# The Networked Data Lab: Analysis plan for Topic 2 on children and young people's mental health

## Satellite analysis for the Leeds Lab

# Contents

## Reasearch rationale, aims, objectives

*Rationale:*
The Leeds NDL team has conducted research to establish gaps in the knowledge of both the Leeds population and Leeds CCG informatics teams regarding mental health services. The team reviewed currently held research and information and conducted focus groups. The team explored the feasibility of pursuing the lines of enquiry generated by this research using the primary dataset, the Mental Health Services Data Set (MHSDS).[1]

The following findings informed the direction of the research towards examining the referral routes of mental health services:

- A recent prevalence report (from NHSD), based on the Leeds CCG Plans 2019-2020, suggests that only 36% of the expected prevalent population is currently receiving mental health support.
- An insight report highlighted multiple routes of referral to mental health services, along with multiple services being used by different demographic groups.
- Amongst these reports and an initial focus group, there was a clear lack of understanding of services and their access routes amongst young people.
- The first task and finish group highlighted referral routes as a significant area of interest. This was focused on the ways Children and Young People (C&YP) with mental health needs were identified by the service providers, and how C&YP access support on their own accord. Of particular interest were demographics comparisons between different referral routes, the level of knowledge in C&YP about mental health service access options, and people's lived experience of accessing mental health services in Leeds.

*Proposed Research Question:*
How are children and young people (aged 11+) accessing mental health services in Leeds, do they reflect the demographic picture identified by national prevalence modelling and are these services 'meeting the needs' of this cohort? What, if any, impact has the COVID 19 pandemic had on referrals, service use and outcomes for this cohort?

*Supplementary Questions:*
Exploration of these questions will be dependent on additional resource joining the analytical team

- Deep dive into the use of crisis services from referral, supplementary service use and outcomes. Understanding of whether:
    - C&YP are 'known' to services before they enter crisis
    - C&YP use 'other' services prior to entering crisis
    - C&YP are 'discharged' post use of crisis services or referred into other pathways

- Exploration of the confounding factors which could determine a 'successful' outcome to treatment; a successful outcome will be represented by C&YP not using crisis or emergency services within a pre-defined period post discharge:
    - Referral method

[1] Mental Health Services Data Set (MHSDS) - NHS Digital

- Ethnicity
- Age
- Gender
- Deprivation
- Service types
- Disorder – classified using proxy measures due to limited referrals with primary diagnoses (ICD-10) assigned.

# Cohort

**Defining the Mental Health Cohort**

The descriptive analysis will allow us to have a better understanding of who makes up this group. A mental health patient is defined as any patient registered at Leeds GP practice referred to any mental health service from any provider in the region between 1st April 2016 through to 31st April 2021. Only mental health patients aged 11-25 years at date of referral will be included in our analysis.

All Patients referred to mental health services will be included in Output 1 and 2. For Output 3, patients without a valid LDM pseudonym will be excluded from the analysis. In Output 4, patients who have died or moved out of Leeds will be omitted from the data where there is sufficient information to confirm death or relocation.

# Methods

The NHSD prevalence report categorises patients into three age-bands: 11-16, 17-19 and 20-25 years old. Using the same categories will allow comparison between age-bands, and with national prevalence data. Comparing C&YP (11-16 years old) and adult patients (19-25 years old) will enable an exploration of demographic variations in those age-bands, whilst the 17-19 age-band will enable study of the transition from C&YP to adult services.

**For all analyses the total size of the cohort and the number of individuals with missing or unknown information will also be reported.**

The analysis will be split into three (possibly four) outputs, detailed below:

**Output 1: Demographics of mental health cohort**

This output will characterise the mental health cohort to understand inequity and pattern of access to children's MH services. Demographic variables including age (band), gender, ethnicity, and deprivation will be used. Supplementary data about young people is less routinely collected such as sexual orientation, Child Protection (CPP) status, whether they supervise other children or if they are a young parent. Including these variables will add further context to the cohort demographics or identify missing data and poorly completed fields.

Demographic and supplementary variables (and interactions) will be summarised by counting the distinct number of patients in each category

**Interactions of interest:**

- Mental Health Service team types referred to – Demographics and supplementary variables
- Source of Referral to Mental Health services – Demographics and supplementary variables

**Output 2: Referral routes of mental health cohort and services accessed**

This output will quantify routine MHSD data to understand how and why mental health patients access services. The source of referral, reason for referral, mental health services requested, and specialist teams they are referred to will be broken down by demographic variables from Output 1. The results will be compared with the prevalence estimates to determine the proportion of population being over-represented in services from NHS Digital Survey.

Our providers have explained that clinicians are often reluctant to clinically diagnose children and young people due to existing stigma around mental health conditions impacting their education and wider life. Consequently, ICD-10 codes are not attributed. Poorly populated clinical coding limits capacity to identify clinical reasons for referral to mental health services. However, the prevalence data is grouped into four broad categories: emotional, behavioural, hyperactivity and other less common mental health disorders. There is potential to assign these categories from the administrative data available (such as source of referral, services requested and care professional types). This is subject to approval from both providers and clinicians.

Referral and Service variables (and interactions) will be summarised by counting the distinct number of patients, referrals, and care contacts in each category.

**Interactions of interest:**

- Mental Health Service Team Type Referred To – Demographic variables
- Mental Health Source of Referral – Demographic variables

**Output 3: Outcomes of referrals or transition of C&YP patients to adult services**

Output 3 will assess whether services are ‘meeting the needs’ of patients, by understanding parallel use of other services and outcomes on discharge.

