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

Rafal Kulakowski, Roberto Fernandez Crespo, Tom Clutterbuck, Jodie Chan, Owen Melbourne and Matthew Chisambi

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## Research rationale and objectives

Over the last decade the number of patients on consultant-led Referral-To-Treatment (RTT) pathways has increased steadily. This problem has been exacerbated during the COVID-19 pandemic, throughout which the number has increased at a higher rate. The backlog of patients post-COVID-19 pandemic includes variety of patients that could not be seen during the pandemic, such as those whose referrals or operations have been cancelled or postponed ([Queen Mary University of London, 2021](#QMUL2021)), as well as patients that avoided seeing a general practitioner (GP) due to fear of infection or to ‘lessen the burden’ on the NHS ([The Health Foundation, 2020](#THF2020)).

Waiting times has consistently been a topic ranked as one of their main concerns regarding the NHS ([NHS England, 2024\*](#NHSE2024)) by the public. As of May 2024, there are 7.6 million patients on waiting lists in England and it’s estimated that the median wait is 14.2 weeks ([The King's Fund, 2023](#Kings2023)). The NHS states that patients have a right to start consultant-led treatment within 18 weeks of referral (or request an alternative provider who could offer them and earlier treatment option) ([Department of Health and Social Care, 2012](#DHSC2012)), and aim to have at least 92% of patients waiting times below this threshold ([Office for National Statistics, 2024](#ONS2024)). However, as of May 2024, only 59.1% of patients were seen within 18 weeks ([NHS England, 2024\*](#NHSE2024)), and this goal has not been met since September 2015 ([British Medical Association, 2024](#BMA2024)). This effect has been seen across all medical specialities ([The King's Fund, 2023](#Kings2023)).

In addition to the number of patients on recorded waiting lists, there are patients considered to be ‘hidden’ from the system, that do not appear in RTT statistics. These are patients that require treatment but have not yet presented to health providers or have not been able to be seen by one ([British Medical Association, 2024](#BMA2024)). From initial interactions with the Patient and Carer Advisory Group established to inform this project, we have heard that most patients experienced waiting for treatment for far longer than 18 weeks, but also had to interact with their GP multiple times before the referral was made. Since the NHS starts the referral to treatment clock only once a patient has been referred to a consultant-led service, these interactions with GPs are not reflected in the recorded waiting times. Furthermore, being aware of current pressures on consultant-led services GPs may be more reluctant to place patients on RTT pathway and may require higher levels of confidence that specialised care is needed then previously before making a referral ([British Medical Association, 2024](#BMA2024)).

**Stakeholder and PPIE engagement**

When discussing this topic with local representatives, we tried to identify which waiting lists are of the greatest significance to our local area. After discussions, hip replacements and cardiothoracic surgery were identified as the most relevant waiting lists to focus on as part of the deep-dive analysis (see Section 3). During the stakeholder engagement sessions, the focus on hip replacements was suggested due to it having one of the longest waits in England with patients reporting poor experiences while waiting, such as pain and reduced mobility. Cardiothoracic surgery was also brought forward as it represents a complex waiting list which is likely to cause considerable additional costs to healthcare providers as it’s expected that patients waiting for cardiothoracic surgery will have higher rates of GP appointments and / or visits to the Accident and Emergency (A&E) department due to high risk of repeat heart attacks or other adverse events. Given these reasons, we decided to further explore these waiting lists in our deep-dive analysis.

**Aims, research questions and objectives**

In this document, we outline our plan to analyse waiting lists in North West London (NWL), explore the demographics of these patients, and the impact of waiting on patients. Our analysis will focus on delivering the following outputs:

