



HBGI
Healthy Brains Global Initiative

Transforming How We Work

*Reflections from HBGI's Lived
Experience Council on
Embedding Lived Experience
Into Organizations and Services*

February 2023



WELCOME TO THE REPORT

Letters from the Leadership



Damian Juma
Chair of the LEC



The past two years have been both inspiring and challenging. The Healthy Brains Global Initiative (HBGI) Lived Experience Council (LEC) is a group of smart, caring, loving, and exceptional professionals who are working at different levels to catalyze change across the mental health spectrum. I have been so fortunate to have shared this incredible and precious time with them, especially during the in-person meeting in Morocco. Meeting folks in person was surreal. Chats and walks after the workshop made it clear we needed more and more time. Departing was hard but the momentum was stronger than ever!

HBGI is fairly new and the best thing about that is that we are in a powerful position to influence the organization's development. The LEC is honored to be a part of this revolution, from having full representation on the HBGI Board to being part of the impact on the ground. We want to ensure HBGI supported interventions deliver meaningful impact to those who need it the most. We know this is ambitious, but we are open to change and disrupting systems that haven't worked before.

The most important thing, however, about my involvement with HBGI is the rich diversity that the organization has and hopes to build. Being supported in all ways to ensure that we deliver on our goals is exceptionally beautiful. This diversity has created a community like no other and we are reaping the benefits. Spearheading this group as their Chair is momentous!

As you dive into this report, I hope it gives you snippets of what we enjoy and want to improve in the near future.



Richard Johnson
CEO HBGI



All our efforts at HBGI are aimed at lifting as many lives as possible by delivering better services for more people with mental and neurological health challenges, including the millions that currently go unheard. We will try to do this directly – using ‘outcomes contracting’ to focus the services we pay for on individuals and on what really matters to each one of them. We will consider the causes and the consequences of their poor mental health. We will also try to do this by listening carefully, gathering and disseminating all the rich learning from this personalized, localized delivery.

The individual and learning are at the heart of what we do.

During our time in Morocco in October 2022, I learned a great deal about the rich personal and professional experience of my colleagues on the LEC. Each one of them brings, with such generosity, their lived experience, in order to keep us centred on the individuals we aim to reach. I am deeply inspired by what they have collectively achieved over the last two years.

In turn, I shared with them my own lived experience, including my cousin’s schizophrenia, my mother’s death during an epileptic seizure, my daughter’s anxiety and my son’s neurodiversity, as well as the PTSD that my four years of work in Afghanistan has marked me with.

Together, we shared our commitment to make our experiences count. To speak loudly and clearly on behalf of the people HBGI is here to reach and serve. To build an organisation that truly embraces individual diversity and potential, and that constantly strives to listen and learn, in order to deliver the maximum impact – for as many individuals as possible.

This report is an important step on the way to achieving this.

What is the purpose of this report?

This report summarizes learnings from HBGI's work with people who have lived experience of mental health challenges. In particular, it summarizes the reflections from the past two years of work with HBGI's LEC and its first in-person workshop in Marrakech, Morocco, held in October 2022 on how to effectively embed lived experience in a mental health organization.

We hope that this report will be of interest to you whoever you are, whether you're a donor or organization looking to center people with lived experience in your work or a person with lived experience looking to learn more about best practices for lived experience involvement or HBGI.

We welcome your thoughts. Feel free to learn more about us at our [website](#) and contact us with any feedback at info@hbgi.org.

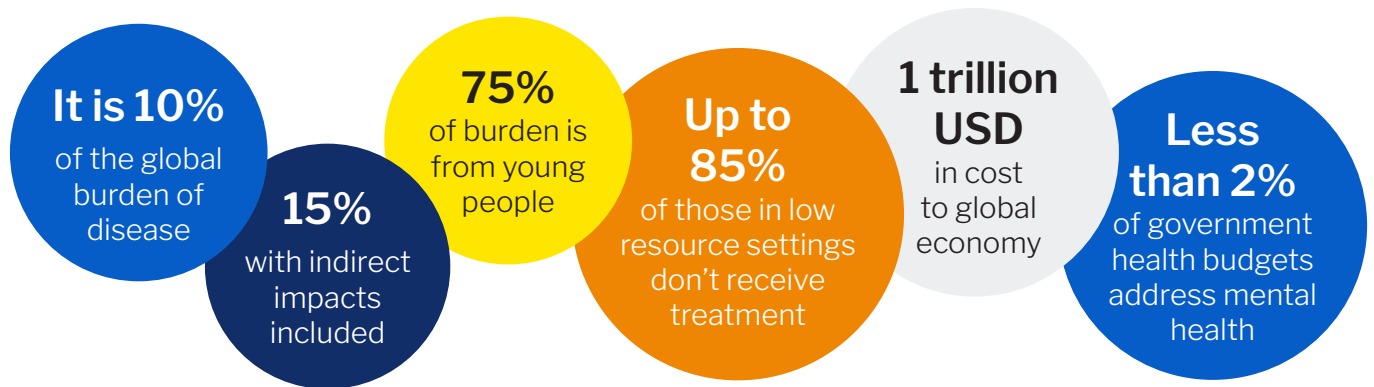
Table of Contents

7	Executive Summary
8	Introduction
9	Introduction to HBGI
9	Recommendations from the LEC for integrating lived experience
10	Impact of the LEC
11	Introduction: Mental Health and Lived Experience
12	Why focus on mental health?
13	What is lived experience? What is lived experience in mental health?
14	Why is integration of lived experience important?
16	How should lived experience be integrated?
17	Introduction to Healthy Brains Global Initiative
18	Who is HBGI?
19	How does HBGI fulfill its commitment to embedding LE?
19	What is the HBGI Lived Experience Council (LEC)?
20	How were individuals on the LEC selected?
21	What has the LEC been doing?
25	Learnings from the LEC
26	Introduction to this section
26	The in-person workshop
31	Key recommendations for integrating lived experience voice
32	Culture
37	Systems
40	Resources
44	The value and impact of the LEC in HBGI
46	The Way Forward
47	Introduction to section
47	Future of the LEC
49	Ongoing conversations
50	Conclusion
51	Acknowledgements
52	Appendix
83	References

EXECUTIVE SUMMARY

Introduction

Why invest in mental health?



Lived experience is...

Someone having personal experience with mental ill-health or neurological health issues themselves, whether in their own lives or with people close to them

Why integrate lived experience? In service design, integrating lived experience leads to...



Integrating lived experience into service provision leads to better outcomes through...

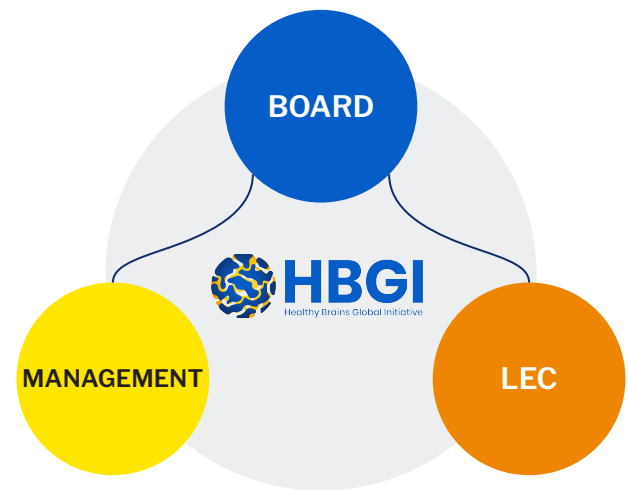


Introduction to HBGI

HBGI was created to address the global gap in the understanding, prevention, and treatment of mental and neurological health conditions. HBGI addresses this critical issue through introducing a new wave of programs using an ‘outcomes-based’ contracting model: paying for outcomes rather than inputs to drive the impact of these programs.

