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## Protocol for a Delphi consensus process for PARTICIPATORY Queer AI Research in Mental Health (PARQAIR-MH)

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# Protocol for a Delphi consensus process for PARTicipatory Queer AI Research in Mental Health (PARQAIR-MH)

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## ABSTRACT

**Introduction:** For artificial intelligence (AI) to help improve mental health care, the design of data-driven technologies needs to be fair, safe, and inclusive. Participatory design can play a critical role in empowering marginalised communities to take an active role in constructing research agendas and outputs. Given the unmet needs of the LGBTQI+ community in mental health care, there is a pressing need for participatory research to include a range of diverse queer perspectives on issues of data collection and use (in routine clinical care as well as for research) as well as AI design. Here we propose a protocol for a Delphi consensus process for the development of PARTicipatory Queer AI Research for Mental Health (PARQAIR-MH) practices, aimed at informing digital health practices and policy.

**Methods and Analysis:** The development of PARQAIR-MH is comprised of four stages; In Stage 1, a review of recent literature and fact-finding consultation with stakeholder organisations will be conducted to define a terms-of-reference for Stage 2, the Delphi process. Our Delphi process consists of three rounds, where the first two rounds will iterate and identify items to be included in the final Delphi survey for consensus ratings. Stage 3 consists of consensus meetings to review and aggregate the Delphi survey responses leading to Stage 4 where we will produce a reusable toolkit to facilitate participatory development of future bespoke LGBTQI+-adapted data collection, harmonisation and use for data-driven AI applications specifically in mental health care settings.

**Ethics and Dissemination:** The PARQAIR-MH aims to deliver a toolkit that will help to ensure that the specific needs of LGBTQI+ communities are accounted for in mental health applications of data-driven technologies. Participants in the Delphi process will be recruited by snowball and opportunistic sampling via professional networks and social media (but not by direct approach to healthcare service users, patients, specific clinical services or via clinicians' caseloads). Participants will not be required to share personal narratives and experiences of healthcare or treatment for any condition. Before agreeing to participate, people will be given information about the issues considered to be in-scope for

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3 the Delphi (e.g. developing best practices and methods for collecting and harmonizing  
4 sensitive characteristics data; developing guidelines for data use/re-use) alongside specific  
5 risks of unintended harm from participating that can be reasonably anticipated. Outputs  
6 from Stage 4 will be made available in open access peer-reviewed publications, blogs, social  
7 media and on a dedicated project website for future re-use.  
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12 **Ethical Approval:** The Institute of Population Health Research Ethics Committee of the  
13 University of Liverpool gave ethical approval for this work (REC Reference: 12413; 24th  
14 July 2023)  
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## STRENGTHS AND LIMITATIONS

- The proposed Delphi study will deliver a toolkit that assists researchers, health care organisations and policy makers decide on how to appropriately collect and use data on sensitive characteristics (e.g. sexual orientation and gender identity) including stakeholder-defined re-use of this data for specific purposes including health service improvement and developing tools for data-driven decision support (i.e. in data science, AI and ML applications designed for LGBTQI+ communities).
- This Delphi study is designed to focus on the intersection of sensitive characteristics and mental health, where similar research has focused on healthcare or sexual health more generally(1).
- The Delphi study will be led by a team from the United Kingdom, with the expectation the consensus process will involve participants largely drawn from Western cultures with similar societal attitudes and legislative mechanisms to protect the human rights of LGBTQI+ people. This will limit the transportability and generalisability of the Delphi process and consensus outputs.

## BACKGROUND

Artificial intelligence (AI), machine learning (ML) and data-driven technologies are expected to deliver novel ways of understanding and improving mental health care (2). In healthcare applications of AI/ML generally, there has been increased focus on the potential for unintended harm arising from biases present in data (3) and resulting from model assumptions. Two striking examples being racial biases in an algorithm deployed to identify increased healthcare needs(4) and commonly-used models for estimating renal function (employing standard biostatistical methods) have been shown to be poorly calibrated for estimating kidney disease in people of colour (5).

The ambition of any data-driven learning health system (6) is to improve the care provided to patients by adapting provision to their specific needs. In the context of mental healthcare, LGBTQI+ communities are known to have specific difficulties arising from

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3 *minority stress* (7,8) including victimisation, internalised prejudice and isolation.  
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5 Consequently, LGBTQI+ people experience higher rates of suicidal distress (9), self-harm  
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7 and suicide (10) and differential lifetime prevalence of the most common mental disorders  
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9 as a function of sexual orientation and gender identity (SOGI), ethnicity and race (11).  
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11 National survey data support these studies, showing that e.g. 3% of gay and bisexual men  
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13 (compared with 0.4% of men in the general UK population) attempted to end their life by  
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15 suicide in 2013(12); over 80% of trans-identifying young people have self-harmed at some  
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17 point in their lives compared to around 10% in the general population (13) and 24% had  
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19 accessed mental health services(14) in the preceding 12 months.

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21 We note that there is variation in cultural and societal definitions of “mental health” and  
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23 “mental illness” (15), including the egregious assumption that LGBTQI+ identity is, by  
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25 definition, a “mental illness” (16,17). In this Delphi process, while we include the  
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27 biomedical definition of mental illness/disorder, we will use an inclusive and broad term –  
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29 “mental distress” – defined as a constellation of experiences that cause distress for the  
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31 person, result in a loss of social, personal or occupational function and/or reduction in  
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33 quality of life. Further, in the proposed Delphi study, mental distress is something for which  
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35 the individual would seek assistance from an external source (e.g. from healthcare  
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37 professionals, or peer/community support), or where other stakeholders identify an unmet  
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39 need (e.g. an LGBTQI+ support community identifying lack of support for a specific set of  
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41 problems in people who remain ‘invisible’ to healthcare services).

## 42 43 **Data Quality**

44  
45 Supporting LGBTQI+ people requires high-fidelity data (18,19). However, such data is  
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47 ostensibly lacking for reasons including:

- 48 • a lack of harmonisation for the recording of SOGI data resulting in fragmented,  
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50 incompatible data (20,21)
- 51 • poor recording rates for local data collection, beyond services focused on, for  
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53 example, cis-gendered gay men and sexual health (12)
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- disclosure of SOGI characteristics to healthcare professionals is low, because LGB people experience healthcare organisations and professionals as threatening (22) and there is evidence that an individual's medical history, immigration status, level of internalised homophobia and degree of connectedness to the LGBTQI+ community are significant factors for disclosure with bisexual men and women being the least likely to disclose SOGI characteristics to healthcare professionals (23)
- misalignment of patient and healthcare professionals expectations around SOGI data collection, resulting in e.g. 80% healthcare professionals believing they may offend by asking about SOGI characteristics compared to 11% of patients reporting likelihood of offence (24)
- accessing healthcare is difficult for LGBTQI+ people, for example, 28% of people in the UK's LGBT National Survey described it was "not easy" to access mental healthcare (14)

## AI, ML and Data Reuse

The straightforward imperative that we *require* better data collection is well documented (25–27), but difficult to implement. Further, there is less evidence on the specific and acceptable uses of data and AI/ML technology to advance the provision of care for the LGBTQI+ community (28). Therefore, there is a need to understand:

- how SOGI data can be **meaningfully collected, stored and processed** in a way that is compatible with the language and norms defined by LGBTQI+ communities
- the **current barriers to disclosure of SOGI** among LGBTQI+ people
- the **acceptable use-cases** for using individual and population level SOGI data collected in routine clinical care

This paper describes a protocol for a Delphi process to develop a consensus on these three questions.