**Table 1. Overview of research objectives**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Objective** | **Objective description** | **All pathways** | **Completed pathways** | **Treated Pathways** |
| **Primary objective – descriptive analysis** | | | | |
| P.O.1 | Describe the distribution of waiting times for completed, and ongoing RTT pathways. | **X** | **X** | **X** |
| P.O.2 | Describe the distribution of waiting times by specialty, treatment and procedure codes | **X** | **X** | **X** |
| P.O.3 | Describe the distribution of waiting times by demographic and geographic characteristics. | **X** | **X** | **X** |
| P.O.4 | Describe the distribution of waiting times by comorbidities and common risk factors. | **X** | **X** | **X** |
| P.O.5 | Describe the reason for ending the pathway by demographic and geographic characteristics, comorbidities, common risk factors, specialty, treatment and procedure codes and waiting times. |  | **X** | **X** |
| P.O.6 | Describe the distribution of numbers of patients with multiple RTT pathways by demographic and geographic characteristics, comorbidities, common risk factors, specialty, treatment and procedure codes and waiting times. | **X** | **X** | **X** |
| P.O.7 | Describe the healthcare activity and estimate costs before and after treatment |  |  | **X** |
| **Secondary objectives – causal analysis** | | | | |
| S.O.1 | Identify patient-level predictors of the waiting times for hip replacements and cardiothoracic surgeries. |  |  | **X** |
| S.O.2 | Describe the procedure specific adverse outcomes by waiting times, as well as demographic and geographic characteristics. |  |  | **X** |
| S.O.3 | Estimate the consequence of waiting times on likelihood of adverse events for hip replacements and cardiothoracic surgeries. |  |  | **X** |
| S.O.4 | Estimate the consequence of waiting times on healthcare costs for hip replacements and cardiothoracic surgeries. |  |  | **X** |

The descriptive analysis will align with the core analysis plan set out by The Health Foundation and will focus on providing a detailed overview of waiting lists across NWL. The causal analysis aims to provide an understanding of the consequence of patients experiencing long waits but will start with a predictive tasks design to understand what features are associated with longer waits, as well as descriptive analysis that dive deeper into adverse events relevant for the selected procedures. This part of the study will be performed with the support of clinical leads with expertise in hip replacement and cardiothoracic surgeries.

## Data and data linkages

This study will be conducted using the Discover database (the deidentified version of the Whole Systems Integrated Care (WSIC) database). Discover is one of the largest depersonalised linked health data sets in Europe, accessible via Discover-NOW Health Data Research Hub for Real World Evidence through their data scientists and Information Governance (IG) committee-approved analysts. It is hosted by Imperial College Health Partners (ICHP) and is made available for research in a Trusted Research Environment (TRE). Discover provides linked coded primary care, acute, mental health, community health and social care records for over 2.7 million patients who live in and are registered with a GP in NWL. This database is fed by data from over 400 provider organisations including 350+ GP practices, two mental health and two community trusts and all acute providers attended by NWL patients. Primary care is from a variety of GP systems including EMIS and SystemOne. The underlying coding structure are READ, SNOMED and MEDCODE for primary care data and ICD-10, OPCS4 and SNOMED for secondary acute and mental health.

## Statistical methods

**3.1** **Study design**

To obtain primary objectives the proposed study will implement a retrospective cohort design following patients who entered waiting lists during the study period. The causal analysis will be performed via a quasi-experimental design utilising matched [ref] or synthetic controls [ref] techniques.

**3.2** **Study period**

The patients referred to treatment between April 1st 2022 and March 31st 2024 will be used to construct the study population. The outcome variables (see **Section X**) will be obtained based on primary and secondary care records between the study start and end date. However, we might change the study period after discussions with our clinical leads in order to ensure that the time period used in this study would be sufficient to allow us to capture potential patient key health outcomes.

Patients found in more than one waiting list (those who are on waiting list for different medical specialities) will only be included once in the cohort, any event after being placed in a waiting list for the first time will be investigated as an outcome. A post-covid period has been selected to ensure that the most recent record is examined.

**3.3** **Study population**

**Cohort 1 – all RTT pathways:** 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).

Exclude those with unknown clock start, patients deregistered before or during the referral date.

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

**Cohort 3 – treated RTT pathways**: 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 (available linkages may vary locally).

*We will also explore the possibility of identifying patient treatment based of SUS data as the coding of patient treatment in the Clock stops table is poor.*

**3.4** **Definitions of outcomes and exposures**

*Preliminary lists are provided and will be validated by clinical leads to include condition specific risk factors.*

Some variables will be calculated for pre-, during-, post- referral date, as well as post treatment with appropriate follow up – timepoints table TBC.

