

# Networked Data Lab PPIE Framework Proposal

## PARTNER LEVEL

Values and Commitments	
<p>We commit to:</p> <p><b>PARTNERSHIP</b></p> <ul style="list-style-type: none"><li>• Ask about what matters and actively listen to your response.</li><li>• Develop skills for better partnership between team members and patients and the public.</li></ul> <p><b>RESPECT</b></p> <ul style="list-style-type: none"><li>• Be clear about our purpose in involving and engaging with patients and the public.</li><li>• Recognise the contribution you make to our work.</li></ul>	<p><b>INCLUSIVITY</b></p> <ul style="list-style-type: none"><li>• Seek and value different experiences and perspectives.</li><li>• Share our work in a way that is accessible and understandable.</li></ul> <p><b>TRANSPARENCY</b></p> <ul style="list-style-type: none"><li>• 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.</li><li>• Welcome constructive challenge.</li></ul> <p><b>RECIPROCITY</b></p>
Goal Outcomes [Partner Level]	
<ul style="list-style-type: none"><li>• Better health for individuals</li><li>• Grow understanding of, and space for, patients, carers and communities as key stakeholders and partners in this work -</li><li>• Grow public trust in the use of data to solve complex health and social care problems</li><li>• Ensure insights from data reflect the real needs of patients, carers and communities</li><li>• That we focus on reducing health inequalities</li><li>• We measure the impact of how PPIE influences commissioning and co-ordination of care in the future</li><li>• We ensure that we feedback the “you said we did” to people/partners involved in the project so that they feel valued and heard</li></ul>	



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	<p>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.</p> <p>From examining the data and engagement – the Mental Health Strategy came up with 3 focus areas – these are listed below</p> <ol style="list-style-type: none"> <li>1. Reduce mental health inequalities</li> <li>2. Improve children and young people’s mental health</li> <li>3. Improve flexibility, integration and compassionate response of services, ie access to services</li> </ol> <p>As topics are Covid themed, Health Watch Leeds had also just undertaken 2 surveys focused on mental health in their regular Covid check in’s. The emerging theme was again, children and young people’s mental health. All this information was sent to Karen at the HF</p>	
<p><b>2. Design {design}</b></p>	<p><b>Programme level – topic 2 – the How</b></p>	
<p><i>Patients and the public can:</i></p> <ul style="list-style-type: none"> <li>• Inform the design of the research study</li> <li>• Clarify the research questions and affirm its importance</li> <li>• Ensure the methods selected are appropriate for patients</li> </ul>	<p>Set up a task and finish group of C&amp;YP with lived experience and interested stakeholders to steer topic 2 with engagement at the heart</p> <p>Set up a workshop with Mind Mate Ambassadors to help shape the research questions</p> <p>Discuss the outcome of the workshop with the C&amp;YP City Comms group and seek further engagement</p> <p>PPIE Steering Group meetings C&amp;YP Task and finish group meetings</p>	<p>W/C 12.4.21</p> <p>W/C 26.4.21</p> <p>4.5.21</p> <p>12.5.21</p>

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<ul style="list-style-type: none"> <li>Assist in creating a recruitment</li> <li>Review and comment on proposed questionnaires and data collection methods</li> </ul>	<p>Attend the People’s Voices Group to present on the NDL and question Attend a Systems call with providers to involve them in shaping of the questions</p> <p>agreed for Data Analysts</p> <p>members of the: C&amp;YP T&amp;F group &amp; C&amp;YP City Comms Group NDL PPIE Steering group</p>	<p>25.5.21</p> <p>4.6.21</p>
<p><b>3. Undertaking the research {delivery}</b></p>	<p><b>Programme level – topic 2 – the How</b></p>	
<p><i>In setting up a steering group to manage / monitor the research, patients and public can:</i></p> <ul style="list-style-type: none"> <li>Steer the project throughout the research process</li> <li>Assist in writing the patient information and consent forms</li> <li>Help ensure that the research is ethical and acceptable to patients and members of the public</li> <li>Aid in designing the detailed protocol</li> <li>Produce research updates that are patient friendly</li> <li>Assist in conducting interviews and surveys</li> </ul>	<p>Members of the C&amp;YP task and finish group and NDL steering group using the Statistical Analysis Plan as a guide</p>	<p>Meet every 6 weeks</p>

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<p><b>4. Analysing and interpreting {delivery / execution}</b></p>		
<p><i>Patients and the public can:</i></p> <ul style="list-style-type: none"> <li>• Assist the research team in developing themes from data</li> <li>• Be consulted to check understanding whether they interpret data in the same way as the research team</li> </ul>	<p>Member of the: C&amp;YP task and finish group NDL Steering Group C&amp;YP City Comms Group Mind Mate Ambassadors</p>	<p>Meet every 6 weeks</p>
<p><b>5. Dissemination</b></p>		
<p><i>Patients and the public can:</i></p> <ul style="list-style-type: none"> <li>• Advise on different avenues for disseminating results</li> <li>• Jointly present the research findings with researchers</li> <li>• Write information for local patient groups / hospitals etc</li> <li>• Assist in getting the research findings published on charity or voluntary organisation websites</li> <li>• Help distribute the research findings within their informal networks</li> <li>• Produce summaries of the research findings</li> </ul>	<p>Members of the: C&amp;YP task and finish group NDL Steering Group C&amp;YP City Comms Group Mind Mate Ambassadors</p>	<p>Meet every 6 weeks</p>

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<b>6. Implementation</b>		
<p><i>Patients and the public can:</i></p> <ul style="list-style-type: none"> <li>• Increase the likelihood that results of research are implemented by adding validity to the findings</li> <li>• Develop patient information for new services / interventions within hospitals, GP surgeries, etc</li> </ul>	<p>Members of the:            C&amp;YP task and finish group            NDL Steering Group            C&amp;YP City Comms Group            Mind Mate Ambassadors</p>	<p>Meet every 6 weeks</p>
<b>7. Monitoring and evaluation</b>		
<p><i>Patients and the public can:</i></p> <ul style="list-style-type: none"> <li>• Have continued involvement with the study to maintain focus and address issues as they arise</li> <li>• Collaborate with researchers to evaluate the research process</li> <li>• Reflect on their role and what they have learned</li> </ul>	<p>Members of the:            C&amp;YP task and finish group            NDL Steering Group            C&amp;YP City Comms Group            Mind Mate Ambassadors</p>	<p>Meet every 6 weeks</p>

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### Networked Data Lab

#### Programme Roadmap

