



LANDSCAPING INTERNATIONAL LONGITUDINAL DATASETS:

**Theory of Change process and a deeper dive into Lived
Experience input**



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BACKGROUND

The Landscaping International Longitudinal Datasets project is a worldwide search of longitudinal datasets with the potential for transformative mental health research that can lead to a step-change in the early intervention of depression, anxiety and psychosis.

The project has been funded by the Wellcome Trust and led by a team at King's College London in partnership with MQ Mental Health Research, the Open Data Institute, Datamind and the Centre for Global Mental Health. The full list of the 3,000+ longitudinal datasets that were identified from across the world as part of this search can be found on the project website www.landscaping-longitudinal-research.com.

Throughout the course of the project, the team based at MQ led on a Theory of Change (ToC) process to articulate a model of **what** steps are needed to create transformation in mental health outcomes. The insight from the ToC process and the findings from the landscaping search informed a list of four main areas of enrichment in existing longitudinal datasets that – if implemented – could improve the type and quality of data collected over time. Subsequently, a meeting with a Lived Experience Expert (LEE) group of individuals with Lived Experience of mental health conditions defined **how** to approach implementing the enrichment of longitudinal datasets and research, informed by the needs and priorities of people with Lived Experience.

METHODOLOGY

An inclusive methodology was adopted to develop a ToC model that is representative of the perspectives of all mental health research stakeholders and useful as a roadmap to guide decisions in research funding and investment. The methodology took the form of a ToC process and comprised a pre-workshop package and an online workshop discussion. Both parts of the process helped gather the individual and consolidated views of various stakeholders.

After the insights from the ToC process were synthesised and incorporated into the landscaping findings, we held a post-workshop meeting with the LEEs, as part of the project's extension. This meeting enabled us to gain further input from this integral group and keep Lived Experience at the heart of the project.

The sections below present in detail the insights gathered through the ToC process and the post-workshop LEE meeting, followed by a brief reflection on what it means that the proposed enrichments for existing datasets are guided by Lived Experience in practice.

THE THEORY OF CHANGE PROCESS

Our aim was to build a model that would outline how to create impact in mental health, that is representative and useful, utilising the baseline of information curated by the longitudinal datasets landscaping search. To do this, we adopted a process with a ‘theory of change’ (ToC) approach.

What is a ‘theory of change’ (ToC) approach?

A ToC is a tool used to describe and understand the process and pathways through which a desired goal or impact could be achieved. In practical terms, it outlines the steps, or intermediate outcomes, that need to happen in order for a final outcome to be realised – in the form of a ToC model.

The approach has been applied to the development and evaluation of public health interventions (Breuer, Lee, De Silva & Lund, 2016¹), including those in mental health (Breuer, De Silva & Lund, 2018²), but is in theory applicable to any initiative aiming to achieve change. In the context of longitudinal data in mental health research, a ToC model can be used to identify the key steps and activities required to bring about improvements in mental health outcomes.

To develop a ToC model that incorporates the perspectives of all mental health research stakeholders, an inclusive four-step process was adopted (Figure 1), with the inclusion of researchers, policymakers, practitioners, LEEs and other key stakeholders, including those in LMICs.

ToC process steps The process followed four steps:



Figure 1: Four steps describing the ToC process

1. Breuer E, Lee L, De Silva M, Lund C. Using theory of change to design and evaluate public health interventions: a systematic review. *Implement Sci.* 2016;11:63. Published 2016 May 6. doi:10.1186/s13012-016-0422-6
2. Breuer E, De Silva M, Lund C. Theory of change for complex mental health interventions: 10 lessons from the programme for improving mental healthcare. *Glob Ment Health (Camb).* 2018;5:e24. Published 2018 Jul 16. doi:10.1017/gmh.2018.13

Figure 2. Sample of pre-work submission form

Theory of Change Development – Defining Goals; Impact and Long Term Outcomes

Delegates were asked to read the background paper and refer to the 1st draft Toc while answering these questions.

Impact

In this process we define impact as; The real-world change you are trying to affect. The change model may contribute towards achieving this impact, and not necessarily achieve it solely on its own.

