

## **#networkeddatalab**

### **Engagement Evaluation Report**

#### **Topic 2 – Access to mental health services for children and young people in Leeds**

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**Date: 13 July 2022**

#### **Context**

The [Networked Data Lab](#) (NDL) is a collaborative network of advanced analytical teams across the UK working together on shared challenges and promoting the use of analytics in improving health and social care. The Leeds Office of the Integrated Care Board (ICB) and Leeds City Council are one of five partners across the country who successfully bid to take part in the initiative.

The project looks at how partners can work together to use data to improve health and care in the UK, against the backdrop of widening health and care inequalities. It is doing this by identifying and analysing three topic specific data sets. The first data set focused on COVID and its effect on shielded patients (also referred to as “clinically extremely vulnerable”) who are the ones deemed the most at risk of becoming seriously ill from COVID. The second is investigating mental health services and their use by children and young people and the third is examining the experiences of unpaid carers.

Healthcare data sets include vast amounts of medical data, various measurements, financial data, statistical data, demographics of specific populations, all gathered from various health and social care data sources. These complex data sets of information are not necessarily useful by themselves; they require linking together followed by appropriate and robust analysis to fulfil their potential to guide improvements in service delivery.

What is linked data? Linked data sets combine information from different organisations and sources to expand the items of information held on individuals. Working in this way enables us to better understand the health of our population and how they use services. This combined data enables us to plan and resource health and care for different populations. For example, dataset A might tell us lots of clinical information about patients with mental health problems, dataset B gives us information about how these patients want to access services, dataset C tells us about how mental health affects people from BAME backgrounds. By combining these datasets, we have a better understanding of mental health services for BAME communities. We can use the insight to design and pay for services for this specific population.

#### **Patient and Public Involvement and Experience (PPIE)**

An important part of the NDL is involving patients and the public in the project. This will ensure that:

- Data is used in a legitimate and transparent way
- We recognise patients, carers and the public as stakeholders with rights, and responsibilities, for publicly funded services, research and education
- We don't make assumptions about people's experiences of health and care
- We focus on reducing health inequalities.

## **What does good PPIE analytics look like?**

Using PPIE in conjunction with data analytics is a new concept, one designed to improve data quality and the analysis process. Good PPIE analytics bridges the gap between the researching team and the public. This means that data analysis doesn't isolate the public group the research is trying to help, which helps us to keep patients at the centre of our research.

Good PPIE analytics is also entirely collaborative. Interpretation of data and the presentation of information involves public voices. This means the drivers of how to use data is done by a range of stake holders, instead of only our analytical teams. By involving the public with data interpretation, this can anchor the process to the public interest. By involving the public with the data presentation development, the team can produce accurate and digestible messages.

In all, good PPIE analytics is the heart of the NDLP pilot project, and it can improve our data, analysis process and information dissemination. For us, this can lead to robust decisions made in the best interest of the Leeds population.

## **How have patients and the public been involved in the project in Leeds?**

### **Topic selection**

In order to involve patients and the public in Topic 2 (Mental Health in children and young people) selection we:

- Invited key partners to a topic selection workshop, including two CCG volunteers, Healthwatch Leeds, Voluntary Action Leeds and CCG Involvement staff.
- Facilitated one of the topic selection breakout groups

Following the workshop, mental health was decided upon as an overarching theme and partners of the NDLP were asked to comment on specific areas of interest. An insight report was created for Leeds using existing insight (appendix A details the insight used).

As well as the insight list, engagement on the Mental Health strategy (Citizen and Stakeholder) was undertaken during autumn 2019. Citizen engagement involved delivering a brief presentation at various public meetings and events. Open discussions were then held which focussed on the proposed priorities and passions. Engagement was also carried out with various third sector organisations, particularly targeting those that work with individuals and groups not previously been consulted in depth about mental health. These included: people who are socially isolated; young people and adults who have recently experienced crises; rough sleepers and people who are homeless; refugees and asylum seekers; prisoners and ex-prisoners.