## RATIONALE

Patient, public and stakeholder involvement in mental health research has an established history and is motivated by (29) stakeholder involvement as an ethical imperative with the expectation that this may improve the quality, relevance and uptake of research (30). Arnstein's "ladder of citizen participation" (31) is often cited as an anchoring principle for meaningful stakeholder involvement and participatory design (32) with contemporary definitions (33) defining PPI as e.g. "a process whereby professionals and those traditionally on the receiving end of their 'expertise' (e.g. patients/service users/marginalised citizens) can collaborate with the goal of achieving outcomes that arguably cannot be achieved otherwise. It should engage the talents and experience of all involved and support the egalitarian relations and conditions needed to make the most of them". In healthcare, the defining summary statement is "no decision about me, without me" (34,35) and adopting this principle of empowerment and co-design for healthcare AI comes with unique challenges (36). Participatory approaches present a necessary step in the safe development of AI systems for delivering positive impact (37) and participatory design can play a critical role in empowering marginalised communities to take an active role in constructing research agendas and outputs; for example, in applications spanning architecture, the environment and planning (38,39), community building (40) and education (41).

A central tenet of AI research applied to healthcare should be that affected communities are active participants in the co-design and production of services and technologies to avoid (usually) unintended harms, to mitigate unforeseen consequences of technical processes and the avoidance of socio-technical "blind spots". In the application of AI specifically to LGBTQI+-inclusive mental healthcare, the interaction of minority stress (7) with the stigmatisation of mental illness more generally (42) presents a quagmire of acceptability, safety and healthcare equity concerns. We argue that these can only be addressed through a participatory process that identifies how services and technologies understand, collect, codify and use the communities' data to ensure they benefit. In health sciences, the Delphi technique has been useful for establishing a consensus on "complex issues where

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3 knowledge is uncertain and incomplete” (43) and where evidence synthesis from e.g.  
4 experimental or epidemiological data is difficult (44). Consistent with our aims for  
5 PARQAIR-MH, the method can enable a diversity of perspectives to be represented during  
6 consensus development.  
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## 10 11 12 **Focus** 13

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15 The proposed Delphi process will focus attention on data that is expected to be collected  
16 routinely and in clinical settings (whether public, private or third-sector providers). We  
17 will not consider the re-use of data from e.g. social media sources, blogs or other self-  
18 publishing platforms. The three primary domains will be  
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23 1. How best to collect sensitive SOGI data in routine clinical practice / interactions  
24 with healthcare providers  
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- 27  
28 2. Barriers/obstacles for LGBTQI+ communities including disclosure as well as  
29 people’s choices around how they access any services (public, private or third-  
30 sector) that inform why SOGI data might be systematically missing from public-  
31 sector healthcare data  
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- 34  
35 3. Parameters for acceptable re-use of SOGI data beyond recording for the fidelity of an  
36 individual’s health record  
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40 Factors that explicitly address the most appropriate models of healthcare service design  
41 and delivery (14,45) – that certainly affect people’s experiences and future engagement  
42 with providers – will be out-of-scope for PARQAIR-MH because the focus is on ways to use  
43 data to improve LGBTQI+ affirmative care.  
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## 49 **METHODS/DESIGN** 50

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52 The multistage consensus method will follow recommendations for the Delphi technique  
53 (46) using repeated rounds of a semi-structured questionnaire with feedback from a group  
54 of stakeholders.  
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3 The Delphi process comprises multiple stages and is overseen by an executive committee.

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5 The stages are:

- 6  
7 1. problem definition
- 8  
9 2. selection of working groups
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11 3. three sequential Delphi rounds, with the third round including repetition/revision  
12 of the final round alongside an estimate of consensus between participants until a  
13 pre-defined level of agreement is reached
- 14  
15 4. transcribing, summarising and analysis of the concluding Delphi round to include  
16 final estimates of agreement/degree of consensus for the three domains
- 17  
18 5. reporting on findings and development of consensus statement for dissemination

## 25 26 **Working Group**

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28 The PARTicipatory Queer AI Research for Mental Health (PARQAIR-MH) working group will  
29 include:

- 30  
31 1. an **executive committee** responsible for the overall execution of the project,  
32 organisational/operational processes to conduct and disseminate and report on the  
33 Delphi process. This group will consist of the authors of this manuscript.
- 34  
35 2. an **advisory working group** who will lead the final-stage consensus meeting and be  
36 drawn from experts from the machine learning, ethics, health policy, mental health  
37 professionals and patient and public involvement (PPI) stakeholder groups.
- 38  
39 3. a **survey group** of people (with similar composition to the advisory group) who will  
40 participate in the Delphi survey

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42 The advisory and survey groups will be composed of:

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44 1. people with lived experience of mental health service use from the LGBTQI+  
45 communities

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2. people representing charities, NGOs (non-governmental organisations) and other campaigning groups focusing on the mental health of people from the LGBTQI+ community
  3. domain experts drawn from mental health professionals, invited to participate from national and international LGBTQI+ communities to include people with lived experience of mental health problems.

## Patient and Public Involvement Statement

Co-author Julia Hamer-Hunt, a lived-experience practitioner, consulted on the principles and design of the Delphi process from conception to the final draft of this protocol. The Executive Committee will be assembled by a targeted approach through the author's professional networks, alongside open calls on social media, to ensure a diverse, equitable, inclusive and representative panel of stakeholders (including patients and public) to oversee the Working Group and execution of the Delphi consensus process.

## Stage 1: Literature review

To focus the initial round of the Delphi process, the authors of this protocol will review existing literature to identify:

- barriers to accessing mental health support implicated in the current lack of robust public sector data
- existing healthcare guidelines for the collection of SOGI data for LGBTQI+ people
- studies of perceptions, attitudes and experiences to disclosure of SOGI data in healthcare settings for LGBTQI+ people
- example applications of AI in LGBTQI+ mental health support to include those that expose benefits, risks and harms specific to that community

This review will include both published, peer-reviewed academic literature, governmental, NGO and charity surveys as well as publicly-available national policy documents. Special

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3 attention will be given to surveying the ethics and fairness literature, to identify promising  
4 approaches for ensuring privacy and safety of AI systems. The glaring absence of analyses  
5 of disparate impact of AI on queer communities (47) further justifies the need for a deeper  
6 community involvement.  
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11 Following a review of the literature, the executive committee will produce a summary of  
12 the findings alongside a draft Terms of Reference (ToR), describing the project aims, scope  
13 and intended deliverables and outputs. This will be circulated to stakeholder groups  
14 selected by the executive committee, using their own and their organisations' professional  
15 networks with coverage including:  
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- 19 • NHS and University Patient and Public Involvement/Engagement groups
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- 21 • Clinicians working in the mental health sector
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- 23 • Ethicists
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- 25 • AI researchers and data scientists
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- 27 • NGOs and charity stakeholders for LGBTQI+ mental health
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34 The stakeholders approached to review the ToR will also be invited to join the advisory  
35 group to ensure appropriate representation.  
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## 38 39 **Stage 2: Delphi Process**

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42 **Outcome:** a consensus statement that describes

- 43 1. LGBTQI+ community preferences for collecting, recording and harmonising SOGI  
44 data
- 45 2. the parameters for the acceptable (re)use of SOGI data for improving healthcare  
46 systems to include the following example use-cases:  
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  - 49 – the use of automation (e.g. AI-driven chatbots or recommender systems)
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- 3 – decision support (e.g. identifying risk factors for individual people)
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- 6 – configuring/commissioning services (e.g. auditing SOGI data for adapting
- 7 existing, or developing new, services)
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- 10 3. a checklist for AI developers to ensure a new project aligns with the needs and
- 11 preferences of the LGBTQI+ community
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## 14 Design