Long Term Outcomes

In this process we define Long Term Outcomes as; The final outcome the change model is able to change on its own. This will be the primary outcome of the work undertaken and be able to be evaluated.

The draft Toc defines the impact we are seeking to achieve as;

Advance the understanding of how brain, body and environment interact in the trajectory and resolution of anxiety, depression and psychosis with a view to finding new and improved ways to predict, identify and intervene as early as possible in each of anxiety, depression and psychosis in ways that reflect the priorities and needs of those who experience them.

It presents the barriers to this impact as being;

1. Mental health problems are a tangle of biological, psychological and social factors that cannot be resolved by pulling on any single thread and that such problems are dynamic, with symptoms changing substantially over varying timescales.
2. There is known to be great heterogeneity within existing and imperfect diagnostic categories. In order to gain real traction into our understanding of how brain, body and environment interact in the trajectory and resolution of anxiety, depression and psychosis, researchers must be able to follow relevant, diverse groups of people over relevant timescales and with a variety of data collected as frequently as possible.
3. Data sharing and data access – problematic for several longitudinal datasets
4. Populations covered by existing longitudinal datasets not a good representation of the whole world.
5. Mental health science is siloed, both in terms of disciplines and sectors, which might make it difficult to agree on what longitudinal data enrichment is necessary to benefit the most disciplines and sectors.

The draft Toc defines the Long Term Outcomes we are seeking to achieve as;

1. Greater access to high quality, globally-distributed and representative mental health data
2. Strong measures of mental health included in longitudinal datasets
3. Mental health data embedded in other types of data or mental health data supplemented with other types of data
4. Coordinated approach across various mental health datasets
5. Increased input from those with lived experience of mental health problems at all stages of the pipeline

3. Based on your refined view of the impact, how would you define or refine the assisting Long Term Outcomes of the change that is needed

4. Please explain the rationale and any assumptions you have made in defining the Long Term Outcomes above

1. How would you alter or better refine the impact statement to reflect your view of the need

2. What barriers have not been described in the current list that you think need to be addressed for impact to be made possible?

5. What indicators would be required to evaluate the success of these Long Term Outcomes

PRE-WORKSHOP PACKAGE

The inclusive process began with a series of pre-workshop submissions to a package that summarised the background of the project and included questions based on the baseline findings of the landscaping search. Thirty-eight stakeholders were asked to submit their perspectives on the current state of mental health research and the challenges that need to be addressed in the context of using longitudinal data to enhance mental health outcomes. More specifically, they were presented with a draft ToC model and asked to better define the barriers faced with utilising longitudinal datasets for first mental health research and ultimately the reduction of mental ill health; and to provide feedback on a draft impact statement (Figure 2).

Twenty-six responded to the pre-workshop package and this information was then used to inform a draft impact statement and long-term outcomes. The pre-workshop responses also helped structure the design of the workshop discussion which was intended to facilitate open and inclusive dialogue.

WORKSHOP DISCUSSION

Following the pre-submissions from key stakeholders, MQ organised a multi-stakeholder online workshop to co-produce a ToC model for the development and use of longitudinal datasets for global mental health research. The online workshop took place on January 17th, 2023 and brought together 31 key stakeholders, such as researchers, policymakers, practitioners and seven LEEs, from seven countries, including several LMICs.

During the workshop, participants discussed two draft impact statements and potential long-term outcomes. Once established, they worked backwards through the ToC model starting with the definition and goals of impact (i.e., where we want to get) and moving forward to outcomes, outputs and activities (i.e., where we are).

Based on the pre-work submission, an updated version of the ToC model was presented to the workshop delegates to stress test, analyse and fill the gaps in the model. They worked together in breakout rooms and as a wider group to try and identify the key drivers of change and the intermediate outcomes that need to be achieved in order to bring about improvements in mental health outcomes. The outcome of this co-production process has been a visualisation and understanding gained from the perspectives and needs of the mental health community, and which can be used to guide future research design.