**Table 2. Definitions of waiting lists variables**

| **Variable** | **Details** | **Type of variable** | **Data Sources** |
| --- | --- | --- | --- |
| Waiting list clock start | Time at which the patient was put on a waiting list | Date | National\_WL\_ClockStarts |
| Waiting list clock stop | Time at which the patient was taken out of the waiting list | Date | National\_WL\_ClockStops |
| Reason for clock stop | Reason for which patient was taken out of the waiting list | Categorical | National\_WL\_ClockStops |
| Patient treatment | OPCS code describing the treatment that the patient received | Categorical | National\_WL\_ClockStops |
| Medical speciality | Medical speciality treating patients in waiting list | Categorical | National\_WL\_ClockStops |

**Table 3. Definitions of demographic and geographic variables**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **Details** | **Type of variable** | **Data Sources** |
| **Demographic Characteristics** | | | |
| Age | Age at date of referral will be calculated from the month of birth recorded in patient index.  Month of birth since the deidentified data doesn’t hold exact dates. | Integer | PatientIndex |
| Age group | Age group at date of referral | Categorical | PatientIndex |
| Sex | Currently recorded as patient’s gender; ‘FEMALE’, ‘MALE’, or ‘UNKNOWN’ | Categorical | PatientIndex |
| Ethnic group | Patient’s ethnicity, using ethnic group classification | Categorical | PatientIndex |
| IMD decile | The Index of Multiple Deprivation decile of the LSOA of the patient’s current residential address. | Categorical | PatientIndex |
| **Geographic characteristics** | | | |
| Borough (residence) | One of nine categories: Ealing, Hillingdon, Brent, Harrow, Hounslow, Westminster, Kensington and Chelsea, Hammersmith and Fulham, non-NWL | Categorical | PatientIndex |
| Primary Care Network (PCN) | The PCN that the patient’s current GP practice belongs to. | Categorical | gpnetworks\_earlyadopters. |
| LSOA (residence) | The LSOA of the patient’s current registered address | Categorical | PatientIndex |

**Table 4. Definitions of comorbidities and common risk factors**

| **Risk Factor** | **Details** | **Type of variable** | **Data Sources** |
| --- | --- | --- | --- |
| Smoking status | Smoking status, defined as one of the following four categories, will be derived based on the most recent coded value in primary care: “Smoker”, “Non-smoker”, “Ex-smoker”, or “Unknown” (if no codes indicating status are available). | Categorical | gp\_events |
| BMI value | Measure of patient’s weight in relation to their height. Nearest value to the index date up to 1 year from index | Continuous | gp\_events |
| BMI category | If a patient does not have a BMI value, we will report on BMI categories (e.g., “BMI ≥ 30”) if these are available. | Categorical | gp\_events |
| Electronic Frailty Index (eFI) | Electronic Frailty Index, a measure of patient frailty, incorporates 36 deficits constructed using 2,171 CTV3 codes | Continuous | PatientIndex |
| Long term conditions (LTCs) | The presence of a set of long-term conditions flagged in existing Discover Now LTC table – ask clinical lead which conditions are of most interest | Set of Binary variables | FactPatient\_ LongTermConditions |
| Comorbidity status | Recorded as “Single LTC”, “Comorbidity”, “Multimorbidity”, and “NA” for no record of LTC | Categorical | FactPatient\_ LongTermConditions |