15 The Delphi process will consist of three sequential rounds:

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- 20 • **Round 1:** Participants will be presented with short vignettes describing either
- 21 existing (from the literature review) or hypothetical use-cases for SOGI data
- 22 collection and re-use. Participants will be shown questions relating to these
- 23 vignettes with categorical responses and invited to provide narrative (free-text)
- 24 elaborations explaining their reasoning for endorsing their answer. Thematic
- 25 analysis of the narrative responses will guide generation of the round 2 survey
- 26 process.
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- 33 • **Round 2:** The Round 1 participants will be presented with an anonymised summary
- 34 of the group's Round 1 responses. For items in Round 1 with  $\geq 70\%$  agreement, the
- 35 items will be presented as "agreed upon" and no further revisions/voting will be
- 36 requested. For any additional items that emerged/were suggested, a categorical
- 37 response and narrative text answer will be invited in the same format as Round 1.
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- 43 • **Round 3:** A final round will aggregate responses from Round 2 to deliver a) items
- 44 which have been agreed by consensus (defined as  $\geq 70\%$ ) b) items that remain
- 45 outstanding or contentious and could not be agreed upon and are reported as such.
- 46 The resulting consensus statement will be drafted, edited and distributed to the
- 47 Round 1 and 2 participants.
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### Stage 3: Consensus Meeting

The output of the three Delphi rounds will be presented to a focus group for discussion and final agreement on the format of the consensus statement. Participants invited to this group will be:

- NHS and University Patient and Public Involvement/Engagement groups
- The executive committee
- Delphi rounds 1–3 participants
- Clinicians working in the mental health sector
- Ethicists
- AI researchers and data scientists
- NGOs and charity stakeholders for LGBTQI+ mental health

Importantly, we recognise that consensus may be difficult to achieve for certain topics and themes; for example, some participants might have a strong opinion that automation of any aspect of mental healthcare delivery is unacceptable. Given the complexities of defining consensus (48), themes where consensus cannot be reached will be reported and highlighted in the final toolkit and guidance.

### Stage 4: Outcomes and Dissemination

At the consensus meeting, the outputs deemed necessary and sufficient for a toolkit will be discussed; for example, the format and medium for the researcher “checklist” and any guidance documents that would need to accompany this. It is anticipated this will take the form of a recommendations white paper and case-study format similar to e.g. (49–51).

Following this, the executive committee will invite the advisory group to contribute to writing a summative report for submission to an open-access, peer-review journal.

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3 The key outputs (toolkit and guidance documents for replicating the Delphi process) and  
4 findings (consensus statement including open-access, peer-reviewed papers) will be made  
5 available on a website (similar to the equator network, [https://www.equator-](https://www.equator-network.org/)  
6 [network.org/](https://www.equator-network.org/)) that will be maintained by the executive committee. The aim is to provide a  
7  
8 participatory design-inspired open and transparent process for communities and  
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10 organisations to either deploy the consensus and toolkit in their own localities, or to  
11  
12 replicate the process to derive locally-informed versions of the toolkit/consensus.  
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16 Stakeholder involvement in all outputs from the proposed Delphi process will be  
17 transparent and explicitly described, including composition of the Executive Committee  
18 and Working Group. Specific patient and public involvement (PPI) will be reported using  
19 the GRIPP2(52) reporting guidelines.  
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## 25 **DISCUSSION**

### 26 **Scope and Generality**

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29 Existing work on SOGI data collection and harmonisation reflects a largely Western  
30 geographical focus including the European Union, United Kingdom and United States (18–  
31 20). The pending 2022 UN Report to the Human Rights Council (53) on SOGI emphasises  
32 healthcare equity for LGBTQI+ communities (including data collection/harmonisation as a  
33 key enabler) while previous UN mandate reports (54) acknowledge under-representation  
34 from regions of the world with hetero-normative cultural norms or where people from  
35 LGTBQ+ communities are persecuted. Similarly, different societies and cultures’  
36 formulation of mental illness in terms of aetiology, stigma, implications for individuals,  
37 family and wider society vary to the extent that a dominantly Western biomedical model  
38 (that emphasises the individual as the locus of mental illness and disorder) is seen as  
39 unhelpful (see (15) for a review). While the overarching PARQAIR-MH process remains  
40 general, the outcome of its initial application in the United Kingdom will be limited and  
41 localised in its immediate practical utility; necessitating replication studies.  
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## Limitations

The patient and public perception of clinical applications of AI is relatively under-studied; one systematic review (1) of 23 mixed-methods studies found no studies specifically addressing mental healthcare. The review exposed some polarisation around themes of accountability (of a decision made using AI), concern around “boundary cases” (i.e. rare diseases or uncommon situations) and a divide around risk of worsening or improving healthcare outcomes, equity and justice. Importantly, they note that the perspectives of under-represented groups were rarely included or studied in the sampled literature.

Given this, we expect similar polarity in our Delphi process which may limit the extent to which consensus can be reached – given this, we will report separately on subsets of items achieving consensus, those where no consensus could be reached and a clear description of contentions arising in both subsets.

## Protocol Re-use and Utility

Considering the rising need for a wider community involvement in AI design, and this being one of the very first AI participatory studies designed specifically for the LGBTQI+ population, we are hoping that the proposed protocol will help inform a multitude of future participatory research directions. Indeed, the issues of data collection, data use, fairness and safety, are central to AI development across mental health care, healthcare, as well as numerous other domains and use cases.

Consistent with the central tenets of participatory design, this protocol needs to be applied locally, to capture the local variation in perspectives, needs, and healthcare systems. Repeated application of the protocol may result in different consensus statements, reflecting these local differences. We would therefore strongly encourage worldwide replication studies, complementing the initial study planned in the United Kingdom. In terms of utility, PARQAIR-MH aims to help inform digital health policy and the design of inclusive mental health care technologies going forward.

## Ethics and Dissemination

Participants in the Delphi process will be recruited by snowball and opportunistic sampling via professional networks and social media (but not by direct approach to healthcare service users, patients, specific clinical services or via clinicians' caseloads). Participants will not be required to share personal narratives and experiences of healthcare or treatment for any condition. Before agreeing to participate, people will be given information about the issues considered to be in-scope for the Delphi (e.g. developing best practices and methods for collecting and harmonizing sensitive characteristics data; developing guidelines for data use/re-use) alongside specific risks of unintended harm from participating that can be reasonably anticipated. Outputs from Stage 4 will be made available in open access peer-reviewed publications, blogs, social media and on a dedicated project website for future re-use.

## AUTHOR'S CONTRIBUTIONS

This protocol was conceived, designed and written by all five authors listed. All authors have reviewed and approved the final manuscript.

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## COMPETING INTERESTS

DWJ and AK are partially supported by an NIHR grant (AI\_AWARD02183) which explicitly examines the use of AI technology in mental health care provision. NT and KRM are

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employees of Google DeepMind, an AI research company. JHH has no competing interests to declare.

For peer review only

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# BMJ Open

## Defining Acceptable Data Collection and Re-use Standards for Queer Artificial Intelligence Research in Mental Health: Protocol for the Online PARQAIR-MH Delphi study

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# Defining Acceptable Data Collection and Re-use Standards for Queer Artificial Intelligence Research in Mental Health: Protocol for the Online PARQAIR-MH Delphi study

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## Abstract

**Introduction:** For artificial intelligence (AI) to help improve mental health care, the design of data-driven technologies needs to be fair, safe, and inclusive. Participatory design can play a critical role in empowering marginalised communities to take an active role in constructing research agendas and outputs. Given the unmet needs of the LGBTQI+ community in mental health care, there is a pressing need for participatory research to include a range of diverse queer perspectives on issues of data collection and use (in routine clinical care as well as for research) as well as AI design. Here we propose a protocol for a Delphi consensus process for the development of PARTICIPATORY Queer AI Research for Mental Health (PARQAIR-MH) practices, aimed at informing digital health practices and policy.

