

#NetworkedDataLab – Communications and Engagement Plan

Context

The [Networked Data Lab](#) is a new 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. NHS Leeds CCG and Leeds City Council are one of five partners across the country who have successfully bided for £400,000 to take part in the initiative.

The project will look at **how partners can work together to use data to improve health and care in the UK**, including addressing COVID-19 and widening health and care inequalities. It will do this by identifying and analysing three data sets over two years. The first data set will focus on shielded patients (also referred to as “clinically extremely vulnerable”). This group of patients are the ones deemed the most at risk of becoming seriously ill from COVID. They were advised not to leave their homes and to minimise all face-to-face contact. In most parts of the UK, this policy was paused at the end of July.

Healthcare data sets includes a vast amount of medical data, various measurements, financial data, statistical data, demographics of specific populations, gathered from various healthcare data sources. For example, a data set might give us lots of information about bowel cancer. This is useful in the treatment of the disease but on its own its use can be limited.

Linked data sets allow us to combine similar information from different organisations. 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 information about bowel cancer, dataset B gives us information about how cancer patients want to access services, dataset C tells us about how cancer affects people from BAME backgrounds. By combining these datasets, we have a better understanding of bowel cancer services for the BAME community. We can use the insight to design and pay for cancer services for this specific population.

Patient and Public Involvement and Experience

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

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

What does good Communications look like?

Communication with wider stakeholders about the NDL is another important aspect of the project. This will ensure that:

- We raise the profile of the project and build understanding of the NDL among national policy makers
- Develop and understand the value of linked health and social care datasets
- Show stakeholders how the project can provide useful resources that will inform decision-making
- Show how multiple organisations can work together to provide services to a local population.

What does good PPIE look like?

The aim of the PPIE lead role is to:

'Ensure that the patient and public voice is considered throughout the life of the project and support communications elements of the work'

The objectives of the PPIE role are to:

- Involve patients and the public in identifying the three data sets
- Provide a range of inclusive methods to involve patient and the public in the project
- Provide assurance that patient and public voice is being used to shape the project
- Grow public trust in the use of data to develop quality, safe and inclusive health and care services
- Work with PPIE leads from other partners in the programme to develop and share best practice
- Ensure that insight into the needs of patients and the public is robust
- Provide evidence that involvement with patients and the public has shaped the work of the project (you said, we did)
- Work with colleagues in the CCG Communications team to implement the NDL communications plan.

At the end of the project the PPIE lead will produce a brief report to:

- Outline how patients and the public have been involved in the project
- Outline how patients and the public feedback has shaped decision-making in the project
- Outline key learning from the project with regards to patient and public engagement
- Provide examples of how we have promoted the work of the NDL

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 sphere. 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 NDL pilot project, and it can improve our data, analysis process and information dissemination. This leads to robust decisions made in the best interest of the Leeds population.

Governance/Structure

HF Existing networks/ CCG/LA tbd/ NDP Project Meetings

NDL PPIE Steering Group

Purpose: To steer the NDL PPIE project throughout the life of the programme.

Membership: CCG Volunteers, Healthwatch, Analyst, NDL PPEI Lead, NDL Project Manager, NDL Project Assistant, Living in Leeds rep

NDL PPIE Task and Finish Groups (C&YP mental health)

Purpose: To steer the NDL PPIE project throughout the life of the topic by advising on the:

- design of the research study
- research process (delivery)
- analysing and interpreting (delivery and execution)
- dissemination
- implementation
- monitoring
- evaluation

Membership C&YP: CCG volunteer, Mindmate Ambassadors, Provider representation, NDL PPEI Lead, NDL Project Manager, NDL Project Assistant, C&YP Comms Group representative, C&YP Commissioner

NDL PPIE Task and Finish Groups (Topic 3)

Purpose: To steer the NDL PPIE project throughout the life of the topic by advising on the:

- design of the research study
- research process (delivery)
- analysing and interpreting (delivery and execution)
- dissemination
- implementation
- monitoring
- evaluation

Membership Topic 3: CCG volunteer, lived experience rep, provider representation, NDL PPEI Lead, NDL Project Manager, NDL Project Assistant, Commissioner

Associated documents:

Appendix 1 NDL PPIE Framework for operational detail and timelines.

Appendix 2 PPIEPlan on a page