###### **Table 5. Definitions of adverse events of interest for secondary objectives**

|  |  |  |  |
| --- | --- | --- | --- |
| **Outcome Name** | **Details** | **Type of variable** | **Data Sources** |
| Death (all cause) | Death (all cause) recorded in the patient index table. | Binary | PatientIndex |
| Month of Death | Month of death (all cause) recorded in the patient index table. | Date | PatientIndex |
| **Outcomes for cardiothoracic surgery** | | | |
| Myocardial Infarction | Any primary care record of, or hospitalisation with, a diagnosis of myocardial infarction. | Binary, Date | GP\_Events  SUS\_AE  SUS\_OP  SUS\_APCSpell |
| Stroke (ischaemic) | Any primary care record of, or hospitalisation with, a diagnosis of ischaemic stroke. | Binary, Date | As above |
| Unstable angina | Any primary care record of, or hospitalisation with, a diagnosis of unstable angina. | Binary, Date | As above |
| Transient Ischemic Attack (TIA) | Any primary care record of, or hospitalisation with, a diagnosis of TIA. | Binary, Date | As above |
| Peripheral Arterial Disease | Any primary care record of, or hospitalisation with, a diagnosis of peripheral arterial disease. | Binary, Date | As above |
| Revascularization | Any primary care record of, or hospitalisation with, a revascularization procedure. | Binary, Date | As above |
| Stroke (haemorrhagic) | Any primary care record of, or hospitalisation with, a diagnosis of haemorrhagic stroke. | Binary, Date | As above |
| **Outcomes for hip replacement** | | | |
| TBD | TBD | TBD | TBD |

**Table 6. Definitions of healthcare utilisation variables**

| **Variable** | **Details** | **Type of variable** | **Data Sources** |
| --- | --- | --- | --- |
| **Primary care utilisation** | | | |
| No. of GP appointments | Count of unique GP event dates where more than one code is recorded, in order to attempt to remove admin codes where the patient did not attend. | Continuous | GP\_Events |
| Primary care prescriptions for pain | Count of prescriptions recorded in GP\_prescriptions data, selection of SNOMED required. Repeated SNOMED descriptions for the same day will be ignored. | Continuous | GP\_Prescriptions |
| Primary care prescriptions for mental health | Count of prescriptions recorded in GP\_prescriptions data, selection of SNOMED required. Repeated SNOMED descriptions for the same day will be ignored. | Continuous | GP\_Prescriptions |
| Sick notes | Number of Med3 certificates recorded in primary care during the waiting period | Continuous | GP\_Events |
| **Secondary care utilisation** | | | |
| No. of A&E attendances | Count of AE attendances, split by department type. | Continuous | SUS\_AE |
| No. of Secondary care admissions | Number of spells, split into admission type (emergency, elective, day case, other) | Continuous | SUS\_APCSpells |
| No. of outpatient appointments | Number of appointments, split into attended, did not attend, or cancelled. | Continuous | SUS\_OP |
| Days spent in hospital | Total number of days a patients spent admitted in secondary care. Calculated from spell start and end dates. | Continuous | SUS\_APCSpells |

**3.5 Statistical approaches**

This section describes the analyses that will be performed to address the primary and secondary research objectives. The planned analysis will start with data quality checks which will involve investigating whether waiting lists data sets align with the number of patients waiting for treatments as recorded in SUS data. The details of these quality checks will be agreed after consultations between the wider NDL team and NHSE team currently investigating waiting lists.

**3.6** **Methods for addressing missing or erroneous data**

Missing data and erroneous data checks will be implemented prior to starting analysis on all listed variables. As a first step the numbers of NAs per covariate will be summarised. Secondly, for numerical or time variables validity thresholds will be established to remove any non-sensical entries. These entries will be replaced with NAs. After that the pairwise missingness relationships between features will be examined using *GGally* ([Schloerke et al., 2024](#Schloerke2024)) package. An approach to addressing missing data will then be selected on a per-covariate bases. The following list summarises these approaches and describes the circumstances in which these will be implemented.

1. **Treating NAs as its own category:**
   * *When*: This approach is suitable when missingness is informative and may carry important information. For categorical variables, treating NAs as a separate category allows the model to distinguish between missing and non-missing values explicitly.
   * *Advantages*: Retains all available information. Maintains the original structure of the data. Suitable for categorical variables where missingness may have meaningful interpretations.
   * *Considerations*: It can introduce bias if missingness is not random and may increase the complexity of the analysis and interpretation. Note that since many extracted variables will represent binary flags, for example, presence or absence of specific diagnosis, for these variables the lack of an entry will always be interpreted as a lack of diagnosis.
2. **Removing patients with NAs in a specific covariate:**

* *When*: Appropriate when the proportion of missing data for a specific covariate is low and therefore can be deleted without losing substantial information.
* *Advantages*: Simple and straightforward. Eliminates missingness for the selected covariate.
* *Considerations*: This can lead to loss of valuable information, especially if the proportion of missing data is substantial. May reduce the sample size and statistical power. If missingness is not random key subset of the study cohorts may be omitted in the analyses.

