

Networked Data Lab

Patient and Public Involvement and Engagement (PPIE) Framework Proposal

Values and Commitments

We commit to:

Partnership:

- Ask about what matters and actively listen to your response.
- Develop skills for better partnership between team members, patients and the public.

Respect:

- Be clear about our purpose in involving and engaging with patients and the public.
- Recognise the contributions you make to our work.

Inclusivity:

- Seek and value different experiences and perspectives.
- Share our work in a way that is accessible and understandable.

Transparency

- Share what we have learnt from our work to involve and engage with patients and the public, and the impact that it has had on our work.
- Welcome constructive challenge.

Goal outcomes:

- Better health for individuals.
- Grow understanding of, and space for, patients, carers and communities as key stakeholders and partners in this work.
- Grow public trust in the use of data to solve complex health and social care problems.
- Ensure insights from data reflect the real needs of patients, carers and communities.
- That we focus on reducing health inequalities.
- We measure the impact of how PPIE influences commissioning and co-ordination of care in the future.
- We ensure that we feedback the “you said, we did” to people and partners involved in the project so that they feel valued and heard.

National Institute for Health Research Framework

Stage 1: Identifying and prioritising (initiation)

Timeframe: November 2020 to February 2021

Patients and the public can:

- Help inform research priorities (for example, through local user groups and organisations).
- Be consulted about research topics and priorities important to them as service users.
- Collaborate with researchers to identify topics for research.
- Identify topics for research themselves.

In order to involve patients and the public in Topic 2 selection we:

- Invited key partners to the topic selection workshop, including two CCG volunteers, Healthwatch Leeds, Voluntary Action Leeds and NHS Leeds CCG involvement staff.
- Ran a topic selection breakout groups

Mental health was decided on as the topic and partners were asked to comment on specific areas of interest. An insight report was created with the following pieces of insight:

- Leeds Mental Health Framework engagement
- I statements (Adults)
- We Statements (Children and Young People)
- Future in Mind, 2016 - 2020
- Black, Asian and minority ethnic Children and Young People's Health Needs assessment (in development)
- The Big Leeds Chat, 2018 & 2019
- Mental Health Crisis in Leeds – Healthwatch Leeds
- Mentally Healthy Leeds engagement – Public Health
- Public Engagement for Leeds Mental Wellbeing Service
- The State of Men's Health Report 2017
- The State of Women's Health 2019
- Leeds in Mind, Mental Health Needs Assessment 2017 series including Adult/Perinatal and Children and Young People
- Roads, Bridges and Tunnels workshop findings
- Leeds LGBT mapping document

As well as the above 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 consulted in depth about mental health. These included:

- people who are socially isolated
- young people and adults who have recently experienced crises
- rough sleepers
- 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 – these are listed below

1. Reduce mental health inequalities
2. Improve children and young people's mental health
3. Improve flexibility, integration and compassionate response of services, ie access to services

As topics are COVID-19 themed, Healthwatch Leeds had also just undertaken two surveys focused on mental health in their regular COVID check-ins. The emerging theme was again, children and young people's mental health. All this information was sent to Karen at the Health Foundation.

Stage 2: Design

Timeframe: April – June 2021

Patients and the public can:

- Inform the design of the research study
- Clarify the research questions and affirm its importance
- Ensure the methods selected are appropriate for patients
- Assist in creating a recruitment
- Review and comment on proposed questionnaires and data collection methods

In order to involve patients and the public in Topic 2 selection we will:

- Set up a task and finish group of C&YP with lived experience and interested stakeholders to steer topic 2 with engagement at the heart.
- Set up a workshop with MindMate Ambassadors to help shape the research questions.
- Discuss the outcome of the workshop with the C&YP City Comms group and seek further engagement
- Host PPIE Steering Group meetings
- Host C&YP Task and finish group meetings

Stage 3: Undertaking the research (delivery)

In setting up a steering group to manage / monitor the research, patients and public can:

- Steer the project throughout the research process
- Assist in writing the patient information and consent forms
- Help ensure that the research is ethical and acceptable to patients and members of the public
- Aid in designing the detailed protocol
- Produce research updates that are patient friendly
- Assist in conducting interviews and surveys

Members of the Children and Young People's task and finish group and NDLS steering group will use the Statistical Analysis Plan as a guide.

Stage 4: Analysing and interpreting (delivery / execution)

Timeframe: Meet every six weeks

Patients and the public can:

- Assist the research team in developing themes from data.
- Be consulted to check understanding whether they interpret data in the same way as the research team.

Members involved in this includes:

- C&YP task and finish group
- NDL steering group
- C&YP city communications group
- Mindmate ambassadors

Stage 5: Dissemination

Timeframe: Meet every six weeks

Patients and the public can:

- Advise on different avenues for disseminating results
- Jointly present the research findings with researchers
- Write information for local patient groups / hospitals etc
- Assist in getting the research findings published on charity or voluntary organisation websites
- Help distribute the research findings within their informal networks
- Produce summaries of the research findings

Members involved in this includes:

- C&YP task and finish group
- NDL steering group
- C&YP city communications group
- Mindmate ambassadors

Stage 6: Implementation

Timeframe: Meet every six weeks

Patients and the public can:

- Increase the likelihood that results of research are implemented by adding validity to the findings
- Develop patient information for new services / interventions within hospitals, GP surgeries, etc

Members involved in this includes:

- C&YP task and finish group
- NDL steering group
- C&YP city communications group
- Mindmate ambassadors

Stage 7: Monitoring and evaluation

Timeframe: Meet every six weeks

Patients and the public can:

- Have continued involvement with the study to maintain focus and address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role and what they have learned

Members involved in this includes:

- C&YP task and finish group
- NDL steering group
- C&YP city communications group
- Mindmate ambassadors