

# MIND THE GAP:

## Lived Experience Council Involvement

June 2022



**HBGI**  
Healthy Brains Global Initiative

# INTRODUCTION & REFLECTIONS

We at HBGI are committed to integrating lived experience perspectives at every level of its work. As part of this commitment, we work closely with our Lived Experience Council, including in our recent study [Mind the Gap](#).

This document summarizes reflections from that process and provides a set of Council guidelines for lived experience engagement.

Some **key reflections** from our study included:

- Importance of involving young people in the process itself;
- Coordination, communication, and transparency are key;
- Taking sufficient time to ensure meaningful involvement;
- Deliberate facilitation of meetings important to challenge existing power dynamics;

- Tapping fully into the resources and expertise of people involved;
- Acknowledgement of contributions and speedy compensation appreciated;
- Avoiding tokenism (i.e. holding up participation as a trophy without putting in necessary time to do it meaningfully);
- Accessibility, particularly around providing alternate ways to be involved

This study was a learning process for all involved, and we greatly appreciate the flexibility and passion of our Council members throughout the process. We hope by sharing our honest takeaways and reflections, we can help others who are considering how to involve lived experience in their organization.

Please read on for the full set of guidelines generated by our Council.



To achieve a truly participatory approach, we partnered with members of our Lived Experience Council at every step of the process:



**From selection of consultants:** having two members serve on the selection committee for the consultancy



**Providing guidelines** for lived experience engagement written by Council members (see Page 3)



**Steering of the project itself:** having three members attend weekly check-ins with the research team and included on all written communications



**Dissemination:** inviting Council members to the Board meeting where results were presented

We made sure meetings were recorded for accessibility purposes and offered compensation for the time Council members put in to ensure sustainability of their involvement.

# GUIDELINES FOR LIVED EXPERIENCE ENGAGEMENT IN RESEARCH

Our Lived Experience Council established these guidelines to set the stage for ethical and equity-based participation of lived experience in global brain health research. These are to serve as a checklist while gathering data to avoid repeating harmful and exclusionary research practices and move towards expanded, inclusive methods to generate novel ideas.

3

Enhance co-production using an intersectional approach. Include service users, people working in health, academia, social care research and policy.

4

Ensure data protection policies, consent and easy-to-follow formal complaint processes are outlined clearly.

## RESEARCH AND DATA GATHERING METHODOLOGY

1

Diverse data collection methods: using generative design research activities like card sorting and ecosystem mapping, and by pursuing broad lines of enquiry, FGD (focus group discussions) and addressing themes regarding: personal views and opinions on the mental health ecosystem, personal and community-based mental health experiences, and mental health research participation.

2

Diverse data sources beyond published research and white papers: Social media posts (use targeted hashtags, demographics), grey papers, memoirs, online and offline blog posts and article.

## COMPENSATION/ REIMBURSEMENT

5

People with lived experiences are experts by experience; there is a need for a structure for financial compensation.

6

Reimbursement mechanisms need to consider the hurdles experienced by different people and compensate accordingly- internet costs, travel costs, time spent and extent of contribution.

7

Mentoring and skills development using meaningful tools can also be strongly considered as compensation mechanisms.

8

Compensation to be appropriate to geography and access of participants (ex: No Amazon gift cards for participants in places without Amazon, could consider grocery cards of equal value!)

9

Have a variety of incentive options, task-based incentivization could be considered- giving participants autonomy to choose appropriate compensation.

## DIVERSITY AND INCLUSION

10

Ensure that participants are a mix of genders, ages, sexualities, ethnicities and backgrounds, people with different experiences of brain/mental health challenges.

11

Reach out to- advocacy organizations, patient organizations, peer networks, research organizations across the world, mental health centres and universities for participants.

12

Respect for cultural values, beliefs and differences. Soliciting feedback from people with lived experience through tools like Focus Group Discussions can help to start mental health conversations.

13

HBGI can have an impactful role in dismantling the system of oppression and racism (in certain geographies, regions), change the traditional research paradigm, challenge global researchers to do better (for local communities).

## POWER BALANCE, COLLABORATION, TRANSPARENCY

14

Implement the power of collaboration and partnerships- by acknowledging the value of lived experience knowledge and being mindful of long-established colonist research practices.

15

There is no room for tokenism - the symbolic practice of including underrepresented groups for the sake of representation and not inclusion.

16

Research should be conducted and produced in language that is accessible to both participants and researchers (bi-directionality). If the results of the research are only understandable to the scientific community, it has failed.

17

Accountability - we must be consistent about sharing outcomes and democratizing access to results. Be clear and transparent to participants about the impact and contribution of their lived experience.

18

Privacy of identifying data as well as gathered information is to be ensured at all times. Participants should be clearly notified of mechanisms used to safeguard privacy and given autonomy to withdraw at any time.

## ACCESSIBILITY

19

Those responsible for engaging / recruiting people with lived experience should have a clear understanding of possible barriers to inclusion and participation, and take measures to address these.

20

Specific barriers to note: technology (particularly smartphones and data), language (check for use of interpreters, translators, having documents/surveys/meetings in different languages)

21

Promote involvement opportunities in a way that reaches the right young people. Use their platforms, language, and networks.

22

Reach out to participants using a variety of different channels and accessible formats - both online and offline.

23

Ask participants about their preferred means and tools of engagement and use data-gathering methods accordingly.

24

Please be aware that participants may not use specific language that aligns with WEIRD (western, educated, industrialised, rich, democratised) standards, to define one's own, or a family member's, mental health challenges. When researchers fail to engage accordingly, it impedes people's ability to engage in brain health research. Researchers need to make the effort to widen use of language and celebrate + document the differences in language instead of relying heavily on standardization.

25

Educate participants about the value of their contributions to brain health research.

## MENTAL HEALTH SAFETY

26

Ensure steps are in place at the start of the research process to help people with lived experience to consider how they would like to be supported if they are struggling with their mental health.