FAIR Voices: Co-developed guidance for FAIR data sharing in qualitative research with Patient and Public Involvement

Sofia Gameiro[1], Harriet Quinn-Scoggins[2], Kellie Snow[3], Lucy Brookes-Howell[4], John Gallanders[5], Kai Thomas[6], Amy M. Russell[7], Adele Battaglia[5], Jan Davies[5], Hameed Khan[5], Ian Palmer[5]

[1] School of Psychology, Women's Health Research Wales Centre, Cardiff University, gameiros@cardiff.ac.uk | [2] PRIME Centre Wales, Division of Population Medicine, School of Medicine, Cardiff University A| [3] University Library Service, Cardiff University | [4] Centre for Trials Research, Cardiff University | [5] Public and Patient Partner, Cardiff University| [6] School of Psychology, Cardiff University | 7 Leeds Institute of Health Sciences, University of Leeds

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Introduction

There is growing expectation for research teams to engage with open qualitative science but little guidance to support this (Tamminen et al., 2021). FAIR qualitative data sharing often means following FAIR principles when sharing the word-based data that is given by people when they talk to researchers or the notes researchers make when watching people, that is, ensuring the data is Findable, Accessible, Interoperable, and Reusable. In health and care research, the use of Patient and Public Involvement (PPI) and co-production approaches are now considered a key marker of good research practice (NIHR, 2022). **The aim of the FAIR Voices project was to co-develop guidance with PPI partners to support co-produced decision-making about FAIR qualitative data sharing**.

Methods

Three co-design workshops, followed by a period of document drafting, with additional per demand meetings, led to the co-development of two outputs: a set of principles to promote co-production of FAIR qualitative data-sharing practices, and a step-by-step guidance document to support research teams to share qualitative data in a FAIR way.

Results

Six principles to promote co-production of FAIR qualitative data-sharing practices

Working together

People involved in research should help decide how data is shared. PPI partners offer vital insights and should receive the support and training they need.

Protect people taking part

Only share data when it's safe and won't harm anyone's privacy or respect. PPI partners should help assess risk such as the chance of identifying participants.

Institutional support and governance

Research institutions and funders should create easy-to-understand policies and offer resources for safe data sharing with PPI input.

Informed consent

Participants must fully understand what sharing their data means. Consent should be clear, specific to the data being shared, and separate from consent to participate in the research.

Equality, Diversity and Inclusion

Processes should be inclusive. PPI can help ensure consent materials and data sharing reflect diverse needs and protect everyone, as needs and risk can vary for the communities involved.

Data ownership

Everyone involved should have a say in how data is used. PPI contributors should join early discussions. Decisions should focus on public good while respecting the needs of participants.

Step-by-step guidance to support FAIR qualitative data sharing

The guidance is organised chronologically, covering a sequence of five steps considered necessary to make qualitative data FAIR, which are summarized below. Scan the QR code to access the full guidance.

Step 1. Planning
Reflecting holistically and with PPI partners about key factors necessary to ensure that data are shared ethically and fairly, e.g., legal and policy frameworks, training and resources needed.

Step 2. Informed consent
Deciding on key information needed to ensure informed consent and how this should be communicated to participants. Considering the most appropriate way of obtaining consent.

Step 3. Data de-identification
Deciding on how to de-identify the data to minimise risk of participants being identified and how this is explained to participants.

Step 4. Access control
Deciding on how to identify and share the data, including where the data should be shared and the need to restrict access to (some subsets of) the data.

Step 5. Rights management
Putting in place ways to allow and manage reuse of the data, usually via creating a Data Access Committee, that is, a group of people who review and approve data access requests.

Conclusion

Engaging with qualitative open science can be risky and research teams should be supported in this endeavor. PPI partners were highly engaged with the project and saw their role as critical but stressed a need for resources and training to enable them to make meaningful contributions. Overall, there is a need to build critical mass and amplify discussions about open qualitative science, including obtaining participants' views of the practices implemented.

References: NIHR. (2022). Patient and Public Involvement and Engagement Resource Pack. Retrieved 20.90.2024 from PPIE resources for staff; Tamminen, K. A., Bundon, A., Smith, B., McDonough, M., Poucher, Z., & Atkinson, M. (2021). Considerations for making informed choices about engaging in open qualitative research. Qualitative Research in Sport, Exercise and Health, 13(5), 864-886. | This work was co-developed in the context the FAIR Voices project, which received an award from the Cardiff University 2023 Research Culture Fund.