To accomplish this mission, we ensure the voice of people with lived experience informs every part of our organization through our Lived Experience Council (LEC).

The LEC is composed of people with a wide variety of lived experiences from backgrounds diverse across geography, gender, age, race, ethnicity, education and professional experience. The LEC has been with HBGI from the beginning and has shaped the organization.



Currently it is composed of 12 individuals, working across three workstreams.

As part of its commitment to the LEC, HBGI held an in-person meeting in Marrakech, Morocco in fall 2022. This report summarizes takeaways from that meeting and the past two years of work with the LEC.

Recommendations and LEC examples for integrating lived experience

CULTURE

Foster and celebrate diversity

The LEC created a diversity pledge committing to open, compassionate conversations

Ensure inclusivity and wellbeing

The LEC takes regular breaks and has set clear guidelines for how to work with people with lived experience

Emphasize adaptability

The LEC has been flexible in shifting membership, workstreams, and workplans

See beyond someone’s lived experience

HBGI recognizes and learns about the skills of LEC members beyond their LE

SYSTEMS

Choose governance structures that are fit for purpose

The LEC Chair was established as full voting member of HBGI Board

Create avenues for open communication

The LEC creates regular evaluation reports between the LEC and management

CULTURE

Support skills development

HBGI Management and the LEC offer training sessions to the LEC members to address any identified skills gap

Provide logistical support

HBGI provides honoraria and coverage for data costs in a way that works for the LEC members

Conduct a resource assessment

HBGI assessed and committed sufficient budget and human resources upfront to create the LEC

Impact of the LEC

What value has the LEC brought to HBGI?



Transformed governance structures, leading to a shift in how the HBGI Board operates to prioritize lived experience leadership



Ensured accountability and adherence to values in HBGI and its partners, by participating in interviews and selection for consultants



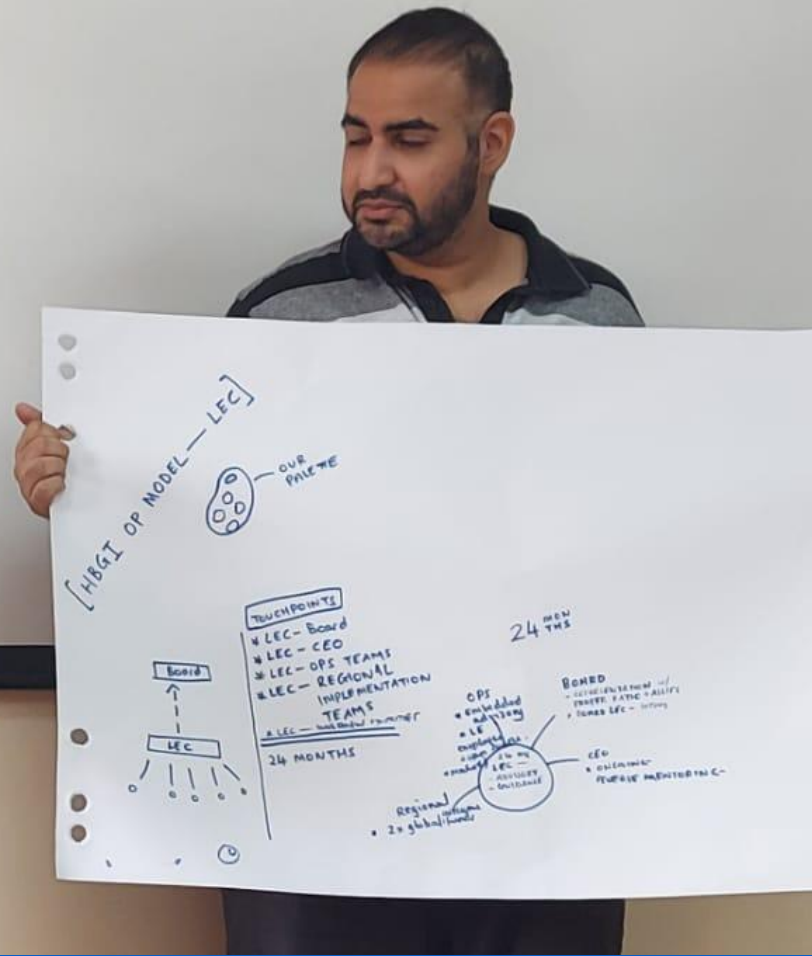
Shaped organizational culture to be more inclusive of people with brain health conditions and from different geographies



Was essential in creating consulting work and other products, like HBGI's [Mind the Gap Report](#) and the McKinsey Health Institute's [Brain Health Dashboard](#)



Has helped HBGI mobilize funding (**75,000USD** solely for lived experience integration) as well as being a key part of mobilizing HBGI's core startup funding



INTRODUCTION: MENTAL HEALTH AND LIVED EXPERIENCE



Why focus on mental health?

Mental and neurological health conditions account for nearly 10% of the global disease burden, 15% if indirect impacts on physical health are included.^{1,2} Seventy-five percent of this burden originates in young people between the ages of 11 and 24.¹ Yet, up to 85% of people in low resource settings receive neither diagnosis nor treatment.³

The effects are particularly acute for vulnerable groups. Poor mental health is mixed up with a wide range of personal and social challenges, from unemployment to child pregnancy, from homelessness to addiction, from domestic abuse to HIV patients dropping out of

treatment. It is inextricably linked with poverty and social exclusion and drags on the recovery from every disaster and conflict.⁴

Mental health conditions present more than \$1 trillion in cost to the global economy every year.⁵ Despite this, countries spend less than 2% of their health budgets on addressing poor mental health.⁶

Unless concrete, and coordinated action is taken, by 2030 mental health conditions will be one of the top three causes of morbidity and mortality globally.⁷

FOR YOUR INFORMATION



The LEC recognizes that historically, persuasive arguments to address mental health have focused on disease burden, economic loss, and adverse social impacts. LEC hopes to shift the conversation from a deficit or disease-focused model to a human rights based approach, whereby the motivation to prioritize mental health is grounded in the human rights of all people.

Carlos Lurrari and Jaclyn Schess (LEC Members)

What is 'lived experience'?

What is 'lived experience' in mental health?

Lived experience refers to experiential knowledge of a particular phenomenon. This can be thought of through the following definitions:

- *“Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representation constructed by other people”⁸*
- *“The experience(s) of people on whom a social issue, or combination of issues, has had a direct impact”⁹*

Within the mental and neurological health landscape, lived experience can refer to someone with personal experience with mental

or neurological challenges, whether they have lived with the condition themselves or have cared for a friend or family member with the condition. Someone can have one or multiple lived experiences.¹⁰ Someone with lived experience is also sometimes referred to as a “service user”, as they are the ones who will use or be affected directly or indirectly, by the service being provided.

In the context of mental health, HBGI defines lived experience as: *“Someone having personal experience with mental ill-health or neurological health issues themselves, whether in their own lives or with people close to them”.*

FOR YOUR INFORMATION



Lived experience: is knowledge that comes from experiential knowledge (such as an individual’s personal experiences living with a condition) rather than formal academic training.