Other service use by C&YP before and during treatment will be determined by linking mental health patients to their SUS records and aggregating number of AE attendances, Community Health contacts, in-patient admissions and bed-days, out-patient appointments, out-of-hours (OOH) appointments, 111 calls, and adult social care activity.

Post-treatment outcomes will be reviewed by analysing mental health service discharge, onward referrals into other MH services, transition to adult services, and changes in coded assessment scores.

Analysis of 17-19 year olds will focus on the mental health of people transitioning from C&YP to adult services and reveal pathways (or lack of) between C&YP outcomes and adult service

referrals. This may also indicate whether C&YP patients who are not referred to adult services ultimately rely on crisis services.

Outcome and transition variables (and interactions) will be summarised by counting the distinct number of patients, referrals etc in each category.

**Outcome and transition variables:**

- Referrals closed
- Onward referrals
- Crisis services accessed
- A&E attendances
- In-patient (IP) admissions
- Out-patient (OP) services

**Interactions of interest:**

- Outcome and transition variables – Demographics
- Outcome and transition variables – Referral and Services variables

**Output 4: Use of crisis services by mental health cohort pre, during and post COVID lockdown (subject to analytical capacity)**

Building on the descriptive analysis of Output 3, Output 4 will be a deep dive into the use of crisis services by C&YP from referral to supplementary service use and outcomes. Patients will be included based on whether:

- C&YP are 'known' to services before they enter crisis
- C&YP use 'other' services prior to entering crisis
- C&YP are 'discharged' post use of crisis services or referred into other pathways

Interrupted time-series analysis will be used to determine the difference in access to crisis services for each group above, before (pre), after (post) and possibly during lockdown. It is expected that there was a significant level change for all groups, but also a difference in magnitude between groups.

## Data

Our analyses will rely on the following data sources: -

- Mental Health Services Data Set (MHSDS) for patient demographics, referrals and services accessed, clinical diagnoses (limited availability), mental health disorder categorisation, outcomes and transitions variables.
- Secondary Uses Service (SUS) such as MH services provided as outpatient care, other parallel services provided to patients, services provided to patients following discharge from MH services.
- Improving Access to Psychological Therapies services (IAPT) for information on C&YP transitioning to adult services
- Primary Care Records
- Adult social care data extracts

- External open data sources and/or APIs for the Index of Multiple Deprivation (IMD), NHS Data Dictionary (R package), Organisation Data Service (ODS), clinical coding (TRUD, snomedCT)[2]
- Qualitative data captured through the NHSD prevalence report and applied to the Leeds population.

## Data Linkage

The data sources available will be linked at patient level (where possible)

- Direct and indirect linkage according to MHSDS schema version 4.0.
- Patient level data linkage from MHSDS records to data assets in the Leeds Data Model (SUS, IAPT, ASC) through bridging files to local pseudonym.

## Limitations

- Most new referrals don't have a primary diagnosis (ICD-10) recorded which limits our capacity to categorise patients and their healthcare activity according to mental health disorder. In addition, direct comparisons with mental health disorders reported in NHSD prevalence report become difficult, although attribution based on service type is being considered.
- Inconsistency of data content and data item completion between providers
- Difference in cohort coverage between providers, many providers also serve distinct age-ranges which may need to be accounted for in service comparison.
- There are multiple versions of MHSDS schema in use depending on intermediate database (IDB)[3] submission date which potentially require separate "Extract, Transform, Load" (ETL) protocols to assemble longitudinal datasets.
- Multiple versions of bridging files exist depending on IDB submission date and approximately 10% of patients in MH cohort do not have a bridge to the pseudonymised key in the Leeds Data Model (LDM). This impacts cohort size for analysis in output 3 and 4 where the MH cohort will be linked to health service use in other LDM data sets. Output 1 will also detail the number of patients with/without a bridge to LDM pseudonym.
- The IDB submission process to MHSDS has changed over time, with some fields retired on version changes, again restricting longitudinal datasets to certain variables.

## Statistical methods

Output 4 will utilise pseudo-experimental methods to quantify the real-world impact of.

- Whether patients are known to other mental health services prior to crisis access.

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[2] Technology Reference data Update Distribution TRUD (digital.nhs.uk)
[3] Refers to step in NHS Digital MHMDS submission process further information here

- COVID-19 lockdown period(s) on access to mental health crisis services in Leeds.

Crisis service activity pre-COVID19 will be characterised between April 2016 and February 2020, assessed for periodicity (seasonality), annual trends and the stability of population (patients added and removed from the Mental Health cohort). Several other predictor variables will be considered (age, deprivation etc) and included in the time series model if suitable.

If the data is suitable, then interrupted time-series analysis will be used to quantify the changes in service activity pre, post and possibly during COVID-19 lockdown(s). This technique is used primarily to understand the impact of a clinical / service intervention over time, but the national COVID-19 lockdown impacted all services. Therefore, identifying a suitable counterfactual is difficult in these circumstances and it may be more fruitful to look at differences between groups previously known / unknown to mental health services.

There may be limitations on historic data (back to April 2016) due to the improvement of data collection and quality over time. However, the core variables (referrals, care contacts, etc) are expected to be good quality throughout, with supplementary variables being more heavily affected.

## Dissemination and engagement

The outputs and findings from this analysis will be distributed in accordance with the Leeds Lab NDL Comms plan – see separate document for further details.