**Methods and Analysis:** The development of PARQAIR-MH is comprised of four stages. In Stage 1, a review of recent literature and fact-finding consultation with stakeholder organisations will be conducted to define a terms-of-reference for Stage 2, the Delphi process. Our Delphi process consists of three rounds, where the first two rounds will iterate and identify items to be included in the final Delphi survey for consensus ratings. Stage 3 consists of consensus meetings to review and aggregate the Delphi survey responses, leading to Stage 4 where we will produce a reusable toolkit to facilitate participatory development of future bespoke LGBTQI+-adapted data collection, harmonisation and use for data-driven AI applications specifically in mental health care settings.

**Ethics and Dissemination:** PARQAIR-MH aims to deliver a toolkit that will help to ensure that the specific needs of LGBTQI+ communities are accounted for in mental health

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3 applications of data-driven technologies. The study is expected to run from June 2024  
4 through January 2025, with the final outputs delivered in mid- 2025. Participants in the  
5 Delphi process will be recruited by snowball and opportunistic sampling via professional  
6 networks and social media (but not by direct approach to healthcare service users,  
7 patients, specific clinical services or via clinicians' caseloads). Participants will not be  
8 required to share personal narratives and experiences of healthcare or treatment for any  
9 condition. Before agreeing to participate, people will be given information about the issues  
10 considered to be in-scope for the Delphi (e.g. developing best practices and methods for  
11 collecting and harmonizing sensitive characteristics data; developing guidelines for data  
12 use/re-use) alongside specific risks of unintended harm from participating that can be  
13 reasonably anticipated. Outputs will be made available in open access peer-reviewed  
14 publications, blogs, social media and on a dedicated project website for future re-use.  
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18 **Ethical Approval:** The Institute of Population Health Research Ethics Committee of the  
19 University of Liverpool gave ethical approval for this work (REC Reference: 12413; 24th  
20 July 2023).  
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## 23 Strengths and Limitations

- 24 • This Delphi study examines the intersection of data science, artificial intelligence  
25 and mental health care for LGBTQI+ communities advancing on similar research  
26 that has focused on healthcare or sexual health  
27
- 28 • Delphi studies enable a participatory approach to the development of consensus  
29 recommendations and guidelines  
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- 31 • The Delphi study will be led by a team from the United Kingdom, which may limit  
32 the generalisability of Delphi outputs to regions with similar societal attitudes and  
33 legislative mechanisms that protect the rights of LGBTQI+ people.  
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## 38 Background

39 Artificial intelligence (AI), machine learning (ML) and data-driven technologies are  
40 expected to deliver novel ways of understanding and improving mental health care (1). In  
41 healthcare applications of AI/ML generally, there has been increased focus on the potential  
42 for unintended harm arising from biases present in data (2) and resulting from model  
43 assumptions. Two striking examples being racial biases in an algorithm deployed to  
44 identify increased healthcare needs (3) and commonly-used models for estimating renal  
45 function (employing standard biostatistical methods) have been shown to be poorly  
46 calibrated for estimating kidney disease in people of colour (4).  
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51 The ambition of any data-driven learning health system (5) is to improve the care provided  
52 to patients by adapting provision to their specific needs. In the context of mental  
53 healthcare, LGBTQI+ communities are known to have specific difficulties arising from  
54 *minority stress* (6,7) including victimisation, internalised prejudice and isolation.  
55 Consequently, LGBTQI+ people experience higher rates of suicidal distress (8), self-harm  
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3 and suicide (9) and differential lifetime prevalence of the most common mental disorders  
4 as a function of sexual orientation and gender identity (SOGI), ethnicity and race (10).  
5 National survey data support these studies, showing that e.g. 3% of gay and bisexual men  
6 (compared with 0.4% of men in the general UK population) attempted to end their life by  
7 suicide in 2013 (11); over 80% of trans-identifying young people have self-harmed at some  
8 point in their lives compared to around 10% in the general population (12) and 24% had  
9 accessed mental health services (13) in the preceding 12 months.  
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12 We note that there is variation in cultural and societal definitions of “mental health” and  
13 “mental illness” (14), including the egregious assumption that LGBTQI+ identity is, by  
14 definition, a “mental illness” (15,16). In this Delphi process, while we include the  
15 biomedical definition of mental illness/disorder, we will use an inclusive and broad term –  
16 “mental distress” – defined as a constellation of experiences that cause distress for the  
17 person, result in a loss of social, personal or occupational function and/or reduction in  
18 quality of life. Further, in the proposed Delphi study, mental distress is something for which  
19 the individual would seek assistance from an external source (e.g. from healthcare  
20 professionals, or peer/community support), or where other stakeholders identify an unmet  
21 need (e.g. an LGBTQI+ support community identifying lack of support for a specific set of  
22 problems in people who remain ‘invisible’ to healthcare services).  
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## 26 Data Quality

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28 Supporting LGBTQI+ people requires high-fidelity data (17,18). However, such data is  
29 ostensibly lacking for reasons including:  
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- 31 • a lack of harmonisation for the recording of SOGI data resulting in fragmented,  
32 incompatible data (19,20)
- 33  
34 • poor recording rates for local data collection, beyond services focused on, for  
35 example, cis-gendered gay men and sexual health (11)
- 36  
37 • disclosure of SOGI characteristics to healthcare professionals is low, because LGB  
38 people experience healthcare organisations and professionals as threatening (21)  
39 and there is evidence that an individual’s medical history, immigration status, level  
40 of internalised homophobia and degree of connectedness to the LGBTQI+  
41 community are significant factors for disclosure with bisexual men and women  
42 being the least likely to disclose SOGI characteristics to healthcare professionals  
43 (22)
- 44  
45 • discrepancy between patient and healthcare professionals expectations around  
46 offending people by asking about SOGI characteristics, resulting in e.g. 80%  
47 healthcare professionals believing they may offend by asking about SOGI  
48 characteristics compared to 11% of patients reporting likelihood of offence (23)
- 49  
50 • accessing healthcare is difficult for LGBTQI+ people; for example, in the UK’s LGBT  
51 National Survey, 72% of people who had tried to access mental healthcare (24% of  
52 respondents had tried) described it as “not easy” (13)  
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## Appropriate Data Use

The straightforward imperative that we *require* better data collection is well documented (24–26), but difficult to implement. Further, there is less evidence on the specific and acceptable uses of data and explainable AI/ML technology to advance the provision of care for the LGBTQI+ community (27–29) and this problem pervades healthcare data re-use more generally. For example, a recent piece of investigative journalism on the UK Biobank claimed that “*Sensitive health information donated for medical research by half a million UK citizens has been shared with insurance companies despite a pledge that it would not be*” (30). In response, UK Biobank responded robustly (31), arguing their stewardship of the data meant that “*Researchers from insurance companies are treated like all other commercial or academic researchers*” and that the examples cited in (30) all had “*met the required tests of involving suitably qualified researchers and being health-related research in the public interest*”. Biobank’s current patient information leaflet (32) under the section “*Who will be able to use my information and samples?*” explicitly states: “*Insurance companies and employers will not be given any individual’s information, samples or test results*”. Biobank participants might understand this to mean that insurance companies with direct commercial interest in decisions about them will never be given their individual data for the purpose of e.g. assessing their insurance liability or risk. However, because insurance companies can be considered suitably qualified commercial researchers, participants might hold different opinions on *any* use of data in Biobank for purposes linked to the insurance industry on the grounds it cannot be health-related research in the public interest.