Someone with formal and/or academic training, if they have lived experience, can be both a user and provider of mental health services. For example mental health practitioners such as psychiatrists, psychologists, nurses, and peer support workers living with mental health conditions.

Lived experience expertise: is when someone with lived experience applies learnings from their personal experience in order to influence mental health policy and practice in a professional setting. These engagements build their own unique skill as advocates.

But lived experience expertise is about more than just deploying one's own lived experience. Lived experience expertise is understanding why and how to integrate lived experience more broadly, while recognizing that each person's lived experience is individual to them and cannot be replaced by others. Lived experience expertise is vital when you develop systems to integrate lived experience.

Why is integration of lived experience important?

Historically, in many professional and personal settings, people with lived experience of mental health conditions faced stigma and disempowerment. They saw their perspectives deprioritized in favor of people deemed to have superior academic or technical "expertise". Even in cases where these experts have their own lived experience, that part of their experience historically was seen as a source of "bias", not an asset.

Yet integrating lived experience improves outcomes across all parts of the healthcare system, from system design to research and service provision.

Integration of lived experience in healthcare service design has been shown to lead to the following benefits:^{11, 12}

- Quality improvement (patient satisfaction, shorter length of hospital stay, reduction in medical error);
- Making services more accessible (through increased provision of information, simplifying appointment procedures, improving transport, ensuring access for those with disabilities);
- Commissioning of new services to support treatment (advocacy initiatives, creating employment supports, crisis services);
- Increase in empowerment for service users and lived experience advisors;
- Decrease of stigma, particularly when people with lived experience were involved in training of mental health workers, and increased openness in organizational culture.

Since 2000, countries such as Australia and the UK recognize the necessity of lived experience integration towards ensuring recovery-oriented service provision and increasingly require services to demonstrate that they are collaborating with service users.^{13, 14}

Moreover, integration of lived experience has been shown to lead to better research outcomes through:^{11, 16, 17}

- More culturally appropriate and relevant research, tailored to the needs of service users;
- More representation and retention of diverse populations in studies and clinical trials through improved recruitment and retention, as a result of better communication;
- Better dissemination and uptake of evidence by service users and communities.

In service provision, integration of lived experience often occurs through “peer support” or engaging people with lived experience in providing care to individuals with mental health conditions. Benefits of this approach include:^{18, 19}

- Improvements in community integration and social functioning;
- Reduction of substance use among service users with co-occurring substance abuse problems;
- Increased satisfaction with services and, in some studies, increased quality of life;
- Increased stability in employment and education;
- Increased feelings of empowerment;
- Decreased hospital re-admission rates and longer time spent in the community.

Too often the very people a service is intended to support and benefit—the people with lived experience—are left out of the process of decision-making about their own care and aspects of the service more broadly.

Recognizing the unique and irreplaceable value of experiential knowledge is a necessary shift in delivering more meaningful outcomes for people living with mental and neurological health challenges.



Carlos Lurrari
LEC Member



Imagine you have a blind researcher who studies vision. They understand what makes something red, what makes someone see the color red. But without ever seeing the color before, would you say they really understand what red is? It's the same thing with mental health. Does someone who studies mental health conditions really understand the nuances and what it is like to live with that condition?

How should lived experience be integrated?

The short answer is: purposefully, at every level of your organization or program, and right from the outset.

Lifespan's Lived Experience Framework²⁰ developed for the Black Dog Institute in Australia describes the benefits of and how lived experience can be integrated for mental health services in all elements of project development. The framework outlines engagement at the level of the:

- Individual;
- Service or program;
- Organization;
- Policy and strategy.

For example, at the policy level, individuals are engaged in developing, implementing and evaluating policies and strategies to help ensure these are reflective and responsive to perspectives of people with lived experience.

TWO EXAMPLES OF LIVED EXPERIENCE INTEGRATION



The Lancet Commission on Ending Stigma and Discrimination was co-produced by people with lived experience (PWLE), where PWLE were involved at various levels, from being among Commissioners and Advisors, to Co-chairing the Commission. Lived experience views and recommendations were also obtained through a Global Lived Experience Survey and poetry submissions.

The National Alliance on Mental Illness (NAMI) requires that most Directors have lived experience as a peer or family member in its bylaws.

Thank you to Charlene Sunkel and Carlos Lurrari (LEC Members) for sharing these examples.

Accordingly, HBGI is committed to embedding the perspectives of those with lived experience in every aspect of its work and has been since its inception. An initial framework for HBGI's work can be found in [Appendix 2](#).



INTRODUCTION: HEALTHY BRAINS GLOBAL INITIATIVE

Who is HBGI?

HBGI was established in collaboration with the World Bank and with the support of the World Health Organization and UNICEF. Our early funding was largely from the Wellcome Trust, Johnson & Johnson and Otsuka. We were set up to address the global lack of prioritization and funding for mental health - the biggest unmet health and social challenge impacting more than one billion people globally, creating an economic burden of more than \$3 trillion.

HBGI addresses this critical issue through introducing a new wave of programs targeting poor mental/brain health and its causes and consequences. We use an 'outcomes-based' contracting model, i.e. paying for the outcomes rather than the inputs, to drive the impact of these programs, to minimize waste and to increase accountability – as well as to encourage innovation and localization.

Mental health is cross-cutting and touches us all throughout our lives. HBGI's programs might entail services delivered in mainstream health provision, but they might also focus on wider livelihoods issues such as poverty, child

pregnancy, newborn mortality, alcohol and substance use, or unemployment. The service providers might be NGOs (public or private sector), local or international, or governments.

With the oversight of a Board of Directors and an experienced Management team, and with guidance from our LEC, we operate in three ways:

- Pooling the funds of donors into Regional or Thematic Outcomes Funds (e.g. a Fund for Africa or a Fund for Technology), which HBGI manages and uses to contract new programs, identified in partnership with stakeholders, with HBGI as the 'outcomes funder'.
- Working with individual donors who have an interest in particular populations or challenges, to contract and oversee specific programs for these donors.
- Supporting fund holders, such as governments, to design and mobilize contracted programs, building and operating performance management systems to drive the outcomes and impact of these programs.

More about outcomes funding and HBGI's background can be found in the [Appendix](#), particularly Appendices [0](#) and [1](#).

Key to our success is ensuring the voice of people with lived experience informs every part of our organization. One way in which we do this is through our LEC.

How does HBGI fulfill its commitment to embedding lived experience?

One of the central principles of HBGI is that the organization embeds lived experience in every aspect of its work. This principle has been put into practice from an early stage, starting from the recruitment of people with lived experience into HBGI's founding Working Groups in mid 2020 and expression of widespread support for lived experience integration at HBGI's 2020 Global Leadership Meeting.

In response to this commitment, HBGI's Management team conducted an informal literature review of over thirty peer-reviewed papers on involvement of people with lived experience in research and services and undertook consultations with a number of individuals with expertise in embedding lived experience.

From this work, the team assembled a slide deck outlining a framework and plan for HBGI to meaningfully integrate lived experience perspectives at every level of the organization ([Appendix 2](#) for framework). The plan focuses on creating sustainable mechanisms to ensure lived experience incorporation at every stage of the organization.