From examining the data and engagement – the Mental Health Strategy came up with 3 focus areas for Leeds: these are listed below

1. Reduce mental health inequalities
2. Improve children and young people's (C&YP) mental health
3. Improve flexibility, integration, and compassionate response of services, i.e., access to services

As topics were Covid themed, Healthwatch Leeds had also just undertaken 2 surveys focused on mental health in their regular Covid check in's. An emerging theme was again,

children and young people's mental health. This insight was collated and sent to the Health Foundation and the topic of children and young people's mental health was decided upon nationally.

## **How have patient's and public feedback shaped decision making?**

Firstly, a workshop with MindMate Ambassadors was organised to help shape the research question. We also attended their meetings to feedback and get a wider perspective throughout the project. A question they were interested in exploring was the experience of accessing mental health services for young parents and people from the LGBTQ plus community. A task and finish group of C&YP with lived experience and interested stakeholders was set up to steer topic 2 with engagement at the heart. Membership of the group included the data scientists, public health, MindMate Ambassadors, CCG volunteer, Healthwatch Leeds, GP, mental health providers, Leeds Academic Health Partnership, Mental Health commissioner. The group met ten times during the life of the project and helped:

- Inform the design of the research study
- Clarify the research questions and affirm their importance
- Steer the project throughout the research process
- Assist the research team in developing themes from data
- Consult and check their understanding of the data interpretation in the same way as the research team.

## **What difference has PPIE made to the project?**

Involving PPIE within the project has created several positive benefits.

"An integrated approach to analysis which involves patients, commissioners, local government and 3rd sector providers to prioritise our aims, help interpret the data and disseminate results has been extremely useful.

The cross-collaboration and insight from Task & Finish groups which include patients, commissioners, service providers, analysts and project leaders has been interesting and added local context to real world data".

### **Alex Brownrigg – Data Scientist**

"This project has involved and engaged patients and third sector groups at every stage. This included formulating research questions at the outset through to interpreting results of the analyses and the agreeing the important messages to be disseminated. This cooperative model of collaboration has worked well, and I feel the patient voice has really been heard".

### **Patricia McKinney – CCG Volunteer**

"It has been a fantastic opportunity for Northpoint to be able to work with the NDL. As a provider it is crucial that we can collate and flow quality patient data to best support children and young people's mental health. The NDL were able to analyse our data journey, understand the key factors that had enabled us to improve our data quality and supported us to identify further areas for improvement going forwards. We hope the report and our learning will help support other services to improve MHSDS data quality for children and young people".

### **Helen McGlinchey - Head of Service & Clinical Lead, Northpoint**

One of the key messages from the output of topic 2 was the quality of mental health data. As a result, we were unable to answer specific questions raised by the MindMate ambassadors. Due to the membership on the C&YP Task and Finish group a separate workstream was created immediately with a data scientist and a mental health provider to look at the problems and come up with recommendations for commissioners, providers, and partners. (see appendix B) Throughout the analytical process, the analysts reported back findings and the group could input the lived experience and provider perspective in real time.

Once the analysts had completed their research, both the MindMate ambassadors and the C&YP task and finish group helped develop key messages. These themes have since been documented on a template and have been discussed at various meetings with commissioners, provider groups, public health, mental health crisis group and have fed into the many mental health work streams within the city. Progress on the findings will be followed up.

## **Key Learnings for PPIE**

- Having a task and finish group which included people with lived experience and professionals worked well rather than having two separate groups. Having decision makers listening to people's lived experience is powerful as well as when other issues come up i.e., unpopulated data: the group could very quickly action a separate work stream.
- Having two PPIE groups was not needed. Initially we set up an overarching PPIE steering group as well as the C&YP task and finish group. Two groups were not needed so mid-way through the project we disbanded the PPIE steering group.

Associated documents:

Appendix A NDL PPIE Framework for operational detail and timelines.

Appendix B Unpopulated data report