This example illuminates relevant themes for LGBTQI+ communities—namely, the need to understand:

- how SOGI data can be **meaningfully collected, stored and processed** in a way that is compatible with the language and norms defined by LGBTQI+ communities
- the **acceptable use-cases** for using individual and population level SOGI data collected in routine clinical care

This paper describes a protocol for a Delphi process to develop a consensus on these questions.

## Rationale for a Participatory Approach

Patient, public and stakeholder involvement in mental health research has an established history and is motivated by (33) stakeholder involvement as an ethical imperative with the expectation that this may improve the quality, relevance and uptake of research (34). Arnstein’s “ladder of citizen participation” (35) is often cited as an anchoring principle for meaningful stakeholder involvement and participatory design (36) with contemporary definitions (37) defining PPI as e.g. “a process whereby professionals and those traditionally on the receiving end of their ‘expertise’ (e.g. patients/service users/marginalised citizens) can collaborate with the goal of achieving outcomes that

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3 arguably cannot be achieved otherwise. It should engage the talents and experience of all  
4 involved and support the egalitarian relations and conditions needed to make the most of  
5 them". In healthcare, the defining summary statement is "no decision about me, without  
6 me" (38,39) and adopting this principle of empowerment and co-design for healthcare AI  
7 comes with unique challenges (40). Participatory approaches present a necessary step in  
8 the safe development of AI systems for delivering positive impact (41) and participatory  
9 design can play a critical role in empowering marginalised communities to take an active  
10 role in constructing research agendas and outputs; for example, in applications spanning  
11 architecture, the environment and planning (42,43), community building (44) and  
12 education (45).  
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16 A central tenet of AI research applied to healthcare should be that affected communities are  
17 active participants in the co-design and production of services and technologies to avoid  
18 (usually) unintended harms, to mitigate unforeseen consequences of technical processes  
19 and the avoidance of socio-technical "blind spots". In the application of AI specifically to  
20 LGBTQI+-inclusive mental healthcare, the interaction of minority stress (6) with the  
21 stigmatisation of mental illness more generally (46) presents a quagmire of acceptability,  
22 safety and healthcare equity concerns. We argue that these can only be addressed through  
23 a participatory process that identifies how services and technologies understand, collect,  
24 codify and use the communities' data to ensure they benefit. In health sciences, the Delphi  
25 technique has been useful for establishing a consensus on "complex issues where  
26 knowledge is uncertain and incomplete" (47) and where evidence synthesis from e.g.  
27 experimental or epidemiological data is difficult (48). Consistent with our aims for  
28 PARQAIR-MH, the method can enable a diversity of perspectives to be represented during  
29 consensus development.  
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## 34 Aims of the Delphi Study

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36 The application of data-driven technologies to high stakes applications – such as healthcare  
37 – requires high fidelity, comprehensive and therefore sensitive data to help mitigate biases,  
38 improve fairness, prevent inequality and to ensure representation. Consequently, stewards  
39 and guardians of such highly granular data must describe (as unambiguously as possible)  
40 the parameters on who will use this data and for what purpose. The aims of this Delphi  
41 study are therefore:  
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43

- 44 1. To establish consensus on how to collect, code and harmonise SOGI data in the  
45 context of improving provision of mental healthcare.  
46
- 47 2. Assuming high-fidelity SOGI data is collected and available, to establish consensus  
48 on the scenarios and use-cases for acceptable re-use of this data in data-driven  
49 technologies (e.g. AI, ML, population health and epidemiology) – including  
50 identifying use-cases that (according to the community stakeholders) constitute  
51 absolute "hard no" and qualified "potentially yes" cases  
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54 The study will deliver the following outputs:  
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1. A 'best practice' toolkit, defined by LGBTQI+ community stakeholders, for AI developers, data scientists and health care institutions to implement when collecting and recording SOGI characteristics for the people they serve. While this toolkit will be developed specifically for mental healthcare, some insights may be informative for other health and social care contexts
2. An online 'playbook' describing concrete example scenarios of SOGI data use that are clearly unacceptable or that may be acceptable with qualifications or with specific safeguards and conditions
3. Open-access academic paper(s) that summarise the outcomes of the Delphi study, directing stakeholders (policy makers, institutions and teams/individuals) on best-practice for using data-driven technology in the context of LGBTQI+ people and mental health

Our focus for the Delphi study will be on data that is expected to be collected routinely and in clinical or health settings (whether public, private or third-sector providers). Therefore, we will not consider the re-use of data from e.g. social media sources, blogs or other self-publishing platforms. Factors that explicitly address the most appropriate models of healthcare service design and delivery (13,49), while certainly relevant for people's experiences and future engagement with providers, will be out-of-scope for PARQAIR-MH due to the specific focus on ways to use data to improve LGBTQI+ affirmative care.

## Methods/Design

The multistage consensus method will follow recommendations for the Delphi technique (50). The fundamental principles of Delphi approaches are to exploit the "wisdom of crowds" (multiple experts), to collect anonymous feedback, and to iterate over multiple-rounds (51). These principles remain a constant feature of Delphi studies but the method has been applied to (and modified to account for) different objectives (e.g. policy issues, decision making (52)), applications (e.g. healthcare research (53–55)) and mechanisms of executing the Delphi process – notably, the adaptation of the traditional Delphi to online-based platforms (56).

The Delphi process comprises multiple stages, is overseen by an executive committee (the authors of this protocol) and an advisory working group (composed of representative stakeholders). In outline (see Figure 1), the stages are:

1. Conduct literature review, recruit advisory working group, and define terms of reference
2. Advisory and executive working groups collectively define the first questionnaire for the Delphi rounds; simultaneously, the advisory working group and executive group will advertise and manage recruitment of the survey group
3. Three sequential Delphi rounds are completed anonymously by the survey group participants via a secure web-based online platform.

4. Defining the final consensus on the outputs of the Delphi rounds and a final consensus meeting with the executive, advisory working and survey groups
5. The executive and advisory working group then build and deliver outputs (web-based toolkit, guidance including concrete example scenarios, and open-access papers summarising findings)

## Patient and Public Involvement Statement

Co-author Julia Hamer-Hunt, a lived-experience practitioner, consulted on the principles and design of the Delphi process from conception to the final draft of this protocol. The Executive Committee will be assembled by a targeted approach through the authors' professional networks, alongside open calls on social media, to ensure a diverse, equitable, inclusive and representative panel of stakeholders (including patients and public) to oversee the Working Group and execution of the Delphi consensus process.

## Working Groups: Composition and Recruitment

The PARTicipatory Queer AI Research for Mental Health (PARQAIR-MH) working group will include:

1. an **executive group** responsible for the overall execution of the project, organisational/operational processes to conduct, disseminate and report on the Delphi process. This group will consist of the authors of this manuscript.
2. an **advisory working group** who will lead the final-stage consensus meeting and be drawn from experts from the AI/machine learning, ethics, health policy, mental health professionals and patient and public involvement (PPI) stakeholder groups. We will aim to recruit 10 people to the advisory group.
3. a **survey group** of people (with similar composition to the advisory group) who will participate in the Delphi survey. This online survey group will be open to any interested (self-selecting) stakeholders able to provide informed consent and able to access the online survey. Our aim is to recruit a minimum of 50 participants to meet the heuristic of requiring approximately 30 to 50 participants (57–60). Of note, we expect attrition over the three Delphi rounds, but as consensus requires participants to complete all stages (and these will be conducted synchronously, with everyone asked to complete rounds in a certain time-period before the study progresses to the next round), we will not recruit additional participants to account for those leaving the study after only completing one or two rounds.

The advisory and survey groups will be composed of:

1. people with lived experience of mental health service use from the LGBTQI+ communities
2. people representing charities, NGOs (non-governmental organisations) and other campaigning groups focusing on the mental health of people from the LGBTQI+ community



3. domain experts drawn from mental health professionals, invited to participate from national and international LGBTQI+ communities to include people with lived experience of mental health problems.