In order to create truly inclusive systems of lived experience engagement, HBGI decided to go to the people who understood lived experience engagement best: people with lived experience themselves. To lead this work in a thoughtful and systematic way, HBGI formed a Lived Experience Council of experts with lived experience of mental and neurological health conditions.

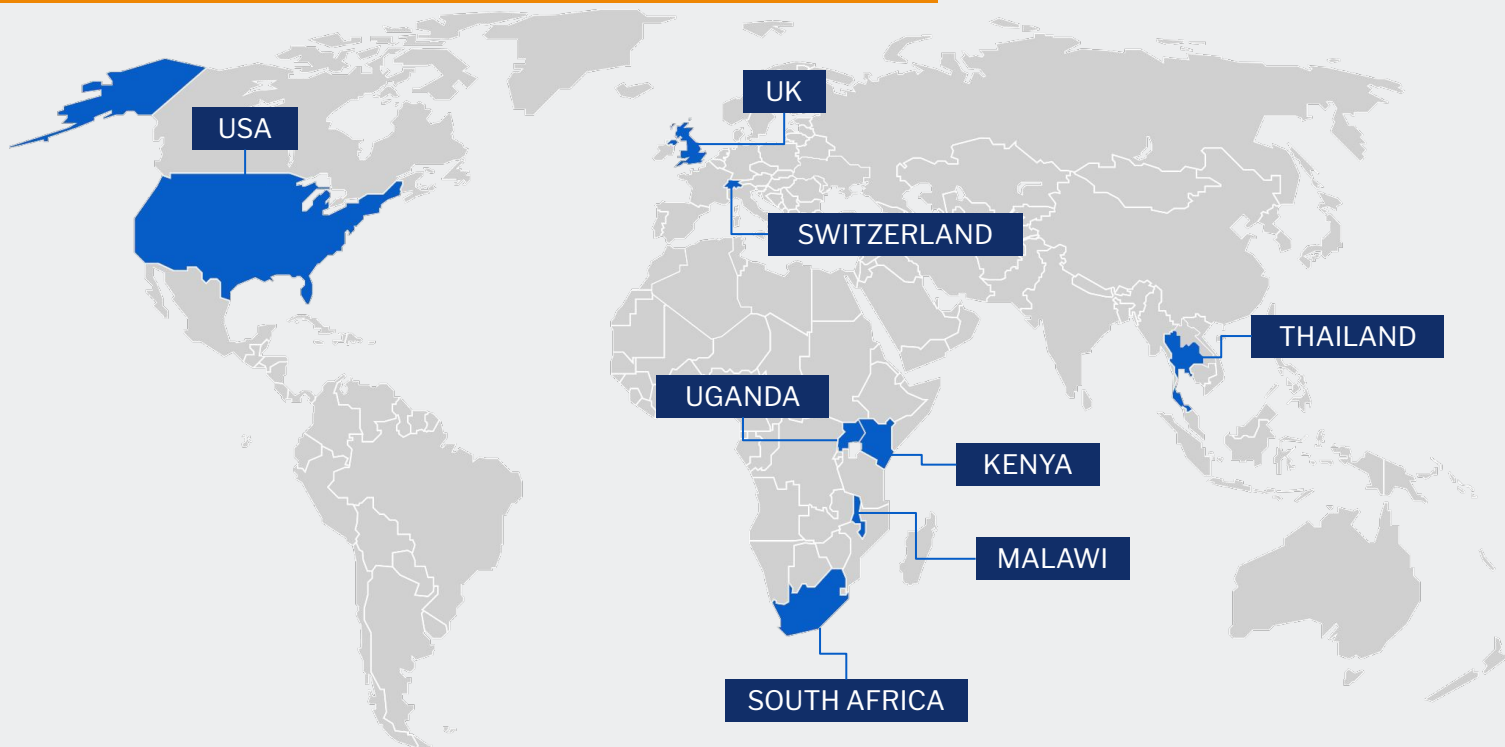
What is the HBGI Lived Experience Council (LEC)?

HBGI's LEC exists to ensure the voices, perspectives and expertise of people with lived experience of mental and neurological health challenges are embedded within HBGI.

The LEC is currently comprised of 12 individuals who have been part of HBGI since its inception. The LEC is intentionally composed of people

with a wide variety of lived experiences from backgrounds diverse across geography, gender, age, race, ethnicity, education and professional experience ([Appendix 3](#)). While the LEC strives for diversity, it is important to acknowledge that no group can fully represent all voices of lived experience.

THE COUNTRIES LEC MEMBERS ARE FROM



LEC members and leaders receive an opt-out honorarium and are reimbursed for costs associated with HBGI work, including any time outside of the expected commitment and data costs. The LEC has a workplan aligned to the wider HBGI's workplan and is structured into workstreams that aim to accomplish items set

out in the workplan. The LEC is supported by HBGI Board and Management liaisons to ensure synergy between each part of HBGI. The LEC is a vibrant part of HBGI; a creative, vocal group of advocates who are committed to seeing change in mental health on both an individual and a systems level through a lived experience lens.

How were individuals on the LEC selected?

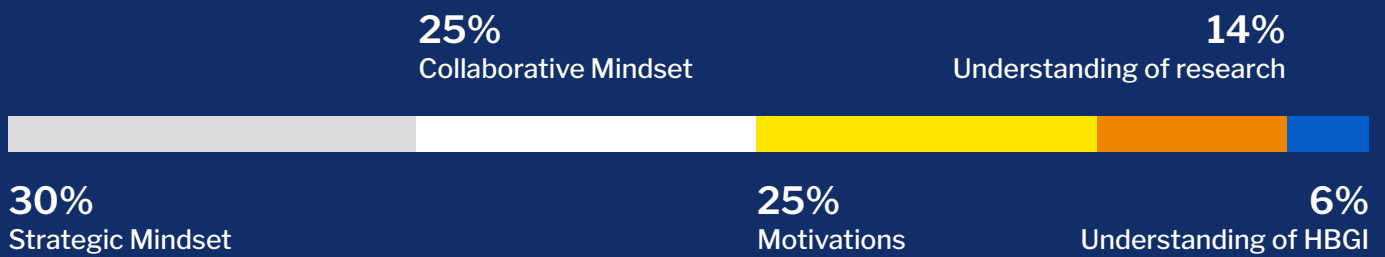
The LEC was selected through a rigorous process consisting of a written application and interview. The initial LEC consisted of 25 members, having received almost four times as many applications as it could accept.

To evaluate the applications, the HBGI team created a framework based on consultations and a spreadsheet used by the Black Dog

Institute in evaluating its lived experience consultants. Broadly, this framework aimed to evaluate applicants based on the characteristics listed on the next page.

Please note: at this time, HBGI was a research-focused organization and had not yet developed a plan to use contracted programs to deliver learning along with delivery of outcomes.

SELECTION CRITERIA FOR LEC MEMBERS



- 1. Strategic mindset (30%)**
(e.g. ability to use individual experience to inform broader scope of work)
- 2. Collaborative mindset (25%)**
(e.g. experience working in teams)
- 3. Motivations (25%)**
(e.g. interest in making a global impact and improving outcomes in research field and creating a more equitable culture around brain health)
- 4. Understanding of research (14%)**
(e.g. previous experience or interest in brain health research)
- 5. Understanding of HBGI (6%)**
(e.g. understanding that HBGI's impact will not be immediate and that HBGI is in startup phase)

More detail about these selection factors and the application process can be found in [Appendix 4](#).

What has the LEC been doing?

