Defining acceptable data collection and reuse standards for queer artificial intelligence research in mental health

The online PARQAIR-MH Delphi study

Joyce DW, Kormilitzin A, Hamer-Hunt J, et al. Defining acceptable data collection and reuse standards for queer artificial intelligence research in mental health: protocol for the online PARQAIR-MH Delphi study. BMJ Open 2024;14:e079105. doi:10.1136/ bmjopen-2023-079105

Background

Need for AI in Mental Healthcare

Artificial intelligence (AI) and machine learning (ML) are expected to deliver novel ways of understanding and improving mental healthcare. However, there is a need to ensure these technologies are fair, safe, and inclusive.

Unmet Needs of LGBTQI+ Community

The LGBTQI+ (Lesbian, Gay, Bisexual, Transgender, Queer and Intersex, and more) community faces unmet needs in mental healthcare, including higher rates of suicidal distress, self-harm, and mental disorders due to minority stress.

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Challenges in Data Collection

Lack of Harmonization

Fragmented, incompatible data due to lack of standardization in recording SOGI (Sexual Orientation and Gender Identity) data

Poor Recording Rates

Low rates of data collection beyond services focused on specific groups like cis-gendered gay men

Low Disclosure

LGBTQI+ individuals often hesitant to disclose SOGI characteristics to healthcare professionals

Healthcare Access

Difficulty in accessing healthcare for LGBTQI+ people, with 72% describing it as "not easy" in UK surveys

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Appropriate Data Use

- Calls for *better health-data collection* are common, yet translating them into practice remains difficult.
- There is **little guidance on when and how AI/ML-driven analyses of health data are appropriate—especially for sexual-orientation and gender-identity (SOGI) data relevant to LGBTQI+ care.**
- The UK Biobank controversy illustrates the broader problem:
    - Investigative reporting alleged that insurance companies accessed participant data despite promises to the contrary.
    - UK Biobank counters that such companies are treated like any other "suitably qualified" researchers conducting health-related work in the public interest.
    - Participant leaflets state insurers and employers will not receive individuals' data, yet the definition of "researcher" creates ambiguity and potential mistrust.
- Key take-aways for LGBTQI+ data stewardship:
    - **Develop community-aligned methods to collect, store and process SOGI data** (using terminology and norms defined by LGBTQI+ people themselves).
    - **Define transparent, widely accepted use-cases for both individual-level and population-level SOGI data gathered in routine care** (e.g., clarify when commercial entities may access such data and for what purposes).

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Rationale for Participatory Approach

Ethical Imperative

Patient, public, and stakeholder involvement in mental health research is an ethical imperative expected to improve the quality, relevance, and uptake of research.

Empowerment

Participatory design plays a critical role in empowering marginalized communities to take an active role in constructing research agendas and outputs.

Addressing Unique Challenges

The interaction of minority stress with the stigmatization of mental illness presents complex issues of acceptability, safety, and healthcare equity that can only be addressed through a participatory process.

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Aims of the Delphi Study

Establish Consensus on Data Collection

Determine how to collect, code, and harmonize SOGI data in the context of improving provision of mental healthcare

Define Acceptable Data Reuse

Establish consensus on scenarios and use-cases for acceptable reuse of SOGI data in data-driven technologies

Develop Best Practice Toolkit

Create guidance for AI developers, data scientists, and healthcare institutions on implementing SOGI data collection

Create Online Playbook

Describe concrete example scenarios of acceptable and unacceptable SOGI data use

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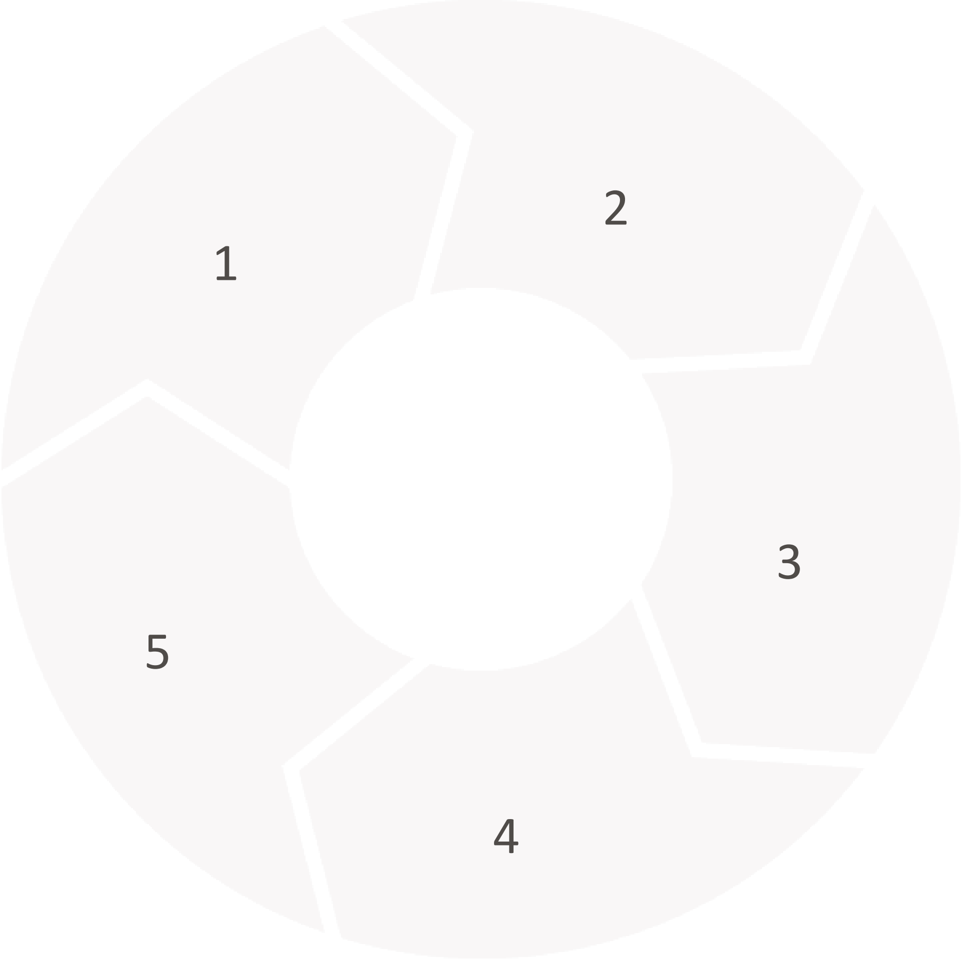
Study Design: Delphi Method