Recruitment for the advisory working group will be via snowball and opportunistic sampling using the executive committee's professional networks (spanning mental healthcare, patient-and-public involvement, science/engineering, charities and support networks for LGBTQI+ people in the community and technology industry):

- directly approaching community groups and charities supporting LGBTQI+ people with an interest in mental health
- directly approaching LGBTQI+ policy leads in the UK's National Health Service (NHS) and the Royal College of Psychiatrists
- by arranging an online "town hall" event, announcing the PARQAIR-MH initiative with publicity on public social media (X/Twitter) platforms and closed community platforms (e.g. Queer in AI) to publicise the initiative and invite participation

Recruitment for the survey group will be conducted similarly to the advisory group, but in addition, we will request support in cascading publicity/advertising for participation in the survey group (those completing the three Delphi rounds) to people known to or using charity/community groups and again, using colleagues in the executive and advisory group's respective professional networks.

Participants will not be financially compensated for their contributions, but with their consent will be given attribution on the project's website and acknowledged in academic publications. People volunteering for the advisory working group will be offered co-authorship on academic publications.

A particular challenge with online Delphi studies is that participants will be self-selecting, and it is difficult to achieve appropriate representation e.g. across sexual orientation and gender identity as well as different stakeholder sectors. We believe that it is unethical to ask volunteers to describe their SOGI characteristics in order to selectively invite people to ensure diversity and representation in these groups. We acknowledge that this may limit the representativeness of these groups; we will instead describe the groups' composition and report any impacts this has on the conclusions and generalisability of findings.

### Stage 1: Defining the Terms of Reference and Literature review

To focus the initial round of the Delphi questionnaire, the executive group will review existing literature to identify:

- existing healthcare guidelines for the collection of SOGI data for LGBTQI+ people
- studies of perceptions, attitudes and experiences to disclosure of SOGI data in healthcare settings for LGBTQI+ people

- example applications of data-driven technology (in particular, AI) in LGBTQI+ mental health support to include those that expose benefits, risks and harms specific to that community

This review will include both published, peer-reviewed academic literature, governmental, NGO and charity surveys as well as publicly-available policy documents. Special attention will be given to surveying the ethics and fairness literature, to identify promising approaches for ensuring privacy and safety of AI systems. The glaring absence of analyses of disparate impact of AI on queer communities (61) further justifies the need for a deeper community involvement.

Following a review of the literature, the executive committee will produce a summary of the findings alongside a draft Terms of Reference (ToR), describing the Delphi study's aims, scope and intended deliverables and outputs. The ToR will be circulated via email for comments and revision by the advisory working group over a period of 4 weeks to agree on the final ToR.

The executive group will conduct a targeted literature review of existing literature, guidelines and toolkits that inform the aims of this Delphi study and will form the preparatory step for the initial Delphi questionnaire. There are two primary foci for the Delphi study that require a review of literature and other research outputs: a) how to capture SOGI data (so it is complete, valid and collected in an affirming way) and b) the parameters of this data's reuse (similar to responsible data stewardship for AI and data-driven technologies (62)).

Following the framework introduced by Arksey and O'Malley (63), we will search relevant databases (e.g., PubMed and Crossref) for papers and guidance documents published from 2000 to 2024. For the review of data-collection practices, we will employ a combination of controlled vocabulary terms and keywords related to LGBTQI+ communities (e.g., "sexual and gender minorities", "LGBT", "LGBTQI+") and routine data collection in healthcare-related domains (e.g. "routine data", "electronic patient", "electronic health"). Our initial reviews (e.g. described in this protocol paper) revealed that case-studies describing existing practices, guidelines ("playbooks") and toolkits are often not part of the traditional scientific literature and in particular, web-based resources are often less visible as academic outputs. For this reason, we will perform web-searches with similar terms and additionally search websites of relevant organizations (e.g., the World Health Organization and the American Medical Association) for potentially relevant guidance documents.

For the aim of demarcating the parameters of acceptable data-reuse, we will augment the controlled vocabulary terms related to LGBTQI+ communities with terms to capture scenarios, permissible and unacceptable use-cases and search for publicly-available impact assessments relevant to queer-affirming healthcare. Our initial searches suggest a majority of scholarly activity describes existing, or sometimes predicted, harms from e.g. facial recognition technology (64,65). We will need to develop anticipated use-cases and scenarios that might predictably arise in the application of data-driven technology in mental healthcare (or healthcare more generally) which are sparse – a recent exception

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2  
3 being the application of conversational AI to provide mental health support for the  
4 LGBTQI+ community (66) .  
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6 For both targeted reviews, two reviewers from the executive group will independently  
7 screen titles/abstracts (for the research literature) or 'executive summaries' or landing  
8 pages (for web-based resources) to identify eligible artefacts for full review and inclusion.  
9 Reviewers will first attempt to resolve disagreements through discussion; if discussion fails  
10 to resolve disagreements, a third reviewer will break ties. Subsequently, we will review the  
11 full text of eligible documents and artefacts for insights and claims relevant to the two  
12 topics.  
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## 15 **Stage 2: Initial Questionnaire Definition**

16 With an agreed terms of reference – and drawing on examples of existing practice and  
17 assets arising from the literature search – the executive group will draft an initial  
18 questionnaire for the first round of the Delphi process. In parallel to the drafting of the first  
19 questionnaire, the executive group will advertise the online Delphi questionnaire study as  
20 described above (Working Groups: Composition and Recruitment).  
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24 It is anticipated (subject to the literature review and input from stakeholders in the  
25 advisory group) that the content of the first draft questionnaire will cover the following  
26 topics, aligned with the study aims:  
27

- 28 1. LGBTQI+ community preferences for collecting, recording and harmonising SOGI  
29 data
- 30 2. the parameters for the acceptable (re)use of SOGI data for improving healthcare  
31 systems to include the following example use-cases:  
32
  - 33 – the use of automation (e.g. AI-driven chatbots or recommender systems)
  - 34 – decision support (e.g. identifying risk factors for individual people)
  - 35 – configuring/commissioning services (e.g. auditing SOGI data for adapting  
36 existing, or developing new, services)
  - 37
  - 38
  - 39
  - 40
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42 For the initial (and subsequent) questionnaires, it is anticipated that data collected will be  
43 structured (and consensus defined) as follows:  
44

- 45 • Some items will invite participants to provide a two-alternative forced choice (for  
46 example, "Would you prefer to provide information on your sexual orientation by  
47 (A) selecting a label that encompasses both attraction and partnering (e.g.,  
48 heterosexual, gay, lesbian), or (B) providing separate information on your attraction  
49 and partnering preferences?"). For these items, a consensus will be defined as when  
50  $\geq 70\%$  of participants respond with the same answer.  
51  
52
- 53 • Where questions invite an ordinal, positive- or negative-preference response,  
54 participants will be asked to provide an answer on a 7-point Likert scale (for  
55 example, "A clinical service wishes to use it's patient's self-described gender identity  
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3 data to report on the demographics of the service; Is this an acceptable re-use  
4 case?") with anchors "Strongly Disagree", "Strongly Agree" and "Neutral" coded as 1,  
5 7 and 4 respectively. For these items, consensus will be defined as  $\geq 70\%$  of  
6 participants responding with "Agree" or "Strongly Agree" (positive consensus) or,  
7 "Disagree" or "Strongly Disagree" (negative consensus)  
8  
9

- 10 • Some items will present a longer-form scenario, followed by a number of related  
11 questions that invite two-alternative and/or ordinal preference responses; in  
12 addition, if there is scope for nuance or a need for narrative description of why a  
13 particular answer was given, free-text fields will be available for additional  
14 comments. Narrative responses will be summarised and presented e.g. as  
15 "qualifications" to the topics described in the question.  
16  
17