Initially, the LEC consisted of five priority workstreams ([Appendix 5](#)). Over the past two years, those workstreams have completed a number of notable accomplishments with support from the Board and Management liaisons. A more in-depth list can be found in [Appendix 6](#).

A headline summary of the LEC's accomplishments from its inception in early 2021 to 2022 follows:

- **Establishment of the LEC.** Including a detailed workplan, the formation of workstreams (with their own meeting pattern and documentation systems), an executive team, Terms of Reference (including election process, honorarium policies), holiday schedule, and other administrative systems (budget, Google Drive) and policies (diversity pledge). This was set up with support from the Management and Board liaisons.

- **Support and production of advocacy and communications campaigns.** In particular, the LEC spearheaded several social media campaigns with Management support, such as the Read a Book Day, Movember, and Women’s Day campaigns. The LEC also provided lived experience representatives to several high profile events (e.g. [World Bank ministerial event in Chile](#)).
- **Supported development of HBGI’s scientific strategy.** LEC members served on the selection committees for the HBGI scientific lead and consulting company for HBGI’s initial research agenda. They served as full team members for the latter piece of work. From this consulting work, LEC also developed a set of [guidelines](#) for the engagement of lived experience in research.
- **Conducted structured evaluations of both LEC and HBGI ways of working.** More information on these reports (and the reports themselves) can be found in [Appendices 7](#) and [8](#).
- **Held several skill-building workshops.** For both members of the LEC and the larger lived experience community on topics such as sharing your story, impostor syndrome, and activating your lived experience.
- **Created a strong LEC community.** Outside of regular Slack communications and regular meetings, members connect with fun activities like birthday wishes, recipe exchanges, and sharing compliments through Post-It notes!
- **Responded to requests from external parties** for LEC representation, participation, and support on conferences and projects. See the next page to learn about one of these projects: the McKinsey Brain Health Dashboard. [21](#)



- **Facilitated close working with the rest of HBGI.** LEC members attended and presented at Interim Board meetings and contributed to Management-led pieces of work such as HBGI's 2021 white paper (titled: The Vision of the Healthy Brains Global Initiative) and HBGI's Global Leadership Meetings.

In order to reflect and build on these accomplishments, align with HBGI's new operating model, and plan for the future, the LEC and Management team ran an in-person workshop in Marrakech, Morocco during October 2022. This report captures the learnings and next steps from this workshop.

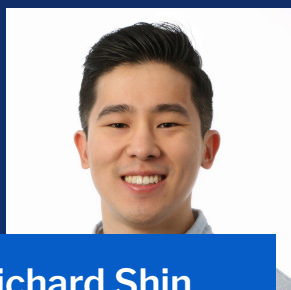
REQUEST FOR LEC INPUT: AN EXAMPLE

The McKinsey Health Institute (MHI), in partnership with HBGI, co-developed an analysis on what's addressable for mental and substance use disorders. It found that:

1. There is considerable physical disorder burden closely associated with mental and substance use disorders;
2. Approximately half of this burden could be addressed by scaling what works, and;
3. Treating these disorders early will lead to better outcomes.

This analysis was published through [an interactive site](#) on the MHI website. HBGI provided scientific as well as lived experience expertise for this effort. In particular, the LEC provided highly complementary, deep insights on what interventions work, how they manifest in real life, and what are the real world challenges and considerations.

Please read on for quotes from the stakeholders involved about the experience of integrating lived experience in the analysis.



Richard Shin
McKinsey

HBGI's Lived Experience Council was an X-factor for our research. The model required (and had) plenty of clinical and scientific inputs, but what tends to be missing in all of the numbers are real voices on what works and how these things manifest in real life. The Council provided exactly that—the ability to get into the decision making process of those who actually receive these interventions, with powerful stories on not only the challenges but also the real impact of getting help. These conversations not only validated the importance of why we need to scale what works but also busted biases or gaps that we could not easily gain from scientific literature or discussions alone. I'm firmly committed to having lived experience be a core part of all work as it only makes the answer better.



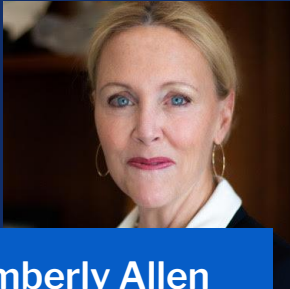
Godfrey Kagaayi
LEC Member

For me, working with McKinsey on such a huge project felt like a great opportunity. Despite the varying opinions, expertise and skills of those who were involved in the project, the lived experience perspective was always prioritised, and consulted at every stage. These basics need to be used as a benchmark when it comes to lived experience engagement.



Jason Grant
LEC Member

Being involved in the McKinsey consultation felt very constructive, important, and safe. My views and opinions were valued in the discussion as were my lived experience colleagues. It felt like there was a genuine dialogue between us all. I was pleased with the outcome of the project and happy to be invited to the report launch as well as to learn more about the pioneering work that MHI is doing.



Kimberly Allen
LEC Member

McKinsey put its best foot forward in all interviews. They are inquisitive, sincere, detailed, and took a true interest in what we had to say. It was a sincerity I could feel. Then, they put it into action.



Andrew Doy
McKinsey

HBGI's LEC helped us bring real voices to something that might have otherwise been less approachable and less tangible. Furthermore, they helped us make the point that approaches to improving brain health should be truly holistic and consider a wide range of support. While discussing our research and model with clinical and academic experts, we tended to stray towards more therapeutic and/or "in-office" interventions. HBGI's LEC broadened our aperture and led to a model more applicable globally. Furthermore, their openness in sharing their stories inspired the team and reminded us of the importance of this work.



LEARNINGS FROM THE LEC



Introduction to this section

In October 2022, following two years of virtual and remote working, ten members of the LEC, three members of the Management team, and two Board members met for a three-day workshop in Marrakech, Morocco.

This section begins by describing specific reflections on the workshop itself, then goes into key recommendations arising from the past two years of LEC work.

The in-person workshop

The aims of the in-person workshop were as follows:

← TO LOOK BACK

Review and reaffirm LEC principles and objectives, reflecting on the past two years of existence, asking questions like:

- What went well?
- What could have gone better?
- What do we change?
- What do we continue doing?
- What do we stop doing?

TO LOOK FORWARD →

Establish best practices for sustainable LEC involvement in the future, mapping the LEC against the new operating model of HBGI and drafting processes to drive involvement and collaboration at every relevant touchpoint. This includes:

- Revising LEC Terms of Reference;
- Setting up processes for responding to external requests;
- Ensuring appropriate compensation of members and that support is properly resourced;
- Establishing and maintaining lines of communication;
- Identifying capacity needs and a capacity-building program;
- Identifying needs and processes for future LEC recruitment.

The specific reflections on the last two years of LEC activity from the in-person workshop can be found in [Appendix 9](#). Below we summarize these takeaways as key recommendations for integrating lived experience voice in your organization.

BEFORE AND AFTER THE WORKSHOP

Workshop attendees recorded before and after videos describing what they were looking forward to in the workshop and, afterwards, what they enjoyed and took away from their time in Morocco together.

Read on for quotes from some of their videos!

BEFORE



Sanju
Sachamuneewongse
LEC Member

"I look forward to getting to know more about where we are heading with HBGI, be able to shape the future of the work we do together, and most importantly I am just enjoying all the hugs of meeting all the fellow LECs after I've been working with them for almost two years and never actually meeting face-to-face. Really excited to be here and see what the future holds for us."

