



# Wellcome Data Prize in Mental Health

## Webinar

May 10<sup>th</sup> 2022



# Wellcome Data Prize in Mental Health – Overview



**Objectives:** The aim of this Data Prize is to support multi-disciplinary teams led from South Africa and the UK to research into anxiety and depression in young people and help answer the question “What works for whom, in what contexts and why?” Selected teams will receive funding to explore existing datasets and to develop impactful digital tools to enable further research.



**Prize structure :** There are three phases to the prize, each six months long:

- Discovery phase: 10 teams will be selected to receive £40,000 of funding
- Prototyping phase: 5 teams will be selected to receive £100,000 of funding
- Sustainability phase: £500,000 will be allocated across 3 winning teams



**Evaluation criteria:** Proposals will be evaluated on impact, innovation and feasibility. As part of the evaluation, key considerations will notably include how teams would have considered data ethics and would have plan to involve lived experience of youth anxiety and depression throughout their work.

# Embedding Lived Experience within Research

*Kate Martin - Shuranjeet Singh - Amarno Inai*

# Embedding Lived Experience within Research

## Lived experience definition:

*We understand lived experience as a unique form of knowledge, insight, and expertise, that comes from having experience of mental health challenges.*

## Expectations for prize participants:

- As part of the teams' evaluation, we will be looking at how teams plan to involve lived experience in their project, notably how they think about meaningful involvement, safeguarding and governance.
- We would be expecting teams to integrate some level of lived experience involvement in their project, though we do not have pre-defined standards. We are aware that depending on the focus on the project, the ways teams might involve people with lived experience will vary depending on what would be most relevant and impactful.
- Given the structure of the prize, lived experience will not shape primary research but could relate, for example, to interpretation of findings that can be nuanced with lived experience expertise; or having support from young people in planning the approach of the project; or having a youth advisory board to guide on decision making

# Dos and Don'ts of Lived Experience Involvement

## Do:

- Make sure lived experience is central to guiding how the research project is designed, implemented, monitored, and disseminated.
- Where possible, involve people with lived experience in writing your application and in preparing for the pitch (if shortlisted).
- Recognise people with lived experience as experts, valuing their expertise as you would with any other member of the project team.
- Involve a diverse group of people with lived experience.
- Compensate or pay lived experience contributors for their involvement and build these costs into your proposal.
- Acknowledge the contribution of lived experience experts to your project, by naming them on your applications and research outputs (if they wish).
- Really take into account what those with lived experience have to say and integrate this into research using lived experience as a guide.
- Discuss topics in a relatable and accessible way to ensure that people can relate to them, and feel included.
- Listen to understand rather than reply.
- Give people with lived experience the opportunity to get involved in different ways depending on what they are comfortable with.
- Give researchers the budget and time to focus conscientiously on the research project. Not giving them such a limited budget and time that involving lived experience becomes a tickbox.
- Be mindful of language used throughout the research - avoid jargon, use everyday language where possible & always include a glossary.
- Make sure to actually incorporate the feedback.

# Dos and Don'ts of Lived Experience Involvement

## Don't:

- Treat people with lived experience as research participants. They should be involved as experts and inform the design, governance, and delivery of the research as, for example: co-applicants or co-researchers, collaborators, embedded colleagues, through advisory groups, or by gathering their perspectives through workshops or online discussions.
- Ask people with lived experience to tell their personal stories or background of mental illness – they may share this but only if they would like to. Instead ask for their opinion and expertise on various elements of your research.
- Involve lived experience in small or inconsequential ways, such as only asking for their opinions after the major decisions about the project have been made or involving them only right at the end of the project when their ideas cannot be incorporated.
- Be too rigid on involvement. Many individuals can contribute in different ways (e.g. in workshops, over email).

# Examples of lived experience involvement

## Lived Experience Infrastructure

Professional LE Lead

LE consultants

LE Advisory Board

Governance

Safeguarding

## Project Design

Help develop application and pitch.

Actively input into development of digital tool proposal.

## Analysis, Deliverables and Outputs

Ongoing involvement in delivering key proposal outputs.

Supported to deliver key outputs.

## Reporting and Dissemination

Contributing to and/or co-authoring reports/publications.

Co-developing research outputs – inc. papers, presentations, blogs.