18 For the first round, the questionnaire will conclude with a free-text invitation to suggest  
19 areas, topics, scenarios or specific questions/items that the participant feels were  
20 neglected and this will be taken into account for the design of round 2.  
21

### 22 Stage 3: Delphi Rounds

23  
24 The Delphi process will consist of three sequential rounds, all conducted via a web-based  
25 questionnaire delivery platform. Each participant will be identified only by an email  
26 address (that they provide on starting the first questionnaire round). IP addresses will not  
27 be retained or used to identify participants or their survey responses. Each email address  
28 will be assigned a unique participant number in a participant table to ensure that the same  
29 participants are responding to each of the three rounds and so that invites for subsequent  
30 rounds can be distributed to those completing the first round. The participant table will be  
31 retained securely and available only to the executive group.  
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34 The three rounds are as follows:

- 35  
36 • **Round 1:** Participants will be presented with direct questions or short vignettes  
37 describing either existing (from the literature review) or hypothetical use-cases for  
38 SOGI data collection and re-use. Participants will be given a fixed time period within  
39 which to complete the questionnaire round. At the end of the period, the executive  
40 group will retrieve responses from the web-platform and store them securely,  
41 identifying participants by their unique participant number and separately storing  
42 the participants email address. Agreement on each question will be conducted as  
43 described above (Stage 2: Initial Questionnaire Definition) alongside analysis of any  
44 narrative responses. The resulting questions, responses and agreement will be  
45 summarised by the executive group and presented to the advisory group in an  
46 online meeting that decides which questions/items are to be retained, modified or  
47 ejected from the subsequent round. For example, items with a clear consensus will  
48 be removed from round 2 whereas items that fail to produce consistent responses  
49 will be modified.  
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- 52 • **Round 2:** The Round 1 participants will be notified via email from the executive  
53 group asking them to participate in the second questionnaire round. This second  
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round will be prefaced with an anonymised summary of the round 1 responses, including indicating which items were subsequently removed due to consensus being reached. As for round 1, at the end of a defined time-period, the round will be ended, data retrieved and analysed for consensus and revision of the questionnaire for the final round.

- **Round 3:** The final round will follow the same process as previous rounds. However, we expect the final round to contain items addressing topics which remain particularly contentious (i.e. where agreement between participant responses remains low). Participants will be made aware that in the final round, any items that do not reach consensus will be reported as areas with uncertain conclusions and they will be reported as such; this is to ensure participants are aware that if they recognize items on similar topics/themes from previous rounds, they should not necessarily modify their responses purely because this represents the final round.

#### Stage 4: Consensus Process

The executive group will collate the rounds of questionnaires, providing a summary of the questions and the corresponding numerical measure of agreement among participants. Attention will be paid to highlighting areas where there remained lack of agreement after three rounds. The advisory group will be consulted via email to enable revision on the summary report before being emailed to all survey group participants who will also be invited to reply with commentary on the report.

A consensus meeting will be advertised to participants in the advisory and survey groups, inviting them to attend and discuss proposals for how the summary report can be presented as outputs to meet the aims of the study. This consensus meeting will be online using a video conference platform and participants at the meeting will be asked to use a pseudonym screen name, and to keep their video feed switched off (i.e. audio only) to help preserve anonymity. The executive group will organise and moderate this meeting, with one member (an experienced social scientist) designated a non-voting chair. In addition, we will invite stakeholders using the executive and advisory group's professional networks. We expect the consensus meeting will therefore have representation from:

- NHS and University Patient and Public Involvement/Engagement groups
- Stakeholders from the survey group (rounds 1–3 participants)
- Clinicians working in the mental health sector
- Ethicists
- AI researchers and data scientists
- NGOs and charity stakeholders for LGBTQI+ mental health

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3 Importantly, we recognise that consensus may be difficult to achieve for certain topics and  
4 themes; for example, some participants might have a strong opinion that the use of  
5 automation and data driven-technologies is unacceptable in any aspect of mental  
6 healthcare delivery. Given the complexities of defining consensus (67), themes where  
7 agreement could not be reached will be reported and highlighted in the final outputs (e.g.  
8 the web-based toolkit, playbook and in academic publications).  
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## 11 Outcomes and Dissemination

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14 At the consensus meeting, the outputs deemed necessary and sufficient for a toolkit will be  
15 discussed; for example, the format and medium for the researcher “checklists”, guidance  
16 and “playbook” documents (describing scenarios and offering advice on acceptability  
17 according to the outputs of the Delphi questionnaires and the consensus meeting’s  
18 recommendations) that we expect to take the form of a recommendations white paper and  
19 case-study format similar to prior work in related areas (62,68,69). Following this, the  
20 executive group will invite the advisory group to contribute to writing a summative report  
21 for submission to an open-access, peer-review journal.  
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25 The key outputs (toolkits, guidance documents, advice for replicating the Delphi process)  
26 and findings (including open-access, peer-reviewed papers) will be made available on a  
27 website (similar to the equator network, <https://www.equator-network.org/>) that will be  
28 maintained by the executive committee. The aim is to provide a participatory design-  
29 inspired open and transparent process for communities and organisations to either deploy  
30 the consensus and toolkit in their own localities, or to replicate the process to derive  
31 locally-informed versions of the toolkit/consensus.  
32  
33

34 Stakeholder involvement in all outputs from the proposed Delphi process will be  
35 transparent and explicitly described, including composition of the Executive Committee  
36 and Working Group. Specific patient and public involvement (PPI) will be reported using  
37 the GRIPP2 (70) reporting guidelines.  
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## 40 Discussion

### 41 Scope and Generality

42  
43 Existing work on SOGI data collection and harmonisation reflects a largely Western  
44 geographical focus including the European Union, United Kingdom and United States (17–  
45 19). The pending UN Report to the Human Rights Council (71) on SOGI emphasises  
46 healthcare equity for LGBTQI+ communities (including data collection/harmonisation as a  
47 key enabler) while previous UN mandate reports (72) acknowledge under-representation  
48 from regions of the world with hetero-normative cultural attitudes or where people from  
49 LGTBQ+ communities are persecuted. Similarly, different societies and cultures’  
50 formulation of mental illness in terms of aetiology, stigma, implications for individuals,  
51 family and wider society vary to the extent that a dominantly Western biomedical model  
52 (that is proposed to emphasise the individual as the locus of mental illness and disorder) is  
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3 seen as unhelpful (see (14) for a review). While the overarching PARQAIR-MH process  
4 remains general, the outcome of its initial application in the United Kingdom will be limited  
5 and localised in its immediate practical utility, necessitating replication studies.  
6

## 7 8 **Limitations**

9  
10 The patient and public perception of clinical applications of AI is relatively under-studied;  
11 one systematic review (73) of 23 mixed-methods studies found no studies specifically  
12 addressing mental healthcare. The review exposed some polarisation around themes of  
13 accountability (of a decision made using AI), concern around “boundary cases” (i.e. rare  
14 diseases or uncommon situations) and a divide around risk of worsening or improving  
15 healthcare outcomes, equity and justice. Importantly, they note that the perspectives of  
16 under-represented groups were rarely included or studied in the sampled literature.  
17

18  
19 Given this, we expect similar polarity in our Delphi process which may limit the extent to  
20 which consensus can be reached. Consequently, we will report separately on subsets of  
21 items achieving consensus, those where no consensus could be reached and a clear  
22 description of contentions arising in both subsets.  
23

