NHS Leeds CCG & City Council Satellite Analysis - Executive Summary

Mental Health of Children and Young People in Leeds

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1 Introduction

A large proportion of mental illnesses develop by early-adulthood (Kessler et al. 2007), with up to 75% of major mental illnesses having presented by age 25 (Solmi et al. 2021). However, despite the increased need during this period, the consistency of help via NHS mental health services varies greatly, particularly around age 18 where patients are transferred from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Additionally, studies across England have shown that the distribution of mental illnesses is not homogeneous across the population, with sexual identity, ethnic background, level of deprivation, and social and family circumstances all contributing to increased levels of mental illness (NHS Digital 2018).

Across Leeds, comparison with prevalence studies (NHS Digital 2018) has suggested that only 36% of the expected population at risk is receiving mental health support, with variations across key factors such as sexual identity and social and family circumstances unknown. This study aims to extend research around this area, and aims to answer the following questions:

> Has the mental health service across Leeds met the needs of children and young people (C&YP; aged 11-25), and to what extent has the service been used across the different communities throughout Leeds? Does this reflect the demographic picture identified by national prevalence modelling?
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> What pathways for referral are used by C&YP, and how does entry into the service and contact once in the service vary across different communities? What effect if any does the transition of care from child/adolescent to adult services have on people's outcomes? How do pathways differ from acute care into dedicated mental health services after mental health related inpatient spells?
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> What, if any, impact has the COVID 19 pandemic had on referrals, service use and outcomes for this cohort?

By looking at both the coverage of mental health services across Leeds and the pathways of people once they're in contact with the service, we can get a full view of the key areas of need for communities.

2 Data Processing

All NHS data-sources used in analysis were available at patient level and were routinely collected, with linkage enabled for most patients via a pseudonymised NHS Number. External data sets were linked in on geography level. The following data sources were used in analysis:

- Mental Health Services Data Set (MHSDS), comprising data from all NHS-funded mental-health organisations. Data included patient lists and associated demographics; referrals, including sources, routes, and outcomes; and care contacts/activities. Data did not include IAPT referrals or IAPT care contacts.
- Secondary Uses Service (SUS), comprising data from all secondary care providers. Data included inpatient, outpatient, and accident and emergency.
- Yorkshire Ambulance Service Data (YAS), including 111 calls.
- Improving Access to Psychological Therapies (IAPT), comprised of data for patients with anxiety and depression.
- Primary Care Records for all Leeds-registered patients (from EMIS & SystmOne)
- Mortality data
- Office of National Statistics census data and population estimates
- LSOA level deprivation data (Indices of Deprivation)

As MHSDS contains multiple duplicate records for every item (such as referral, patient, care contact, etc), we simplified the full data set down and created Views of the tables. These were built by taking only the most recent record per item, meaning that in cases where variables can change (for example scores recorded) only a snapshot of the information was retrieved. However, despite this simplifying the data set allowed for significantly more rapid analysis of the data, with much less complication in de-duplicating records during analysis.

2.1 Study Aims and Cohorts

Four main outputs were identified through discussion with a Task and Finish Group (TFG), consisting of Leeds Networked Data Lab (NDL) analysts, mental health service users, and mental health service providers. For the first output, we aimed to frame patterns of service use and inequalities in service provision through descriptive statistics across key factors. Output two was aimed to quantify patterns of access to mental health services, investigating referral sources and routes, and breaking these down further by demographic factors. Output three looked at the effect of the CAMHS-to-AMHS transition, and more generally the causes of patient dropout. Additionally, in output three we investigated non-dedicated mental health service usage, looking at inpatient spells and comparing patient demographics with those within the mental health service, and analysing patient post-crisis episode entry into the mental health service. Finally, in output four, we quantified the change in the mental health service due to the COVID-19 pandemic and look at the effects on patients before, during, and after the national lockdowns.

It was highlighted by the TFG that a significant amount of work in the past had been performed which focussed on people with depression and anxiety disorders, while relatively little had been done on people with more complex conditions. As such, it was decided that we would focus on non-IAPT services, as these were more likely to cover a range of conditions and needs, and analysis into these would provide the most benefit to services across the city.