SYNTHESIS

The insight gathered from both the pre-workshop submissions and the workshop discussion were used to outline the key barriers facing mental health research and define the impact that stakeholders seek to achieve. Together, these informed the development of the ToC model, which included the desired impact and the goals that need to be fulfilled to approach it.

BARRIERS

Inputs from participants identified the following key barriers:

- Mental health conditions are a tangle of biological, psychological and social factors that cannot be resolved by pulling on any single thread; such problems are dynamic, with symptoms changing substantially over varying timescales. In order to gain real traction into the understanding of how brain, body and environment interact in the trajectory and resolution of anxiety, depression and psychosis, researchers must be able to follow relevant, diverse groups of people over relevant timescales and with a variety of data collected as frequently as possible;
- There is known to be great heterogeneity within diagnostic categories. In addition, much psychiatric research focuses on aspects of behaviour and brain function that are shared across mental health conditions (the 'transdiagnostic' approach). This can make it difficult to link biomedical approaches to 'real world' practices where traditional diagnostic categories are still in use;
- Mental health conditions are highly complex, intensely personal experiences. Individual 'sense-making' of these experiences is heavily dependent on local sociocultural context. This presents a major challenge to efforts to collect harmonised data across different sites, where concepts of mental illness may vary significantly;
- Powerful insights can be obtained when data is compared across sites or aggregated. However, data sharing and data access remains problematic for several longitudinal datasets;
- Populations covered by existing longitudinal datasets are not a good representation of the whole world. The majority of large longitudinal studies are based in high-income countries;
- Mental health science is siloed, both in terms of disciplines and sectors, which might make it difficult to agree on what longitudinal data enrichment is necessary to benefit the most disciplines and sectors.

IMPACT STATEMENT

Two potential impact statements were drafted from the pre-workshop submissions and discussed at the workshop.

Impact Statement A

Advance the understanding of how biological, psychological, and environmental factors at different levels of a person's social ecology interact in the trajectory and resolution of anxiety, depression and psychosis with a view to identifying new and improved ways to predict, identify, intervene, and support long-term mental health outcomes, as early as possible, for individuals, families, communities, and society as a whole, in a way that reflects the priorities and needs of those who experience them, with a focus on making digital phenotypes useful, particularly trans-diagnostic phenotypes, and measuring real-world change.

Impact Statement B

Together with people with lived experience of anxiety, depression, and or psychosis, advancing the understanding of how the biological, psychological, social, and cultural factors interact in the development, trajectory, and resolution of anxiety, depression and psychosis to find new innovative and culturally appropriate improved ways to predict, identify, treat and support in early stages of each of these mental illnesses with personalised and trans-diagnostic approaches to reduce the burden of these illnesses on the individual health-related quality of life, family, community, and the society

Both were felt to have valuable aspects to participants, and included important points, but they were both felt to be long, complex and difficult to digest. It was suggested that each impact statement could be simplified or broken up. However, and most importantly, impact could be facilitated by breaking down the pathway towards the ultimate end goal into three key stages:

- Undertaking enrichment of current longitudinal datasets;
- Creating the required resources and conditions to utilise mental health-enabled longitudinal datasets;
- Using longitudinal data to improve mental health outcomes (see below).

TOC MODEL

Based on the pre-submissions and workshop discussions, the ToC model was developed. This distinguished the desired long-term impact as well as intermediary goals:

- **Starting Premise:** Wellcome sees longitudinal datasets as a critical resource to help researchers advance to understanding how brain, body and environment interact in the trajectory and resolution of each of these conditions. Wellcome believes that such understanding is a vital step to finding new and improved ways to predict, identify and intervene as early as possible in these conditions, in ways that reflect the priorities and needs of those who experience them;
- **Intermediary Recommendations:** Through the delivery of the global landscaping process the most promising datasets were identified and a list of recommendations for enrichment activities undertaken:
 - Preserve and expand targeted populations
 - Improve measurement and collect new data
 - Build infrastructure and facilitate connectivity
 - Promote LEE involvement, community engagement and service user groups.
- **Intermediate Outcome:** Create a global network of mental health enabled longitudinal datasets;
- **Long Term Outcome:** Mental health research impacts policy on interventions and treatment of mental health;
- **Impact:** Reduction the burden of mental illnesses on health-related quality of life, family, community and the society on a global scale.