1. **Removing covariates with too many NAs:**

* *When*: Suitable when certain covariates have a high proportion of missing data and cannot be adequately imputed or treated as a separate category.
* *Advantages*: Simplifies the analysis by focusing on variables with less missingness. Reduces the risk of introducing bias due to imputation.
* *Considerations*: It may lead to loss of potentially important predictors. Requires careful consideration of the impact on the research question and model validity.

1. **Imputation:**

* *When*: Imputation ([Rubin, 1987](#Rubin1987)) is appropriate when missingness is random or can be modelled adequately. It is often used when removing missing data would result in loss of valuable information.
* *Advantages*: Retains sample size and statistical power. Preserves the original structure of the data. Allows for more complete analyses.
* *Considerations*: Imputation methods are likely to introduce bias since several assumptions need to be made for the synthetic data to be generated. The choice of imputation method should be based on the distribution of the data and the mechanism of missingness and may include applying Mean/Median/Mode or regression models.

**3.7 Descriptive Analysis**

The descriptive summary statistics that will be reported for primary objectives and the S.O.2 objective are outlined in **Table 1**. Examples of table shells that will be used to present the results can be found in the Appendix.

###### **Table 7.** **Overview of descriptives statistics to be reported**

|  |  |
| --- | --- |
| **Outcome type** | **Descriptive statistics** |
| Binary | N (%) |
| Categorical | N (%) |
| Count | Count variables will be grouped into ranges (e.g., “Zero”, “1-3”, etc.). The ranges that summarise and communicate the data most effectively will be decided based on early results. |
| Continuous | Mean (standard deviation)  Median (Minimum, Q1, Q3, Maximum) |
| Time to event | Mean (standard deviation)  Median (Minimum, Q1, Q3, Maximum) |

**3.8 Methods for costs derivation**

* Methodology will be developed for primary care costs
* Secondary care costs will be taken directly from the data (including costs of hospital spells and high costs drugs)
* Very broad estimates for social and community care will be made; costs analysis with and without these costs will be conducted

**3.9 Causal analysis**

* Difference-in-difference analysis will be used for analysing costs, index date – referral, groups – grouped based on waiting times
* Competing events cox regression models for time-to-adverse-events. Events to be identified with clinical leads, and group into relevant specialty related events and other adverse events used for censoring. Survival trees could be considered for better handling of nonlinearities
* Pool of potential controls will include patients waiting <18 weeks + any additional filtering established with the clinical leads.
* Matching will be performed with mixture of exact matching led by the clinical expertise and model-based matching using statistical models; non-parametric high-dimensional statistics approaches might be selected if weak models are trained with traditional methods.
* If matching fails to produce balanced controls synthetic controls (Abadie and Gardeazabal, 2003) might be used instead. Synthetic learners (Viviano & Bradic, 2022) should be considered to utilise high-dimensional and noisy data and nonlinear effects on outcomes.

**3.10** **Known limitations**

* We do not have data on private care usage, so we cannot look at how much private care usage increases while people are waiting, or whether people are choosing private care over the NHS from the start due to long waiting lists.
* We do not have data on how long it takes from the time the patient notices an issue to the time they are referred for treatment. For example, if a patient has to visit their GP 5 times before being referred for treatment, this will not be included in our analysis of waiting times.
* Difficult to pick which events should be considered as relating to a wait for the two selected procedure and which should be used censored.
* Extensively sensitivity analysis is needed, not only few cohorts but potentially 100s of different iterations of definitions to test stability of results. Warrants scripting complex loops which test combinations of assumptions.

