Example Research Plan – For Illustrative Purposes Only

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Project Title: Amplifying Voices: Co-creating Inclusive Data Practices for People with SMI

This project will co-develop, test, and evaluate practical guidance for inclusive data collection practices involving people with severe mental illness (SMI). It is a collaboration between DATAMIND and the Social Health Hub, with PPIE members and researchers working in partnership. The goal is to create tools and strategies that reflect the lived experiences of people with SMI and ensure their meaningful involvement in data research.

1. **Project Aims**

- Co-create guidance for inclusive data collection in mental health research involving people with SMI.
- Identify and address barriers to participation in data-focused research.
- Evaluate the usability and effectiveness of the guidance in real-world settings.
- Disseminate findings and tools to researchers, PPIE members, and wider stakeholders

2. **Project Outcomes:**

   The project will produce co-designed best practice guidelines or tools that can be adopted by multiple Hubs to improve how people with severe mental illness (SMI) are involved in research, ensuring inclusivity and meaningful engagement. The project will also develop a tested model of engagement that can be scaled or adapted by other mental health research groups, especially focusing on underrepresented populations, enhancing diversity and reach in future research collaborations.

3. **Methods**

   Co-design Workshops: Three workshops (two in-person, one online) with 20 participants each, including people with lived experience, researchers, and health professionals.

   Expert Advisory Panel: Comprising PPIE leaders from both Hubs, data ethics experts, and mental health professionals, guiding development and ensuring alignment with Hub priorities.

Tool Development: Drafting and refining guidance documents, checklist, and infographic based on workshop outcomes.

Evaluation: Surveys and focus groups will assess the usefulness and accessibility of the tools. We aim to include diverse voices across demographics.

4. **Risk Mitigation Plan**

Risk 1: Low Engagement from Contributors with Lived Experience

Mitigation: Offer flexible formats (online/in-person), provide compensation, ensure contributors are involved from planning to dissemination.

Impact: Builds trust, increases participation, and ensures contributors feel valued.

Risk 2: Miscommunication in Co-Design Sessions

Mitigation: Use plain English, visual aids, and experienced facilitators; provide pre-session materials in accessible formats.

Impact: Enhances understanding, encourages inclusive participation, and reduces confusion.

Risk 3: Ethical Delays or Non-Compliance

Mitigation: Early submission of ethics application; pre-consultation with ethics board; use of existing templates.

Impact: Prevents project delays and ensures compliance with ethical standards.

Risk 4: Data Breach or Loss

Mitigation: Use of encrypted storage, secure data transfer protocols, regular backups, and training on GDPR compliance.

Impact: Minimises the likelihood of data breaches and builds participant trust.

5. **Data Management Plan**

This project will collect both qualitative data (from co-design workshops, interviews, and feedback sessions) and quantitative data (from participant surveys evaluating consent

processes), alongside administrative data such as signed consent forms and attendance records.

Data will be gathered through secure online platforms (e.g., MS Online Surveys, Microsoft Teams) and in-person sessions, with written informed consent obtained in all cases. No physical data will be collected. Anonymisation will take place during transcription of qualitative data.

All data will be stored on encrypted, password-protected servers compliant with GDPR and UKRI guidelines, with access limited to authorised team members. Quality assurance will include monthly checks for completeness, dual verification of transcripts, and survey logic constraints to minimise errors.

Anonymised data and project outputs (e.g., toolkit) will be shared through the DATAMIND Trusted Research Environment (TRE). Personal data will be retained for five years before secure deletion by the University of Manchester.

All data practices will be approved by ethics review, guided by a Data Protection Impact Assessment (DPIA), and monitored by the University's data protection officer.

6. Alignment with Hub PPIE Priorities

DATAMIND: Focuses on ensuring data collection and use are inclusive and person-centred. This project supports this by improving practical approaches to inclusive data gathering.

Social Health Hub: Prioritises engagement and co-production in mental health research. This project supports co-production of materials that address social barriers to research participation.

Timeline (June 2026 – December 2026)

Month	**Activity**
June	Project initiation; ethics submission; advisory panel convened
July	Workshop 1 (Manchester); feedback analysis begins
August	Draft guidance tools created; Workshop 2 (London)
September	Tool refinement; online Workshop 3
October	Evaluation focus groups; draft evaluation report
November	Finalise tools and guidance; dissemination planning
December	Dissemination event; final reporting to funder