

Ethical Considerations for a Mental Health Data Resource

Wellcome is seeking an external supplier to conduct the following:

1. Scope of the work

This proposed activity is part of a broader project that aims to support the development of a future ethical data resource/s to further understanding of the aetiology and resolution of anxiety, depression and psychosis. The activity proposes to take findings from parallel work streams involved in sourcing and identifying core data requirements, to unpack the ethical considerations and explore and articulate potential approaches to mitigate issues arising from collecting, using and/or merging these (likely) sensitive data sets. Consistent with the Mental Health Challenge Area (MHCA) principles, this work will involve persons with lived experience (ie. Wellcome Mental Health lived experience consultants) to “sense check” emerging issues arising from the literature and to ensure that potential ethical issues and mitigation strategies that are not fully reflected in the literature are explicitly accounted for and inform all resources produced for this activity.

This landscaping activity aims to identify potential ethical issues and mitigation strategies related to proposed mental health data collection, use, access, storage and integration of datasets, while also considering implications of any requisite collection and storage based technologies and platforms. This work is critical to support the legitimacy and trustworthiness of any future data resource built or enriched, to encourage diversity and appropriate representation in datasets and to ensure that any primary data collection tools and processes are responsive to the needs and experiences of the communities involved. These considerations will be critical to participation and retention and to the broader reputation of the organisation. It is timely to undertake this work now to inform decision making regarding the content and nature of data collection for future potential data resource/s in the sensitive area of mental health and in diverse geographies from which these datasets will likely be sourced.

This work is viewed as an important exploratory piece aimed at understanding and managing potential participant, stakeholder and organisational risks arising from the creation or enrichment of potentially sensitive data sets. It is being put forward at this time to help inform potential future proposal/s for ethical MH data resource/s and importantly, to support the creation of an evaluative framework and criteria for proposals from potential suppliers/grantees.

The project is intended to “build in” considerations such as representation, potential burdens and risks to data subjects and communities, and mitigation strategies for data collection, analysis, retention, storage and sharing. It aims to do this by critiquing and accounting for the social, ethical and economic implications of the creation or enrichment of MH data resource/s related to anxiety, depression and psychosis.

There are 2 objectives to this activity:

- Create guidance on the collection and use of a critical set of mental health data, ethical issues and mitigation strategies that is reflective of the perspectives of people with lived experience. This critical set of mental health data will largely be collected from early adolescents to young adults and will likely include:

- **Biological samples** for assessment of genetics, epigenetics, microbiome, stress markers, inflammation (e.g. blood, saliva, fecal samples, breastmilk)
- **Brain scanning** (Neurological data)
- **Wearables** for assessment of sleep, movement (geolocal, vital signs)
- **Surveys/interviews** (mental health outcomes, substance use, experience of discrimination, sexism, general experiences of young people, networks and interpersonal relationship, self reporting of physical health)
- **Computer based tasks** for assessment of cognition across various domains eg attentional biases, executive function etc (reaction time, correct/incorrect responses, eye movement data depending on specific task)
- **Ecological Momentary Assessment (EMA)** for assessment of mood fluctuation (surveys/individual questions/likert scales via mobile phone or equivalent)
- **Demographic and locational data** (environmental data)
- **Meta-data from mobile phones/tablets** (screen use)

In addition to the above and while being cognisant of the importance of contextual specificity, broad based issues will also need to be unpacked in relation to:

- Considerations in resource poor/limited settings and,
 - Considerations when linking the above data sets with other data, particularly administrative data
- Create a clear set of criteria for assessing the ethical rigour of proposals for a future data resource that would have a strong focus on data collection from early adolescents to young adults, be inclusive of the proposed data sets and the additional broad considerations noted above (settings and linkages).

2. Expected output

- a. A clear conceptual frame for articulating and unpacking the ethical issues and mitigation strategies considering the primary age range of participants, the nature of the data, the contexts (ie settings), collection tools and the potential implications of linking data.
- b. A literature review adopting the above conceptual frame, which unpacks the ethical issues related to the criteria noted above, providing recommendations for appropriate mitigation strategies.
- c. A consultation with the Wellcome Lived Experience team to “sense check” and enhance the literature review.
- d. A final comprehensive reference that addresses each of the incremental or new data proposed and the additional considerations, highlighting ethical issues and proposing potential mitigation strategies.
- e. A clear set of criteria for assessing the ethical rigour of proposals for a future data resource that would be reflective of the conceptual frame noted above, the data sets, contexts and potential linkages.

3. Preferred timelines

#	Activity	Responsibility	Date
1	RFQ issue to Suppliers	WT	5 Sept 2022
2	RFQ Submissions due	Supplier	30 Sept
3	RFQ Evaluation Period	WT	3 Oct – 21 Oct
4	Notification of Contract Award	WT	24 Oct
5	Contract Negotiation	WT & Supplier	24 Oct – 18 Nov
6	Contract Start Date	WT & Supplier	21 Nov
7	Contract End Date	WT & Supplier	28 Feb 2023

4. Detail requested in the quote

- Outline your approach for delivering the activities and objectives of this RFQ and the methods that will be used for the research – inclusive of your search strategy, and reflecting on how you will work with Wellcome to produce deliverables to a high standard.
- Outline a proposed timeline for development, implementation and delivery of the proposed outputs inclusive of drafts.
- Outline any amendments or additions to the work proposed in this RfQ, including any (reasonable) proposed adjustments to timelines.
- Outline why you are best placed to deliver the work laid out in the RFQ, which may include technical knowledge in relation to mental health and data ethics, relevant networks, previous experience and other relevant information for the delivery of this proposed piece of work.
- Provide a cost proposal excluding VAT, which details and justifies the proposed costs to meet our requirements. (Seemingly costly aspects to your proposal will require further explanation.)
- Highlight any risks which you foresee with meeting the requirements and explain your approach to risk management.

Please also see attached [Wellcome's standard T&Cs](#) which we would contract this work under

Non-Disclosure and Confidentiality - Prospective Suppliers should be aware that inappropriate publicity could have a serious effect upon Wellcome's business. The information contained within this email is deemed confidential and must not be disclosed without the prior written consent of Wellcome unless required by law.

Diversity and Inclusion - Embracing [diversity and inclusion](#) is fundamental to delivering our mission to improve health, and we are committed to cultivating a fair and healthy environment for the people who work here and those we work with. As we learn more about barriers that disadvantage certain groups from progressing in our workplace, we will remove them.

Wellcome takes diversity and inclusion seriously, and we want to partner with suppliers who share our commitment. We may ask you questions related to D&I as part of our procurement processes.

We would be grateful for your response to this enquiry by the **30th September 2022** to RFP@wellcome.org. Please submit any questions you may have with regards to the consultancy when you submit your response and quote.

The point of contact for this RFQ will be:

Olivia Donovan, Procurement Officer

RFP@wellcome.org