AFTER



"It has been great. I think I was very tired and nervous before coming but when I was here and getting to meet people I've worked with virtually for the past two years...it fits right, that was a perfect feeling to have. I had an amazing time here."

Something you really enjoyed most?
"Everyone's company. How much fun we are and how really passionate we are about mental health."

Fun thing you learned about someone?
"All HBGI members are really goofy."



Maureen Gikonyo
LEC Member

"What I'm looking forward to in the workshop is seeing how we can collaborate with different workstreams to make this LEC a success. I'm also interested to get out of the workshop how we can better understand the operational plan and how LEC is contributing towards that. I'm also interested to see how we can bring in new voices and new members from different areas who can also be part of the LEC and to see more young people get involved in such kind of beautiful work."

"Damian is so tall. And that Naeem and Shuranjeet are actually not very serious people in person."

I had a conversation with Jackee on youth mental health. We are going to be bringing change to that."



BEFORE



Shuranjeet Singh
Board Member

“I’m looking forward to reflecting on what we have succeeded with so far as a LEC, the different elements that have helped us to flourish in these particular roles, and also planning ahead, and thinking about how we can learn from the past two years and adapt the LEC and its operations to HBGI’s exciting new strategic and operational direction.”

AFTER

“My experience with the LEC meeting was amazing. It was an absolute pleasure to be able to connect with, listen, and learn from everyone on the Council and HBGI over those three days. The last two years have been difficult in various ways for many of us, and actually the Council and HBGI’s development has been in parallel to the pandemic...it was really really amazing to be able to connect with everyone in person after two years of working together virtually.

“I didn’t know Naeem was that funny in person. I thought he was really really serious. Everytime I’ve spoken to him online he’s really serious. But actually he’s quite funny. Thank you Naeem and thank you everyone else on the Council for a fantastic three days and thank you to HBGI staff for developing the session.”

We also distributed a post-meeting anonymous survey to hear from LEC members about their experience in the workshop. Below see some of the survey takeaways - both positive and constructive - that we will learn from for the next meeting.

SURVEY TAKEAWAYS

- *I am so grateful to have had the opportunity to attend the workshop, to get to know everyone in person. This was incredibly beneficial for our personal relationships as well as building our professional goals together. The accommodations were very nice. I really appreciated that it had a relaxed feel with great amenities. The space that we had for the workshop was very good and I appreciated having refreshments throughout the day. I also really liked the love wall! I loved hearing Richard's presentation on effective contracting. It was very eye-opening on the nature of public-private partnership and mechanisms for improving outcomes.*
- *I really did not like the elevator pitch exercise applied to lived experience. We spend so much time convincing others of the value of lived experience and I didn't think this was a valuable exercise to ask us to do this again (it makes the space feel a lot less safe), as opposed to specifically envisioning how lived experience engages with HBGI.*
- *Overall, I'm grateful for the kindness I experienced throughout our time together. Being part of HBGI is one of the best experiences in my career.*

TIPS ON ORGANIZING AN IN-PERSON WORKSHOP FOR LIVED EXPERIENCE MEMBERS

VISA AND FLIGHTS. If the selected location requires visa applications, allow plenty of time for this process and consider providing support with the application. Examples of support include a letter of support or payment of fees. Our experience was that the LEC members from low-income countries experienced many more challenges in securing their visa than those from other countries.

It is also worth being mindful that flights can be more expensive and arduous. Even though the LEC workshop was held on the African continent, many of our African colleagues had longer travel times than those traveling from other parts of the world. Be aware of these inequities, compensate accordingly, and appreciate your lived experience members for making the trip!

SAFETY. Members from our LEC shared with us that for many people with lived experience, travel can present a significant disruption to health routines. Some people with lived experience may have certain needs associated with travel, for example, having a partner accompany them on their journey or ensuring their health records are on hand and easily accessible in the case of an emergency.

LEC members raised that health insurance is an important issue for people with lived experience to consider when traveling. It is essential for the organization to consider these factors, as they can necessitate additional costs or planning.

WELCOME BOOKLET. Prepare and share with attendees a welcome booklet which not only includes agenda but also helpful information for the in-person workshop such as accommodation contact details, emergency contact numbers, dress code, any per diem allowance, tips, and advice about the location.



Fun activities like these "compliment envelopes" were essential to relationship-building!

REMAIN FLEXIBLE. Have an agenda which is shared ahead of time but be prepared to be very flexible and adaptable. Timings may need to change; agenda items may need to be dropped or replaced.

WORKSHOP SPREAD OVER A LONGER PERIOD. Space your workshop out over a longer period of time, five days instead of three, for example, to ensure it allows for sufficient rest, and that plenty of breaks and reflective periods are built in. This, and the preceding recommendation, are absolutely essential to supporting members' mental health during the workshop.

RELATIONSHIP BUILDING. Build in plenty of informal 'getting to know each other' time. After two years of virtual working, LEC members needed time to build in-person relationships with one another in a fun, relaxed and informal setting, away from the structure of the workshop.

VALUING LIVED EXPERIENCE MEMBERS' TIME. Many lived experience members will have paid employment or other commitments, for example study, outside of their lived experience work. If organizing time away, which involves travel, lived experience members may need to take annual leave. Consider allowing lived experience members to bring along significant others, particularly if workshops will be spread over more days, with more breaks built in.

Key recommendations for integrating lived experience voices

This section summarizes the main learnings and takeaways from HBGI’s past two years of working with the LEC in a set of thematic recommendations for organizations looking to integrate lived experience in their operations. Each recommendation describes a systematic approach to the theme and is accompanied by a concrete example from HBGI’s experience. For clarity, the recommendations are sorted into three categories: culture, systems and resources.

Please note: after the workshop, the LEC wrote a series of Dos and Don’ts for LEC Integration ([Appendix 10](#)). The recommendations detailed in the following section of this report are compiled from notes taken during the workshop, a post-workshop survey, the Dos and Don’ts, and takeaways from LEC evaluation reports ([Appendices 7 and 8](#)).

	Recommendations	HBGI Actions
Culture	Foster and celebrate diversity	<i>Created diversity pledge and commitment to open, compassionate conversations</i>
	Ensure inclusivity and wellbeing	<i>Establishing regular breaks and setting out clear guidelines for how to work with people with lived experience</i>
	Emphasize adaptability	<i>Being flexible in shifting membership, workstreams, and workplans</i>
	See beyond someone’s lived experience	<i>Recognizing and learning about skills of the LEC members beyond their lived experience</i>
Systems	Choose governance structures that are fit for purpose	<i>Established the LEC Chair as full voting member of HBGI Board</i>
	Create avenues for open communication	<i>Production of regular evaluation reports between LEC and Management</i>
Resources	Support skills development	<i>HBGI Management and LEC offer training sessions to LEC members, HBGI Management learns from LEC</i>
	Provide logistical support	<i>Provides honorarium and coverage for data costs in a way that works for members</i>
	Conduct a resource assessment	<i>Assessed and committed sufficient budget and human resources upfront</i>

Culture

Foster and celebrate diversity

Diversity can encompass a number of areas: race, ethnicity, sexuality, age, gender, socioeconomic status, and lived experience, just to name a few. One of the main takeaways from working with our LEC has been the reaffirmation of the importance of diversity.