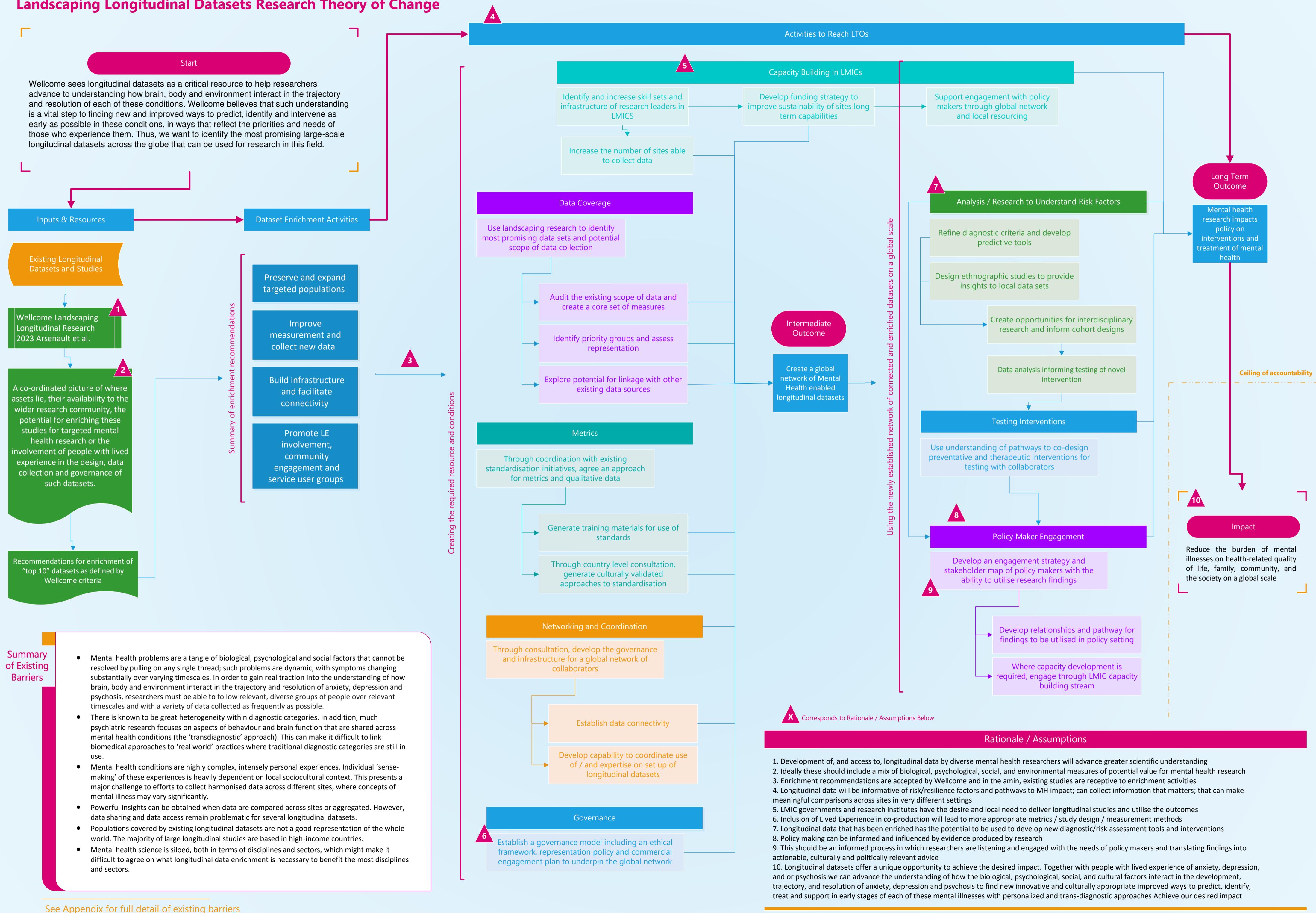
The model differentiated the steps required to achieve the intermediate goals from those required to ensure that, once the goal had been achieved, activities of the global network of longitudinal datasets fully contribute to the envisaged long-term impact. Of course, multiple other factors outside the scope of this project affect the likelihood that the ultimate goal is achieved, including policymaker receptivity to research evidence, the political appetite for investment in mental health services, and the types of mental health support prioritised.