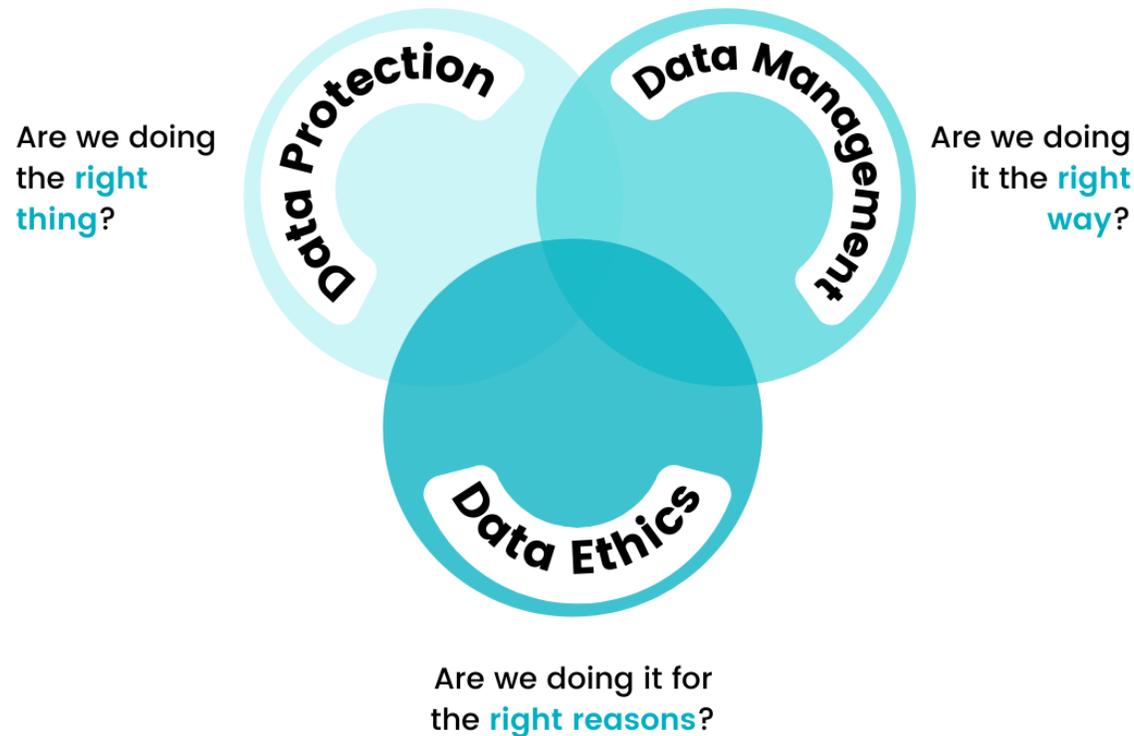
Identifying and enabling best dissemination routes.

# Data Ethics Considerations

*Alessandra Fassio*

# What do we mean by data ethics?

## The 'Data Ethics Ecosystem'



Thinking holistically about motivations, methods and impacts.

Trust, transparency, safety and fairness are all important components of an ethical data project.

Ethics is a chance to reflect on the decisions and actions you have made throughout the project lifecycle, and to create an audit trail that showcases your thinking. It adds value to the design and delivery of a project.

# Ethical use of data: *if your project made front page news tomorrow, how would you feel?*

- Scope

- Can you map the *need* for particular datasets to the question?
- Do you have clarity of what is *in* and *out* of scope?
- *What is the minimum data needed to successfully answer the question?*

- Sources

- Do you have sight of where your data sources are from, and are comfortable with their collection and storage methods?
- Are you confident in these sources?

- Transparency

- How will you ensure your project methodology, and any outputs, predictions or assumptions, are made transparent and accessible?
- Will people be able to challenge and question the data and methods you have used if they wish to?

# **Any harmful uses of your research outputs: *what's the worst that could happen?***

- What language are we using? Is it harmful? Is it accessible?
- What images, graphics, stories are we using? Who could they put at risk?
- What are our results telling us (both positives & negatives) and how could these be used to harm our intended beneficiaries?
- Who is our audience? Why?
- What assumptions and predictions are we making? Are these fair?
- What would happen if we didn't share the outputs of our work?

# **Safeguarding risks for involvement approach for people with lived experience: *how do we protect the privacy and dignity of those we are engaging with?***

- Mental health is a sensitive subject area, and any conversations should be respectful of this.
- There needs to be a well-defined need to involve people with lived experience. This should be of value-add to both parties, and via an activity that is suitable for the demographic you are looking to engage with.
- Appropriate safeguarding reporting procedures and training should be identified and delivered prior to any engagement, including awareness of how to escalate any concerns
- Teams should have an awareness of what could constitute a safeguarding risk in conversation, and how to sensitively manage this in line with reporting procedures
- Protection of privacy is imperative.

**Q&A**

# Concluding remarks



## Key dates:

- Application deadline: June 5<sup>th</sup> 2022
- Pitch dates: 5<sup>th</sup>, 6<sup>th</sup> or 7<sup>th</sup> of July 2022
- First day of the discovery phase: August 8<sup>th</sup> 2022



## For more information:

- Visit the Wellcome website <https://wellcome.org/grant-funding/schemes/wellcome-mental-health-data-prize>



If you are looking for a team: join the Slack channel (link on the Wellcome website)