Different cohorts were used for these outputs:

- Outputs 1 and 2 were centred upon patients known to the mental health service, and so all patients referred to dedicated mental health services (i.e. all patients recorded within MHSDS) between April 2016 - March 2021, who were between 11-25 at age of referral were included, with external data such as census/population estimates included for prevalence comparisons.
- Output 3 required a cross-reference with various healthcare records, and so patients without a valid Leeds Data Model (LDM) pseudonym were excluded from analysis. Output 3 was further split into three segments ("transition," "dropout," and "self-harm"), with different inclusion criteria for each segment.
  - Patients with at least one care-contact as a 17-18 year old between April 2016 - March 2021 were included in the "transition" segment. The primary data set used in this analysis was MHSDS.

  - Patients with at least one care-contact as an 11-25 year old between April 2016 - March 2021 were included in the "dropout" segment. The primary data set used in this analysis was MHSDS.
  - 11-25 year old patients who attended an inpatient spell with a secondary diagnosis of intentional self-harm or self-poisoning (ICD-10 X60-84) at Leeds Teaching Hospitals between April 2016 - March 2021 were included in the "self-harm" segment. Patients who died during or soon-after their hospital spell were excluded from analysis. The primary data set used in this analysis was SUS, and and MHSDS, IAPT, and GP mental health appointments were used to gauge patients' passages into the mental health service post-spell.
- For Output 4, 11-25 year old patients (at time of referral) who were referred to a dedicated mental health service between April 2016 - March 2021 were included for analysis. The primary data set used in this analysis was MHSDS.

2.2 Data Definitions

Some terms are used across analysis, and so definitions are listed here.

- Referral/Service Request - a request made by or on behalf of a patient to one or more mental health (MHSDS) teams for a distinct package of care. Each referral has a date the referral was made, along with the date the referral was either completed, rejected, or cancelled.
- Care contact - a contact with a mental health service (MHSDS) team. Multiple care contacts can be made within one referral, as patients complete their care.
- Care activity - a specific activity within a care contact. Multiple care activities can be made within one care contact, for example if multiple consultation methods are used. For example, if both telephone and SMS services are used within one care contact then this may be recorded as two care activities within the same contact.
- Crisis referral - a crisis referral is a referral to a specific crisis resolution team within the mental health service (MHSDS).
- CAMHS services - Child and Adolescent Mental Health Services are services offered to 0-18 year olds, with a transition into adult services occurring at some point between the ages of 17-19. Generally within our data, the bulk of NHS CAMHS services are offered by Leeds Community Healthcare, and most adult services are offered by Leeds and York Partnership Foundation Trust. However, multiple providers are listed within the data set, each offering services to different cohorts.

3 Methods

Initially for Output 1, descriptive statistics of the users in contact with the services were produced, to gain a picture of the service as a whole. We segmented the service users by age, gender, deprivation level (from a combined Indices of Deprivation score with no health deprivation included), and ethnic background. While we originally aimed to looked further at users split by sexual identity, young carer status, Child Protection Plan status, parental status, and Looked-After Child status, data coverage for these factors was too low to allow any meaningful analysis. These variables were not considered further, but were reported back to mental health providers to allow for possible completion of the data and further analysis at a later date. Next for Output 1 we compared the demographic make-up of the service users to the demographic make-up of Leeds as a whole, based upon both the 2011 census results and mid-year population estimates. For Output 2 we followed a similar approach, but instead looked at differences in service use (such as referral source or service teams accessed) across demographic factors. Again, it was found that data sparsity only allowed for analysis to continue for a broad service team type classification.