A team composed of many different types of people has many benefits: it creates a culture where differences and (respectful) disagreement is encouraged; fosters different ways of thinking, and; leads to creative problem-solving. Working with different people helps you realize the limits - and strengths - of your own unique background and experiences. An organization that embraces diversity will perform better.

Diversity can also be necessary to be reflective of the audience and service users you want to reach (e.g. if you are a global initiative aiming to help underserved populations, you must involve people with that background in leading the work).

Of course, diversity needs to be more than a buzzword. As an organization looking to integrate lived experience, you must make sure to create a space that is inclusive of different types of people and recognize that one person's experience is always unique to them. No one person can represent an entire group. This requires a conscious effort on the part of everyone within the organization, as well as a resource commitment.

The potential of a truly diverse organization is huge and we appreciate greatly the LEC for guiding us in creating a more inclusive organization.

HBGI EXAMPLE



A LEC member in a leadership role made a comment and posted a photo on the general LEC Slack channel that stereotyped an aspect of culture from a certain geographical region. Another member reached out to that member, shared an observation that this comment may not be sensitive to people from that region, and suggested they reach out to members to see how they felt about the comment.

The member took that advice and spoke to other members from the region, some of whom did express concern about the remark. Through these open, reflective, and compassionate conversations, members were able to reflect on communicating across cultures—understanding that bringing together a diverse group across geographies and ages sometimes leads to clashes in communication and that a key part of inclusivity is approaching such situations with humility, compassion, and the aim of helping everyone learn, not assigning blame.

The LEC (led by the member who had made the original remark) decided to create a diversity pledge, to address its commitment to being culturally inclusive and tackling any similar issues with an openness to communication, trust, respect, and forgiveness. Overall, even though it was at times a painful growing process, the incident brought the LEC closer together.

Ensure inclusivity and wellbeing

Ensuring inclusivity and wellbeing in a systematic way is vital for an organization looking to integrate lived experience. Often, people with lived experience expertise are the best people to ask about ensuring inclusion in setting these policies.

Inclusion covers two areas:

1. *Creating environments where it is safe for people to participate as their authentic selves;*
2. *Enabling people to participate in those environments.*

The former may cover things like language, tone and meeting management. The latter involves accessibility and ensuring people are equally able to participate in spaces within your organization.

You may ask such questions as:

- Are people in your organization informed about how to speak about mental health? Are they comfortable and willing to create space for people with lived experience, especially young people who may not be comfortable jumping into conversations or disagreeing with 'experts' in the field?

- Is everyone equally able to participate in meetings, in-person or virtual? Do some people have to pay more for data costs or cannot access good WiFi to participate in video calls? Are you paying people for taking time they might otherwise spend on employment?

Wellbeing is linked but has to do more with safety practices around ensuring good mental health in your lived experience members. For example, it is important to be clear that sharing one's story or lived experience is not a prerequisite to participation and that nobody should feel pressured to share potentially triggering information (and that if they do choose to share, there are appropriate warnings in place for others). For young people with lived experience, it may be helpful to provide mentorship support to assist with adjustment to the work environment.

Another example is around breaks and avoiding burnout. You may ask yourself:

- Are there appropriate breaks in meetings or during the year? Is there a policy around taking leave? Is sufficient time allotted to things like team building and creating a community of mutual trust and support?

HBGI EXAMPLE



HBGI aims to support wellness in its LEC members through providing two extended, month-long breaks: one in August and one during the December-January holiday period.

The LEC also generated [guidelines](#) for consultants HBGI works with, to ensure consultants are aware of how to work with people with lived experience. These guidelines will be followed by a "playbook" that the LEC is currently designing to guide HBGI's interactions with the LEC and ensure that HBGI creates an inclusive environment.

Emphasize adaptability

Especially in a startup organization, cultivating a culture of adaptability is key.

In a startup looking to involve people with lived experience, it is necessary to strike a balance between giving clarity of roles (e.g. setting expectations around hours and type of work) and acknowledging the ever-changing nature of the organization.

While shifts in organizational priorities and staffing can be challenging, the flexibility afforded by a startup can provide a lot of room for more meaningful engagement with people with lived experience. As long as this need for adaptability is adequately

communicated and procedures for wellbeing are in place, not having systems set in stone means that people with lived experience can have a more influential role in building the organization.

Some might be reluctant to include people with lived experience at such an early stage. Some may see it as potentially risky to include people with lived experience in a changing environment. While those risks exist and it is important to be supportive and deliberate in who and how people are engaged, we have found their input to be invaluable. After all, how can you create a truly inclusive, service user-centered organization without involving people with lived experience from the very beginning?

HBGI EXAMPLE



From the beginning, HBGI was clear that the LEC would be operating within a startup environment. Still, there were a number of challenges, including changes in the Management team and in the LEC itself.

Several ways that the LEC has been flexible and adaptive has included the change in its membership (several members dropped out as schedules and the focus of HBGI shifted, but others stepped into larger leadership roles). In addition, the LEC has recently shifted from five workstreams to three to more effectively focus the time of its members. Finally, the LEC has often made changes in workplans, work schedules, and deadlines for workstreams as different HBGI needs came up (e.g. when LEC members provide input on HBGI Management materials).

These examples highlight how important adaptability is when forming a LEC in a startup organization.

See beyond someone's lived experience

Any person is more than one experience and more than the sum of their experiences. Similarly, people with lived experience bring value that goes far beyond their lived experience.

Organizations should create an environment where people with lived experience can bring their whole selves to their work; only seeing someone as their lived experience or that specific personal insight is a disservice to both the person and the organization. Organizations can benefit hugely from the skills, experiences, knowledge and networks people with lived experience bring.

This goes hand-in-hand with an asset-based approach to mental health work and lived experience integration. This approach focuses on a person's strengths and empowers the person to tap into those strengths to face challenges, instead of focusing on one's perceived weaknesses or obstacles. In an organization, this means focusing on how to use an organization's strengths to find solutions and accomplish the organization's vision, rather than focusing on what could go wrong with lived experience integration.



Jackee Schess
LEC Member

In my professional work I am a public health researcher. I am trained in rigorous methods and use these to answer public mental health and substance use research questions. My lived experience, and my interaction with other advocates with lived experience, directly drives my research agenda. I believe strongly that being grounded in the reality of what you are researching is an asset to doing research that has practical and policy relevance.



Kulbir Sandhu
LEC Member

I work in healthcare communications, and every day I make it my work to ensure that the voices and perspectives of a range of people are included in the campaigns I work on. The world is a fairer, more just and ultimately a richer place if we can implement public policy that has lived experience at the heart of it.

Systems

Choose governance structures that are fit for purpose

There are many ways for an organization to integrate lived experience, and you must be deliberate and systematic in choosing how you will do so. Two main ways are:

1. *Integration through representation or advisory roles on individual project teams;*
2. *Creating a separate governance structure of people with lived experience to advise.*

The risk with the first is that individual members may not feel empowered to speak up or selection of lived experience members may not be appropriate, as project planning and decision making is done by the organization, not the person with lived experience. With the latter, the risk is siloing: keeping the lived experience group separate from real decision-making power or the rest of the organization.

At HBGI, we aim to create sustainable systems of lived experience engagement. What that means is that we do not want to take an ad hoc approach to lived experience but one that is deliberate, systematic, and sustainable. With that in mind, we chose to take approach 2, recognizing that we are not experts in lived experience integration ourselves, and that we should

ask people with lived experience to lead us in the development of systems for lived experience integration.

