

ARE MENTAL HEALTH RESEARCH FUNDERS IGNORING VITAL VOICES?

IAMHRF Lived Experience Working Group

FOREWORD

As a person with lived experience, I am encouraged to see that our active participation in mental health research has gained pace. It is good to see materialize what we have always argued for: a recognition of our expertise and value that we bring to the research enterprise.

The existence and the activities of the Lived Experience Working Group of the IAMHRF excite me greatly and are important to me and my community. Having influential funding organizations championing lived experience in decision-making processes, as well as ensuring funded researchers need to involve us, are major steps in the right direction. These steps will benefit the lived experience community and ultimately enhance the quality of mental health care and increase the wellbeing for everyone. I also believe that strong collaboration between research funders and people with lived experience will help break down siloes and build a more inclusive mental health research community. My hope is that the Working Group continues to increase in size as interest in the topic grows. Going forward, this should mean that our input and perspectives will be considered from the start of every funded project. I dream of a community in which lived experience is so pervasive that all research funding organizations have acknowledged us across advisory boards and leadership positions. The outcome of this collaboration is set to be historic, let us work together to determine what type of historical legacy we will leave.



International Alliance of
Mental Health Research Funders

Grace Gatera



RATIONALE

For decades, decisions about mental health research and funding have been made behind closed doors, mainly by academic entities, governments and pharmaceutical companies with the official mandate and power to influence change. While this traditional approach to funding research has led to discoveries and some progress, it has also excluded many relevant stakeholders and contributors from key decisions, especially those who are directly impacted—people living with mental health issues.

However, there is a clear moral imperative to involve people with lived experience (LE) of mental health issues and their carers in research. The mental health field has a long and dark history of stigma, incarceration, conversion therapies, and human rights abuses perpetrated against psychiatric patients. This imperative is also reflected in the **United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD)**, a human rights-based approach to physical and mental health. The principles of equality and non-discrimination, as well as participation and full inclusion, are integral components of this strategic and legal framework. Placing people at the center of health-related choices is more than simply good practice: it is a just and ethical obligation. Many advances in patient care have been achieved over the years by individuals who have been affected by the abuse and who have been pushing for better conditions.

We also risk wasting valuable time and resources on projects with basic practical flaws—flaws that could have been identified and avoided if people with LE and carers were consulted from the very beginning. People with LE who have had first-hand contact with the health care system and services offer invaluable perspectives and insights that have the potential to inform and enrich the research process, thus maximizing the chances for meaningful impact. In fact, their involvement should not be seen as a symbolic gesture; rather, it is absolutely essential if we hope to avoid common pitfalls in conceptual development, project design and delivery and the dissemination of new knowledge.

Unfortunately, attempts to alter the existing paradigm have often been rejected by funders on the grounds of a lack of quantitative evidence of the impact of involving people with LE in research. Rather, it should be understood as their democratic responsibility to involve those who will be most affected by the research, with involvement spanning from planning and shared decision-making to the co-creation of new knowledge. Whilst evidence of impact should not be regarded as a pre-requisite for involving people with LE, it may play a key role in revealing which methods of doing so are the most effective and beneficial.

With time however, the civil sector has grown stronger, and advocacy movements have clamored for inclusion, genuine involvement and change, pushing for the sharing of power. Large organizations and some funding bodies are now throwing their weight and support behind the involvement of people with LE of mental health issues. More importantly, patient advocacy groups across the globe are starting to be listened to, and people with LE have gained some control of their own narrative. Powerful speakers and activists are coming together, not only calling for a seat at the table, but showing how their involvement can be put into action. In fact, some leading health research funders such as the **National Institute of Health Research (NIHR) in the UK and the Patient-Centered Outcome Research Institute (PCORI)** in the US, among others, have launched different guides and principles to include as equal partners people affected by illness in setting research priorities.

However, despite visible progress by some research funders embracing the expertise of people with LE, specific recommendations for change often remain vague and practical steps for successful LE integration remain unclear. In many cases, involvement is still tokenistic, limited to attending a meeting or reviewing a proposal but not sharing decision-making. There are many frameworks available that help guide, illuminate, and evaluate different levels of engagement and impact that people with LE have across activities of an organization.