As such, while the ceiling of accountability has been placed between the 'Long-Term Outcome' and the 'Impact statement', this accountability does not presume ownership by Wellcome of the entire pathway. In fact, more correctly, this particular model requires additional development to define clearly where various actors and agents, including Wellcome, see the scope, capability and ownership of the phases of the model.

Figure 3 (next page):

Diagram of the ToC model illustrating inputs from the ToC process

Landscaping Longitudinal Datasets Research Theory of Change



THE POST- WORKSHOP MEETING

Following the ToC process, the MQ team planned and hosted a meeting with the LEE group with the aim to identify how the implementation of the four areas of enrichment outlined below can be guided by Lived Experience (defined as part of the Landscaping International Longitudinal project. See full report: www.landscaping-longitudinal-research.com/what-we-found?).

AREAS OF ENRICHMENT

- Preserve and expand targeted populations
- Improve measurement and collect new data
- Build infrastructure and facilitate connectivity
- Promote Lived Experience involvement, community engagement and service user groups

The meeting format allowed an in-depth discussion about common barriers or blind spots for research to be effectively guided by Lived Experience, as well as existing and potential best practices which can help to overcome those barriers.

The discussion was based on the following guiding questions:

1. Which of the four areas of enrichment are a priority for Lived Experience?
2. What are the anticipated barriers for meaningful involvement of Lived Experience? And what are existing best practices to address those barriers?
3. How should the progress of implementing the areas of enrichment be disseminated and shared with people with Lived Experience?

In the following section we summarise key insights from the discussions based on these guiding questions.

DISCUSSION

1. Which of the four enrichments are a priority for Lived Experience?

In considering the four enrichments proposed, there was sound consensus among the LEEs about the need to prioritise the promotion of Lived Experience involvement, community engagement and service user groups. This was agreed to be a strategy, on its own, to advance the implementation of the other three enrichments in a way that is responsive to the views and priorities of people with lived experience (who are often also service users), particularly in traditionally underrepresented groups.

The inclusion of people from underrepresented groups was characterised as a persistent challenge in research, despite it being deemed central when promoting the inclusion of Lived Experience, community and service user groups. To effectively reach underrepresented groups, it was agreed that research needs to increase collaboration with community leaders, and efforts to connect with their short- and long-term priorities.

An essential step for this would be to include and work more closely with grassroot and community organisations. Grassroot and community leaders know their communities and understand their priorities, and could be the ‘missing link’ to facilitate communication and adequately engage and empower members from low-income settings.

The LEE group reflected on how working in collaboration with community organisations could also advance the other three enrichments.

- It would help in preserving and expanding targeted populations, as working with the organisations that know these populations helps to enter their worlds and lives more seamlessly, and promotes trust.
- It would help to understand what people with lived experience from underserved communities want to measure and improve, and therefore improve measurement and collect new – and relevant – data. This could then open opportunities to improve routinely collected data and test the relevance and contextual validity of current diagnostic categories and measurements.
- It would help to build bridges for knowledge exchange between research, practice and Lived Experience, increasing connectivity between these groups.

DISCUSSION CONT.