## 24 **Protocol Re-use and Utility**

25  
26 Considering the rising need for a wider community involvement in AI design, and this being  
27 one of the very first AI participatory studies designed specifically for the LGBTQI+  
28 population, we hope that the proposed protocol will help inform a multitude of future  
29 participatory research directions. Indeed, the issues of data collection, data use, fairness  
30 and safety, are central to AI development across mental health care, healthcare, as well as  
31 numerous other domains and use cases.  
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33

34 Consistent with the central tenets of participatory design, this protocol needs to be applied  
35 locally, to capture the local variation in perspectives, needs, and healthcare systems.  
36 Repeated application of the protocol may result in different consensus statements,  
37 reflecting these local differences. We would therefore strongly encourage worldwide  
38 replication studies, complementing the initial study planned in the United Kingdom. In  
39 terms of utility, PARQAIR-MH aims to help inform digital health policy and the design of  
40 inclusive mental health care technologies going forward.  
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## 43 **Ethics and Dissemination**

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45 Participants in the Delphi process will be recruited by snowball and opportunistic sampling  
46 via professional networks and social media (but not by direct approach to healthcare  
47 service users, patients, specific clinical services or via clinicians’ caseloads). Participants in  
48 the survey group will not be required to share personal narratives and experiences of  
49 healthcare or treatment for any condition. The Delphi rounds will be completed online,  
50 asynchronously (as participants may be in different time zones) and pseudonymously  
51 using a web-based, secure platform hosted at the University of Liverpool. Participants will  
52 be required to provide informed consent (via an online form), after reading a participant  
53 information sheet describing the issues considered to be in-scope for the Delphi (e.g.  
54 developing best practices and methods for collecting and harmonizing sensitive  
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3 characteristics data; developing guidelines for data use/re-use), an outline of the risks of  
4 unintended distress arising from participation (in so far as this can be reasonably  
5 anticipated) and informing participants of the options to withdraw and remove their data  
6 from the study. After each Delphi round, participants will be offered the opportunity to  
7 participate in an online debriefing session. Participants volunteering to assist in the final  
8 consensus process (to agree the final output of the Delphi rounds) will be asked to  
9 participate in the online video-conference pseudonymously (i.e. audio-only, identifying  
10 themselves on-screen using a pseudonym). The study, consent processes, data protection  
11 and participant-facing information materials have been approved by the University of  
12 Liverpool's Research Ethics Committee (REC Reference: 12413; 24th July 2023).  
13  
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15  
16 Outputs will be made available in open access peer-reviewed publications, blogs, social  
17 media and on a dedicated project website for future re-use.  
18  
19

## 20 Authors' Contributions

21  
22 The study was conceived and designed by authors D.W.J., A.K., J. HH., K.R.M and N.T. The  
23 drafting and revising of this protocol paper was completed by D.W.J., A.K., J. HH., K.R.M and  
24 N.T. Final approval for the version published was agreed by D.W.J., A.K., J. HH., K.R.M and  
25 N.T. who also agree to be accountable for all aspects of the work in ensuring questions  
26 related to the accuracy or integrity of any part of the work are appropriately investigated  
27 and resolved.  
28  
29

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35 support relating to this work.  
36  
37  
38  
39

## 40 Competing Interests

41  
42 DWJ and AK are partially supported by an NIHR grant (AI\_AWARD02183) which explicitly  
43 examines the use of AI technology in mental health care provision. NT and KRM are  
44 employees of Google DeepMind, an AI research company. JHH has no competing interests  
45 to declare.  
46  
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## 50 Figures

51 Figure 1 Caption: *Stages of PARQAIR-MH Delphi Study*  
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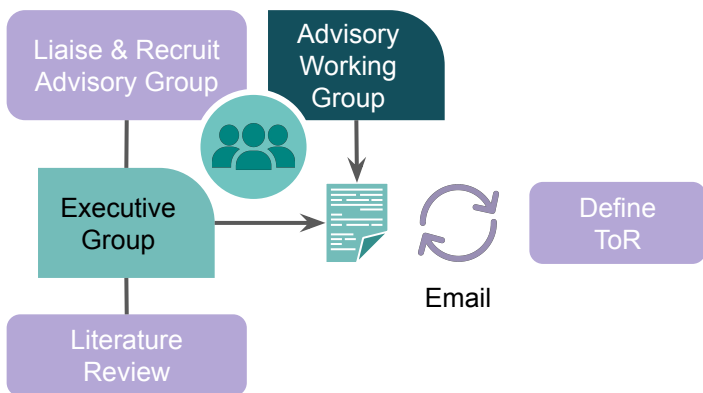
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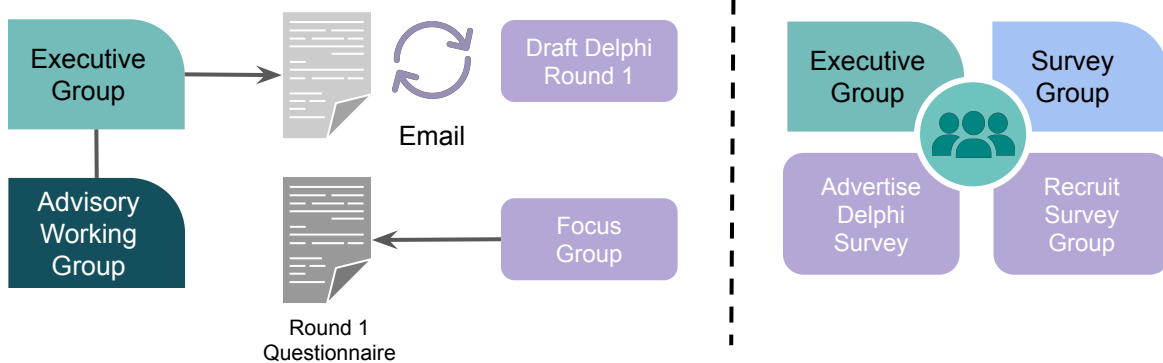
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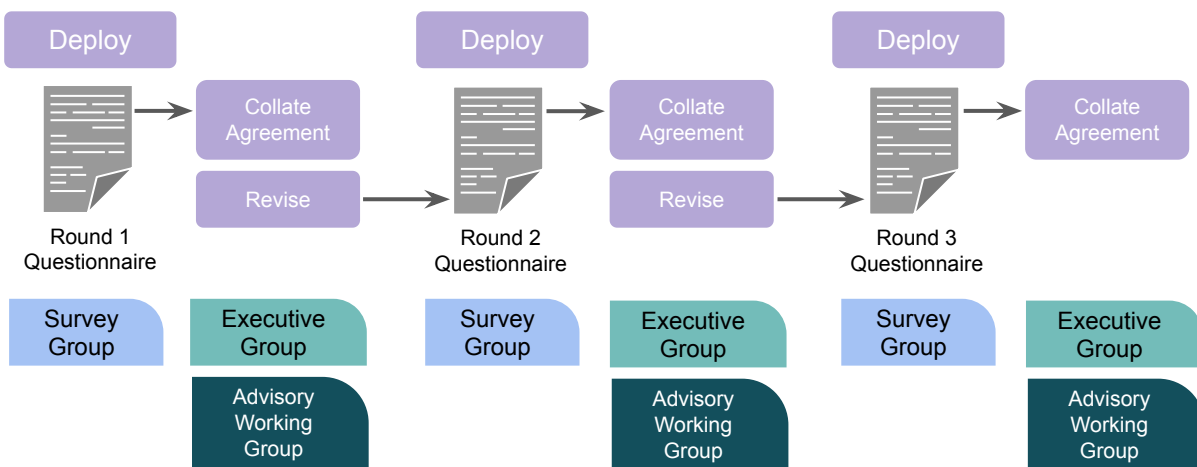
Stage 1



Stage 2



Stage 3



Stage 4