True involvement necessitates a change in the dynamics of the relationships and a cultural shift. Power imbalances can be reduced by elevating people with LE from the status of study subjects or study advisors to partners in decision-making. For example, funders could involve people with LE in leadership roles and encourage more LE researchers to apply for grants. This will equip people with LE with the autonomy and desire to express their viewpoints, leading to a more rewarding experience for everyone involved, and the potential for better results, including improved mental health outcomes. This is an evolving practice and, even for the most forward-thinking funders, there is a long way to go to attain full inclusion of people with LE.

IAMHRF LIVED EXPERIENCE WORKING GROUP

The need to include people with LE in the research funding enterprise was an urgent agenda item at the 2019 annual conference of the **International Alliance of Mental Health Research Funders (IAMHRF)** hosted by the **Wellcome Trust** in London. Research funders in the mental health field carry a particular responsibility in driving the cultural shift, due to their influence on

local and global agendas and their leadership on best practices in research funding and management. The IAMHRF is a network that unites funders on a shared agenda to advance mental health research priorities and drive best funding practice for a better world.

At the 2019 meeting, a handful of organizations came together in a working group to drive the systematic integration of LE across mental health research and funders. Crucially, the principals of LE involvement are engrained in the network's governance—both the Working Group and the IAMHRF's Steering Committee include individuals with LE of mental health issues.

IAMHRF Lived Experience Working Group

Founding members

National Institute of Health Research, UK
Meeting for Minds, Australia & Switzerland
Health Research Board, Ireland
MQ Mental health research, UK
Maitri Foundation, Australia
Mariwala Health Initiative, India
McPin Foundation, UK
Ludwig Boltzmann Gesellschaft, Austria

New members (Fall 2021)

Grand Challenges Canada
Fondation Botnar, Switzerland
Wellcome Trust, UK (co-chair alongside IAMHRF)

OVERARCHING GOAL

To support research funders around the world in their efforts towards adopting an effective and inclusive approach to mental health research funding by actively involving people with LE at all levels of the funding process.

To achieve this goal, the Working Group aims to:

- **Build a common understanding of what LE means in the mental health research context, whilst acknowledging differences in terminology and approaches across the globe**
- **Support research funders to actively involve people with LE of mental health issues as equal partners by exploring what LE involvement entails for research funders in particular**
- **Understand how funders currently involve people with LE in their work.** *What is the level of progress for the mental health research funding sector? What works well? What are the challenges?*
- **Consolidate experiences from individual research funders on how to successfully involve people with LE—assemble and share collective knowledge as a resource for funders**
- **Understand the role of people with LE within a wider mental health research funding strategy.** *What do individual funders seek to achieve? What is the specific role of people with LE in achieving funders' goals?*
- **Understand what people with LE want to achieve as equal and genuine partners of the funding process and how the culture of research funding needs to shift to address the research questions that matter to people with LE.**

NEXT STEPS

The group hopes to ramp up its activities with several targeted collaborative efforts. First, it will conduct a survey to capture LE involvement practices among research funders. The aim of the survey is to understand how funders currently involve people with LE of mental health issues, including their roles, recruitment, and any support or compensation mechanisms in place. The results will be consolidated in a resource for research funders and shared across the IAMHRF network. The objective is to inform and inspire further efforts by funders to involve people with LE and to serve as a baseline to measure progress in the future.

The survey will also help to establish common ground for the development of a 'shared statement', seeking consensus amongst research funders on their collective commitment to involve people with LE. In the Spring 2021, the Working Group held an online workshop for research funders engaged in the topic and laid the groundwork for such a shared statement. In formalizing funders' commitment and agreeing on the basic principles for involving people with LE, the IAMHRF will take a crucial step towards making mental health research funding a more open, collaborative, and transparent process. The statement will build on the work of funders who have pioneered and actively supported the integration of LE for many years, while maintaining flexibility for less experienced organizations. There is a strong recognition that to be successful, all efforts must be undertaken in an atmosphere that fosters collaboration, free experimentation, monitoring, evaluation and potentially failure (when necessary). By showing what works and how it can be done, the Working Group hopes to reduce both the perceived and real challenges of integrating LE, providing mental health research funders with the essential tools to do so.

Authors

This opinion piece was co-written by the IAMHRF Lived Experience Working Group, which includes people with lived experience of mental health issues.