2. What are the anticipated barriers for meaningful involvement of Lived Experience and how can we overcome them?

The LEE group identified five main barriers to achieving inclusive, diverse and meaningful involvement of Lived Experience, as well as some potential ways to overcome them:

Existing barriers	How to overcome them
Digital inequalities	Adopt both digital and non-digital strategies for dissemination and engagement
Lack of relevant incentives	Set incentives in place which take into account the basic, psychological and fulfilment priorities from these populations, as seen by them
Tokenism	Increase decision-making power and influence of Lived Experience
Communication challenges	Increase translational efforts, allow bi-directional communication and avoid jargon
Stigma	Increase mental health awareness on the ground and empower others to challenge stigma

2.1 Digital inequalities

The group agreed that technology needs to be an enabler for Lived Experience involvement in research. However, dissemination and engagement strategies seem to be over-relying on digital channels and platforms to reach people with Lived Experience. This leaves behind populations that have limited – or no – access to technology.

To effectively reach underrepresented groups, it was discussed that research needs to seek these groups where they are, through the channels they use and facilitated by the organisations they trust. This should include non-digital dissemination strategies which are relevant and context-appropriate for these communities. Furthermore, the exact strategy could be catered on a case-by-case basis, advised by LEEs and grassroot organisation leaders from these communities.

2.2 Lack of relevant incentives

Researchers should also consider the needs of community organisations and ensure reciprocity when working with them. Community organisations can be a great way to tap into underserved groups, but they often struggle with financial and capacity constraints to meet the requests for support from their communities. Researchers should take a personalised approach when considering how to share value creation, build trust and increase engagement in research.

For people from difficult to reach communities to participate in research, there need to be relevant incentives in place. This means, incentives which relate to people's needs and priorities, and which allow people to see value in their participation.

These incentives need to take into account the basic, psychological and fulfilment needs of each population. People who struggle covering their basic needs will not see as a priority to participate in research. This is why it is imperative to incentivise involvement by:

- Providing monetary or other material compensation;
- Promoting career development opportunities through links or mentorships with organisations in LMICs;
- Facilitating participation and covering transportation or internet costs;
- Emphasising the impact of participation for mental health research and practice in the community.

It is equally important to allow flexibility to include other incentives, as appropriate for each context.

DISCUSSION CONT.

2.3 Tokenism

While there is increasing involvement of Lived Experience in research, the group discussed that it is common for it to feel tokenistic rather than meaningful. This can happen when they are not consulted throughout the decision-making process, including in final decisions and the sharing of outputs.

LEEs should be empowered to contribute to the creation of project agendas and the setting of priorities, lead discussions and dialogues to facilitate communication, and inform the means of data collection especially when addressing the topics that they consider most significant. This is essential to improve the quality and value of the data collected, as it can help to understand why we may miss out on information somewhere throughout the course of a research project and shed light on any potential blind spots.

It is also important that the outputs of the research they have participated in are brought back and shared – when wanted – with people with the Lived Experience. This promotes research democratisation, engagement and trust. The LEE group indicated that the Landscaping project constitutes a great example of meaningful involvement since the earliest stages of research.

2.4 Stigma

Participating in mental health research implies the admission of mental health difficulties to oneself and others, which can be highly stigmatising. It can take a lot of time and effort for some people to be in a place where they feel comfortable discussing mental health.

A potential strategy to address this barrier is to work closely with organisations to promote dialogue, increase mental health awareness, and empower others to challenge stigma on the ground. This is instrumental to reduce stigma, help people with Lived Experience to feel empowered by – rather than ashamed of – their experience, and to generate more protective and supporting environments for mental health in local communities.

Researchers' awareness of stigma within certain communities can also help shape the approaches by which they seek to include Lived Experience, community and service user groups in their work.

2.5 Communication challenges

There are significant communication and translational barriers for Lived Experience involvement in research.

For example, language differences are a significant barrier since most research activities and outputs are in English, and rarely translated into other languages. This makes it difficult for the non-English speaking world to participate in research, and benefit from it.

Use of jargon is another frequent communication barrier. Even when there can be shared understanding of a construct, technical terms might make it seem like research teams are talking about something different, or worse, that they know more about a mental health condition than someone who has experienced it. This can cause people with Lived Experience to feel unheard and that their knowledge is less valuable than research-based knowledge.

In the final session of the discussion, the LEE group discussed how the progress aspects of the project should be communicated and shared with LEEs, identifying concrete steps which could potentially help to overcome these communication barriers.