## Governance

**Availability of data and materials**

The project will be presented to the data access committee at Information Governance Services Limited to approve access to Discover dataset.

***Ethics approval and consent to participate***

Given the retrospective nature of the study there will be no ethics approval required beyond the Data Access Committee.

## Impact, dissemination and engagement

We have established a Patient and Carer Advisory Group made up of 8 members, all with lived experience of waiting lists for elective care. The group has already fed into our research question development through the sharing of their own lived experience and has reviewed our initial statistical analysis plan to help identify limitations.

We plan to present our interim results to the Patient and Carer Advisory Group to help us understand the trends we are seeing. This will include discussions around anything that resonates them, surprises them, or requires further exploration. We will also work with some members of the group to gather additional insights from patients on a waiting list for a hip replacement or cardiothoracic surgery. This will be done either through interviews, workshops, or an alternative involvement method.

At the end of the project, we will present our final results to the Patient and Carer Advisory Group for further interpretation of the findings. We will also discuss the implications of our findings for future policy and research recommendations, and how best to disseminate the findings to the general public. We will work with several members of the group to develop a lay output to assist in disseminating the findings – in previous topics, this has been an infographic or video. The output will be shared on social media and through relevant community organisations and networks. We will also have several members of the group present the findings and why they matter from a patient perspective to project stakeholders such as our clinical lead.

We will also present the findings to the relevant ICB and provider collaborative groups in NWL and beyond.

## Appendix

**Preliminary Table Shells**

|  |  |  |
| --- | --- | --- |
| **Table A1. Breakdown of patients that have more than one clock start, more than one clock stop, and those without a clock stop** | | |
|  | n | % |
| >1 clock start |  |  |
| >1 clock stop |  |  |
| No clock stop |  |  |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Table A2. Breakdown of patients for each demographic and clinical variable, broken down by what was the reason of their clock stop** | | | | | | |
| Patient pathway characteristics | Treatment – admitted | | Treatment – non-admitted | | Clock stop for non-treatment: clinically appropriate to return patient to primary care | |
|  | n | % | n | % | n | % |
| Total |  |  |  |  |  |  |
| Specialty (one per row) |  |  |  |  |  |  |
| Treatment function (one per row) |  |  |  |  |  |  |
| Procedure Code (one per row) |  |  |  |  |  |  |
| Male |  |  |  |  |  |  |

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Table A3. Breakdown of patients for each demographic and clinical variable, broken down the how long they have been on the waiting list (less than 18 weeks, more than 18 weeks, more than 36 weeks, and more than 52 weeks)** | | | | | | | | | | |
| Patient characteristics | Total | | <=18 weeks | | >18 weeks | | >36 weeks | | >52 weeks | |
|  | n | % | n | % | n | % | n | % | n | % |
| Total |  |  |  |  |  |  |  |  |  |  |
| Borough (one per row) |  |  |  |  |  |  |  |  |  |  |
| Male |  |  |  |  |  |  |  |  |  |  |
| Female |  |  |  |  |  |  |  |  |  |  |
| Age band (one per row) |  |  |  |  |  |  |  |  |  |  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Table A4. Overview of the time patients waiting for treatment, and low long they waited for their first outpatient appointment** | | | | | | | | |
| Patient pathway characteristics | Length of overall referral to treatment wait | | | | Length of ‘referral to first outpatient wait | | | |
|  | Mean | Median | St. Dev | IQR | Mean | Median | St. Dev | IQR |
| Total |  |  |  |  |  |  |  |  |
| Specialty (one per row) |  |  |  |  |  |  |  |  |
| Male |  |  |  |  |  |  |  |  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Table A5. Overview of healthcare utilisations and prescriptions prior to being in a waiting list compared to 4 prior to treatment** | | | | | | | | |
|  | Whilst waiting (per person per week) | | | | 4 months before treatment (absolute) | | | |
|  | Mean | Median | St. Dev | IQR | Mean | Median | St. Dev | IQR |
| Total |  |  |  |  |  |  |  |  |
| Specialty (one per row) |  |  |  |  |  |  |  |  |
| Male |  |  |  |  |  |  |  |  |

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