For Output 3 we took three different approaches to compare the service pathways across a range of demographic factors, and considered the effect of a person's history in the service on their future engagement with the service. Firstly, we modelled each 17-18 year old's transition from CAMHS to adult services using

a binomial GLM, in order to find factors which are related to higher likelihood of a person remaining in contact with the service after they have been transferred. Next, we considered unexpected patient dropout from all services and looked at the related factors by running two survival models (one Cox Proportional Hazards regression model and one Competing Risks regression model), comparing each person's probability of either dropping out unexpectedly from a referral, or being discharged at the end of their referral as expected. Finally, we looked at non-mental health data; focussing on patients at Leeds Teaching Hospitals who have had inpatient spells for injuries related to self-harm or self-poisoning and comparing the characteristics of patients who are referred into the mental health service within a week to those who aren't. We ran a suite of models (binomial GLM, Random Forest, XGBoost, Support Vector Machine, and single-layer Neural Network) to predict each patient's probability of non-referral within a week, and used Partial Dependence methods to investigate each factor's effect on a patient's outcome.

Finally, for Output 4, we considered the effect of the COVID-19 pandemic on the mental health service, and looked to see the changes in referral and discharge patterns across a range of demographic and mental health-related factors. To account for a version change in the mental health data set, we looked at the numbers of referrals and discharges over time from May 2017 to September 2021, splitting the figures into three segments: Segment 1 (May 2017 - March 2020; pre-COVID), Segment 2 (March 2020 - September 2020; broadly during the first wave), and Segment 3 (September 2020 - September 2021; broadly second wave onwards), in order to find both trends in service usage as a whole (ignoring COVID), and the specific effects of the pandemic on service usage. For each time group, we linearly fitted the data to determine both the average level of service use and the direction of change, and we compared the results of this fitting across our demographic descriptors.

4 Key Findings

Clear differences in care patterns were seen by looking across demographic variables. Significant variations in the gender split of patients occur across the age range considered, peaking at mid-adolescence where around 70% of all patients are female (and around 75% of care contacts are for female patients). Variations also occur when looking at patient deprivation; when standardised to the Leeds population we have found that significantly more people in areas of higher deprivation require access to the mental health service, with around 1 in 3 more people in the 10% most deprived areas having had access to the service than those in the 10% least deprived areas. Compounding this is the finding that patients from the 10% most deprived areas require almost 33% more referrals, and experience around twice the number of crises than patients from the 10% least deprived areas. This demonstrates the significant increase in level of need for people from these areas. Finally, we considered how equitably services were used across people from different ethnic groups. Using the 2011 census as a baseline, we found that only just over half the number of people from Black, Asian, and minority ethnic (BAME) backgrounds were using the service than would be expected based upon the underlying population, showing significant improvements needed to ensure equitable care is given to all communities across Leeds.

Next, we focussed on the period of transition, where 17-19 year olds are transferred from childhood and adolescent services (CAMHS) to adult services (AMHS). Consistent with the literature, we found a sustained drop in patient retention around this transition age, with around one in five fewer AMHS patients remaining in contact with the mental health service one year past a referral. Modelling of each patient's transition from CAMHS to AMHS services showed a significant drop in transition likelihood with increasing deprivation, and found that overall, female patients were less likely to successfully transition services than male patients. This result ties in with the demographic picture of services split by gender; while there are more female patients using services, generally as age increases the disparity decreases, with a particularly sharp drop in the proportion of female care contacts occurring around 17-18. It was also found that each person's previous service use affects their likelihood of transitioning successfully, with patients who are in contact with more service teams being found to be more likely to continue care in adult services. Interestingly, patients who experience more referrals have a reduced probability of transitioning successfully, possibly showing that if a patient is re-referred multiple times then they experience worse continuation of care than if they are moved between different teams without needing to completely re-refer, although discussion with service providers

is required to test this hypothesis. Finally, no major differences were found in continuation of care across the transition gap for patients from different ethnic backgrounds.

Broadening our search slightly, we next looked to find factors associated with patients dropping out of services unexpectedly across all ages, rather than just across the transition age. By running two different survival models, we evaluated both factors relating to patient dropout and factors relating to expected closure of services. This was done in order to differentiate between services which experience low retention due to patient dropout and those which experience low retention due to expected reasons, such as those services which solely offer short-term support before onward referral.