DISCUSSION CONT.

3. How should the progress with implementing the areas of enrichment be communicated and shared with Lived Experience?

A recurrent theme throughout the discussion was the need for more investment to tailor and contextualise communication strategies, including both dissemination and engagement. It is not enough to release content, we need to ensure that it reaches people, that it is relevant to them and that it is understood. The group acknowledged that LEEs have a crucial role to play, to ensure language is simple, accessible, allows shared understanding, and promotes knowledge exchange between research, Lived Experience and mental health practice on the ground.

The group re-emphasised the importance of connecting with community organizations based in low-income settings from low-, middle- and high-income countries, to contextualise and tailor communication to the audience, and to make collaborations work more seamlessly. Their input can be invaluable when considering content (i.e., ensuring that it reflects the priorities of their community), language (both ethnic and jargon) and dissemination strategies. Additionally, this communication approach can help to optimise research resources, as it might be more cost-effective to target groups of people and communities rather than trying to separately reach individuals, or using the same approach across all communities.

They proposed that communication strategies should be bi-directional. This means not only disseminating progress, but also allowing for feedback and knowledge exchange between research, practice on the ground and Lived Experience.

Investment and resources dedicated to dissemination and knowledge exchange in research are often insufficient to allow appropriate engagement, contextualisation and communication, particularly in underserved communities across the world. Yet, appropriate investment and allocation of efforts, time and funding could enable these activities. Cross-sectorial and trans-disciplinary collaborations that consider the input of Lived Experience, community and service user groups in their decisions and progress will be fundamental to bridge the existing divide and improve mental health globally.

It is not enough to release content, we need to ensure that it reaches people, that it is relevant to them and that it is understood.

CLOSING REFLECTIONS

What does it mean that these enrichments are guided by Lived Experience?

The Landscaping International Longitudinal Datasets project constitutes good practice in terms of coproduction with key stakeholder groups and meaningful involvement of Lived Experience from early stages in research planning to later stages of dissemination.

The Theory of Change (ToC) process helped to articulate the steps needed for a step-change transformation in the early intervention of depression, anxiety and psychosis globally. This starts with four enrichments identified through this process: 1.) To preserve and expand targeted populations, 2.) To improve measurement and collect new data, 3.) Build infrastructure and facilitate connectivity and 4.) Ensuring adequate involvement of Lived Experience, community organisations and service user groups. The latter should be considered as a cross-area strategy to materialise the other three enrichments.

The post-workshop meeting held with the Lived Experience Advisory group allowed an in-depth discussion about barriers or blind spots for research to be effectively guided by Lived Experience, as well as existing and potential best practices which can help to overcome those barriers.

The discussion was based on the following guiding questions:

- 1.** Which of the four areas of enrichment are a priority for Lived Experience?
- 2.** What are the anticipated barriers for meaningful involvement of Lived Experience?
- 3.** And what are existing best practices to address those barriers?

The post-workshop meeting held with the Lived Experience Advisory group helped to identify potential measures to overcome common barriers for meaningful involvement of Lived Experience in research.

For research to be able to reach under-served populations across the world, one of the key measure identified was to adopt both digital and non-digital communication channels in engagement and dissemination strategies. This helps to account for the variability in access to digital resources, and improves contextualisation. It was also recognised the importance of setting relevant incentives in place to engage with research, aligned with the needs and priorities of LEE, as they see them. LEE should be empowered to influence decisions in research, support translational efforts, and empower others to increase mental health awareness and fight stigma.

A key takeaway from the meeting in terms of how to make all this possible is that investment and resources allocated for Lived Experience involvement should be sufficient and flexible to account for contextual differences, adapt to different needs and reach more diverse populations.

It is also essential to prioritise involvement of community organisations and service user groups – where they exist – as a link with people with Lived Experience in underserved communities. This is also a strategy to advance across the areas of enrichment in ways which are context-appropriate, and catalyse the potential of longitudinal research to improve the prevention, detection and treatment of depression, anxiety and psychosis globally.



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