients. The following statistics will be reported: s- mean, med -median, standard deviation st and iqr

Patient characteristics	*Total*				*Ref_To_F_Outpat*				*F_Outp_to_Dec*				*Dec_to_Treat*			
	s	med	st	iqr	s	med	st	iqr	s	med	st	iqr	s	med	st	Iqr
Total																
Specialty (one per row)																
Male																
Female																
Age band (one per row)																
Ethnicity (one per row)																
IMD (One per row)																
PCN (one per row)																
RF_Alcohol_Use																

For analysing time to death, cancelation, and DNAs the above table will be extended by the following times a) referral to death b) decision to admit to first cancelation/DNA date c) cancelation/DNA date to treatment.

Causal Inference

The following procedures: Cholecystectomy (removal of gall bladder), Diagnostic laparoscopy (for endometriosis) and Stoma reversal has been selected with a stakeholder consultancy. These were identified by stakeholder as easy pathways, impacting quality of life and high impact of health care due to large number of returns for health care services and medication.

The following question will be considered:
What is the effect of waiting for treatment for an additional [x] weeks for [y] procedure on total healthcare A for [z] point of delivery, from referral to [follow up period]?
Where:

- Intervention or exposure [x]: length of wait for treatment, in bins (>18 weeks)
- Procedures [y]: Cholecystectomy (removal of gall bladder), Diagnostic laparoscopy (for endometriosis) and Stoma reversal
- Outcomes [z]: points of healthcare delivery i.e. A&E visits, emergency admissions, days in hospital, GP visits, GP consultations, death
- Follow-up: 6 months between the last patient's treatment date and the fixed end of the study period

The proposed staggered difference in difference (DID) model will be implemented.

3.6 Methods for addressing missing data.

Using open pathway waiting list to fill the gap in clock start and stop, the SUS data to retrieve the procedure codes.

3.10 Known limitations.

- Data quality - lots of missing values for majority of WLMDS variables
- Patient flow between list issues – problem retrieving all data for the patients on lists eg patient with completed record not having referral information and not being present on open pathways
- OPCS present in 80% on open pathways – may need to be retrieved from SUS.
- Cancellation and DNA not populated – in version v1.5 WLMDS Cancelation date no more required, but can be proxy from multiple admission dates

4. Governance

Availability of data and materials

Data for this study will be primarily derived from commissioning data sets. Some of which are known to have limited data on protected characteristics, where possible and required, data linkage to general practice data in the Leeds Data Model will be used to increase data completeness.

Ethics approval and consent to participate.

Ethical approval has been given for all data contained within the Leeds Data Model to be linked and used for the purposes set out within this plan, both through local data sharing agreements and DARS agreements for national data sets.

The legal basis for use of these data in the planning and provision of healthcare allows the use of these data without explicit consent. Though explicit consent is not required, it should be noted as part of the routine data processing of data provisioned for the Leeds Data Model, the data for any person choosing to opt out of allowing their data to be made available for secondary use are excluded.

5. Impact, dissemination and engagement

Please describe.

- How you think each study objective will be useful to your stakeholders and local or national decision-makers.

  The utilisation of the WLMDS to build a decision-making tool to be able analyse the population of patients waiting, understand their characteristics and flag their health deterioration that may suggest a needs for reprioritisation.

- Please outline your plans to involve patients and the public with lived experience of waiting for elective care at key stages in your project.

NDL team will pull together everything we know from patient experience around waiting lists and create an insight report. We will use HealthWatch survey to understand estimate DAG unobservables such as healthcare seeking behaviour. We will have a PPIE volunteer on the project from the beginning who will assure our PPIE process. We will work with our third sector partners (Healthwatch Leeds) to recruit people with lived experience of waiting for treatment in the specific areas we are focusing on. We will use the PPIE framework to evidence how people have influenced the project through each stage of the analytical process (Identifying and prioritising, design, undertaking the research, analysing and interpreting, dissemination, implementation and monitoring and evaluating. Analysts will meet with the Patient/Carer panel at least 5 times during the project to talk through findings and enrich data with real life stories. We will feedback findings with the patient/carer panel and co-produce recommendations together.

- How will you demonstrate how the analysis responded to key priorities raised by the public?

  We will ensure that key recommendations raised by the public will be presented at key decision making board meetings following the findings and we will put together a "you said we did" document where we will evidence how we have listened and what we are going to do

- What groups you will be engaging with to disseminate your results (e.g. charities, patient groups, local government, task and finish group?

  We currently collaborate with Planned Care Board

- How will you share your findings with members of the public that have been involved throughout the project?

  We will create a plain English version of the results and present the findings at a workshop. We will then co-produce recommendations to take to decision makers and share with the HF. We will also publish the reports on our website and create a media release to share to the wider audience.

6. Bibliography

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7. Acknowledgments

- West Yorks ICB in Leeds NDL team - Helen Butters, Alex Brownrigg, Frank Wood
- Waiting List Patients and Carers Panel
- HealthWatch Leeds – Tatum Yip, Isaac Grinnell
- Leeds Health Partnership Stakeholders - Sophie Blow, Tom Daniels, Liz Micklethwaite
- Women Health - Eloise Pearson (WYorks ICB in Leeds), Charlotte Waite (LTHT)
- Leeds Data Model Team – James Lodge, Souheila Fox, Klaudia Sutcliffe
- South Yorks ICB Analytical Team – Barbara Coyle, Matthew Hird
- NHS E EPP Team – Suchi Collingwood, Sandra Rochfort
- NECS DSCRO Team

8. Appendix

If you have any additional materials, you are able to include at this stage, such as clinical or administrative code lists, please include those here.

30	End of the **REFERRAL TO TREATMENT PERIOD**: Start of **First Definitive Treatment**
31	End of the **REFERRAL TO TREATMENT PERIOD**: Start of **Active Monitoring** initiated by the **PATIENT**
32	End of the **REFERRAL TO TREATMENT PERIOD**: Start of **Active Monitoring** initiated by the **CARE PROFESSIONAL**
33	End of the **REFERRAL TO TREATMENT PERIOD**: Did not attend - the **PATIENT** did not attend the first **CARE ACTIVITY** after the referral
34	End of the **REFERRAL TO TREATMENT PERIOD**: Decision not to treat - decision not to treat made or no further contact required
35	End of the **REFERRAL TO TREATMENT PERIOD**: **PATIENT** declined offered treatment
36	End of the **REFERRAL TO TREATMENT PERIOD**: **PATIENT** died before treatment