Literature Review

Conduct review and define terms-of-reference

Output Development

Build and deliver toolkit, guidance, and publications



Questionnaire Development

Define first questionnaire for Delphi rounds

Delphi Rounds

Three sequential anonymous online surveys

Consensus Meeting

Define final consensus on Delphi outputs

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Working Groups

Executive Group

Responsible for overall execution of the project, organizational processes, and reporting. Consists of the authors of the protocol.

Advisory Working Group

Leads final-stage consensus meeting. Includes experts from AI/ML, ethics, health policy, mental health professionals, and PPI stakeholders. Aim to recruit 10 people.

Survey Group

Participates in the Delphi survey rounds. Self-selecting stakeholders able to provide informed consent. Aim to recruit a minimum of 50 participants.

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Participant Recruitment

Recruitment Methods

- Snowball and opportunistic sampling
- Professional networks
- Direct approach to community groups and charities
- Approach to LGBTQI+ policy leads in NHS and Royal College of Psychiatrists
- Online 'town hall' event
- Social media publicity

Participant Composition

- People with lived experience of mental health service use from LGBTQI+ communities
- Representatives from charities, NGOs, and campaigning groups
- Domain experts from mental health professionals
- LGBTQI+ community members with lived experience of mental health problems

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Delphi Questionnaire Content

SOGI Data Collection Preferences

Explore LGBTQI+ community preferences for collecting, recording, and harmonizing Sexual Orientation and Gender Identity data

Acceptable Data Reuse Parameters

Establish consensus on scenarios for acceptable reuse of SOGI data in healthcare systems, including:

- Use of AI-driven chatbots or recommender systems
- Decision support for identifying individual risk factors
- Configuring/commissioning services based on SOGI data audits

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Examples for Questions or Scenarios

To what extent do you agree that individuals should have the right to opt-out of sexual orientation and gender identity data collection without affecting the quality of care they receive? Keep in mind that opting-out might prevent the use of data-driven technology that may improve the care offered to them	Strongly Agree Agree Neutral Disagree Strongly Disagree

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Examples for Questions or Scenarios

Data collected from individuals by a healthcare provider can be re-used, in combination with data from a network of healthcare providers, if it would benefit other people using that network but to deliver this benefit, a third-party might financially profit - for example if a commercial company processes the data on behalf of the healthcare provider network	Agree Disagree

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Examples for Questions or Scenarios

Scenario 2: A publicly-funded healthcare provider (i.e. a hospital or clinic with substantial government support) suspects there is a lack of appropriate support for mental health difficulties identified in the research literature as particularly prevalent for a group of people with a specific sexual orientation and gender identity. The hospital decides to investigate if it can reconfigure or expand its existing services to include specific interventions and support for this group. The hospital routinely asks each patient about their sexual orientation and gender identity.

Proposed Re-use of this Data: The hospital feels that the mental health support it offers to specific individuals could be personalised, or tailored, using automation. By taking an individual's sexual orientation and / or gender identity data alongside other data captured at the point the person accesses the service - for example, demographics, ethnicity and their medical history - the hospital proposes to then use a data-driven algorithm to make recommendations specifically for that individual to help provide tailored interventions for each patient seen by the hospital.

For example: "This 35 year old person has a history of asthma and type I diabetes. People similar to this person are known to be between 1.1 and 1.3 times more likely to have an anxiety disorder. Additionally, they identify as transgender and heterosexual. These additional factors further increase their risk of anxiety disorder to 2.2 to 2.4. Therefore, consider recommending the low-intensity talking therapy service for transgender people".

This algorithm will be developed and tested by re-using de-identified historical data, collected from previous users of the hospital's services.

In your view, is this an appropriate use of the data ?   Agree - Disagree - It Depends

If you d like to participate or help find participants:

https://redcap.link/2l91l043

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Space for Discussion