We find that there are significant differences in patient dropout rates across different ethnic groups, with Asian/Asian British patients significantly more likely to dropout and Black/Black British patients significantly less likely to dropout than white patients. Comparing this to the finding that patients from BAME backgrounds are underrepresented within the mental health service, this suggests that both entry to the service and continued service use is a significant problem for Asian communities across Leeds. This finding has been echoed through conversations with service providers, who noted a barriers to entry for people from South Asian communities particularly. Conversely, although entry into the service is a problem for those from Black communities, once people from Black backgrounds have been referred they are more likely to continue using services until discharge by a clinician. It has been noted that this could be an indicator that only those with the most intense needs gain access to services for people from Black communities, and hence once people are in the service they are more likely to continue their treatment until the end. When looking at the breakdown of service team type across different ethnic groups, we find that proportionally more crisis and psychosis intervention teams are accessed by people from Black backgrounds, potentially validating this hypothesis, although further investigation is required. Similarly, we have found that again increased deprivation level is correlated with increased dropout rate, showing that even though people from more deprived areas are in greater need of services (and experience more crises), they are also more likely to drop out of services, requiring more work to assist people in continuation of care.

Comparing CAMHS and AMHS services, we find that CAMHS services are more likely to experience patient dropout. This goes against the finding that year-on-year patient retention is generally being higher in CAMHS services overall, suggesting that possible routes into the service must be more accessible to allow re-entry after dropout. Further work should be done to compare the routes by which CAMHS and AMHS patients re-enter services after dropping out. Finally, across all service team types we find that Non-IAPT psychological therapy referrals experience patient dropout at a significantly higher rate than community mental health services (HR: 4.25-5.37).

As a comparison, we next compared non-mental health acute care data with mental health referrals, to try to look for possible barriers to service entry. We focussed on inpatients spells related to self-harm at Leeds Teaching Hospitals and looked at the proportion of patients referred into the mental health service post-spell. We used a stack of models to predict each patient's non-referral probability, based upon demographic information, hospital spell information, hospital history data, and service capacity related information. We found that the most useful predictors of non-referral was each patient's age, demonstrating significant differences between CAMHS and AMHS referrals even post-crisis. Interestingly, the next most important factors determining non-referral likelihood were spell-related, history-related, and service-related, with patients known to the service and patients who have had previous crises significantly less likely to be referred after discharge. We have found a slight but sustained increase in non-referral probability with increased service use within the week prior to each crisis spell, suggesting that service capacity may play a role in determining whether patients are able to access mental health services after a self-harm episode. Finally, we have found that interestingly, patients from more deprived areas are slightly *more* likely to be referred into mental health services on discharge, showing more equitable service use across deprivation levels.

Finally, we considered the effect of the COVID-19 pandemic on services. We compared the number of service requests and discharges occurring pre-COVID (May 2017 - March 2020), during the first wave (March 2020 - September 2020), and after the first wave (September 2020 - September 2021), looking for both seasonal trends pre-COVID and changes in service usage across demographic factors and service team types. Across all variables, there was a relatively stable level of service usage pre-COVID, significant increases in referrals and discharges during our "COVID" time-period, followed by general decreases in service use. Generally,

during the COVID peak substantially more referrals per person were made by people living in the most deprived areas than those living in the least deprived areas, displaying the significant increase for need among these areas. We find that there were similarly stark increases in crisis service use during the peak, which correlates well with the finding that people from more deprived areas are significantly more likely to require crisis services than those from less deprived areas. Similar disparities were seen across ages, with younger people (11-16) experiencing a much smaller increase in service use than older people (17+), although while service usage decreased post-COVID for older people, there is an increase in the number of service requests for younger people.

Overall, while disparities in both access to care and continuation of care have been found here, future work should focus on a qualitative investigation into possible causes of these disparities, in order to assist with future planning. Similarly, although simple linear models were found to be good estimators of referral and discharge patterns over time, future work should look to extend these models to fully investigate the effects of the COVID-19 pandemic on the mental health service, possibly by using non-linear models to more accurately assess changes over time, or change-point analysis to precisely pinpoint times when service use changed significantly, rather than prescribing set periods to look at.

References

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