In this model, it is vital to ensure that the group is an integrated part of the organization empowered to take part in decision-making rather than siloed separately or placed at the bottom of the hierarchy.

It is also important to ensure there are clear links to other parts of the organization.

Having people who serve as liaisons and support between groups is really important for ensuring efficiency and transparency.

But this scaffolding must be balanced with fostering a sense of autonomy and allowing people with lived experience to participate in decision-making on how integration should occur.

In the long term, if your organization successfully integrates lived experience, the group may decide it is no longer necessary to exist as a separate entity. Again, the main point here is that governance around your engagement with lived experience must be deliberately structured to foster autonomy, efficiency, and meaningful sharing of decision-making power.

HBGI EXAMPLE



One piece of feedback from the LEC was that the interactions between HBGI's three entities (the Board, the Management team, and the LEC) sometimes felt siloed and unequal. They communicated that the role of liaisons to move between entities was helpful, but was not sufficient to ensure equal decision-making power and embedding of lived experience.

During its presentation of an evaluation report in 2022, the LEC brought this request to the Board. Subsequently the Board Governance Committee formally invited the LEC Chair to join the Board as a full voting member, and the LEC Chair has now accepted that position.

Create avenues for open communication, feedback and transparency

Vital to working well as a team, especially with a global team of people with lived experience, is ensuring open communication, transparency, and avenues for feedback. This must also be approached in a systematic way. As an organization, you might want to ask yourself:

- Do people with lived experience have a clear contact person to go to with organizational or professional questions? Do they have a clear contact person (who may not be on your management team) who they can go to with personal concerns?
- Is there a line of communication so that people with lived experience are aware of what is going on in the organization (including Board and Management)? Are roles and responsibilities clear between groups?
- Is it clear to people in your organization who serves what role and how decisions are made?
- Do people with lived experience have a person or method for providing feedback, especially after events or meetings?
- Does leadership have an open door policy with your lived experience advisors? Do people with lived experience feel comfortable taking advantage of that policy when issues arise?

HBGI EXAMPLE



One of the requests from HBGI's first Interim CEO to the LEC was to provide HBGI with a "Report Card" to evaluate how well HBGI was fulfilling its commitment to embedding lived experience at every level. This Report Card was presented to both HBGI Management and the Board.

Building on that, in 2022, the LEC conducted an anonymous survey of its members, including questions such as "When you were engaged in HBGI Management processes, to what degree do you feel your feedback was valued?" and "When you were engaged in HBGI Management processes, to what degree was your feedback on board?" The answers to these questions generated a number of recommendations on what to do differently and what to continue doing to ensure meaningful involvement of lived experience in HBGI's work.

The 2022 Report Card generated by the LEC, as well as a preliminary evaluation survey from 2023, can be found in [Appendices 7](#) and [8](#).

Resources

Support skills development

Depending on how technical or specialized an organization is, it may be hard for people without skills in that field to engage meaningfully and non-tokenistically.

This issue is particularly important when engaging young people. For example, a young person may find it hard to operate in a corporate setting with frequent use of jargon and find it difficult to engage in meetings even when invited to speak.

For both parties to find an engagement mutually beneficial, skills matching and development is absolutely necessary. Organizations must engage in capacity building and culture shifting in order to create an environment where people with lived experience can fully participate.

In engaging people with lived experience, organizations should ask themselves the following questions:

- Are the people with lived experience you are working with appropriately skilled in areas

your organization focuses on or the language and environment your organization operates within (e.g. a corporate setting)?

- If not, are your people with lived experience open, willing, and have the capacity to learn? Are you willing to support that learning with human and financial resources?

In addition, it's important to ensure you as management are prepared to work with people with lived experience.

- Have you worked with service users before? Have you done your research on how to engage with people with lived experience and how to speak about lived experience and mental health more broadly in a destigmatizing way?
- Have you assessed the language and environment of your organization? Are you taking steps to make it more inclusive and/or to empower people with lived experience to participate in your organization?
- Are you open, willing and have capacity to learn?

HBGI EXAMPLE



There have been lots of learning at HBGI! First, the LEC held skills workshops for its members, covering topics like tackling impostor syndrome and how to activate your lived experience. Evaluations of these sessions were generally quite positive, with members saying it helped them find newfound confidence for challenging situations.

In addition, HBGI Management will be offering training in relevant skills for LEC members. At the in-person meeting, LEC members attended a training session on outcomes contracting led by the CEO. In the future, HBGI Management will be looking for trainers who focus on interviewing, so that LEC members can be more meaningfully engaged in the interview process for future staff members.

Finally, HBGI Management has also learned from the LEC. Management team members speak about gaining a newfound appreciation for the value of lived experience and learning from LEC members in so many ways beyond just their specific lived experience. For example, Management team members have learned to think differently about their own lived experiences, as well as how to communicate more inclusively about mental health challenges (e.g. referring to mental health conditions versus mental health disorders).

Provide logistical support

Underpinning all of the previous recommendations is the importance of providing adequate logistical support. Especially when working as a virtual, global team, it is vital to coordinate logistics to ensure smooth communication across multiple platforms (from setting up virtual meetings to in-person interactions).

Beyond technical logistics, there are also logistics associated with project planning, meeting management, and documentation.

It is important to understand what kind of support the organization needed to provide, either in training people with lived experience to conduct these tasks or in bringing in management support to coordinate.

Without adequate logistical support, it is impossible to involve people with lived experience in an inclusive and equitable way.. Especially during the startup phase of an organization and at the beginning of an organization's engagement with lived experience, this support is key.

HBGI EXAMPLE



HBGI provides an honorarium, as well as coverage for data costs incurred from HBGI-related work, to all LEC members.

The honorarium is given to all members on an opt-out basis, meaning that members do not have to disclose financial need or other potentially sensitive information in order to receive the honorarium.

Providing proper remuneration has been described by LEC members as absolutely necessary to lived experience work, showing that HBGI values lived experience contributions and is committed to ensuring members from different socioeconomic and professional backgrounds can participate in the LEC.

An additional consideration is that remuneration must be provided in ways that are appropriate for members. One member recounted an experience with another organization in which they were given Amazon vouchers (which they were not told would be their form of compensation) that they couldn't actually use in their country. Remuneration must be disbursed appropriately and with clear communication up front.

Finally, in response to feedback from members, HBGI set up a policy to compensate LEC members who incurred additional data costs through participating in HBGI-related work (e.g. calling into Zoom meetings in areas with poor data coverage). This was essential to ensuring equitable participation of LEC members from around the world.

Conduct a resource assessment

Finally, and most importantly to carrying out any of these recommendations, comes assessing what resources (human and financial) you have for lived experience integration.

As the recommendations above show, integrating people with lived experience should be done deliberately, carefully, and in a way that's open to feedback and mutual learning. To support that, it's important to have financial resources so that people with lived experience can be compensated for their time and skills and ensure equitable participation.

It is also vital, especially at the beginning of one's journey to lived experience integration,

to have human resources allocated for support on logistics and communications. It's also essential to have people who are willing to serve as allies within other parts of the organization, serving as vital links of communication and advocates.

If you as an organization are not able to devote those resources to support lived experience integration, it's important to think about how you can address these needs. It may mean seeking external support to cover these costs or reconsidering how you engage with lived experience. The important part is being transparent with yourself and with others, including your people with lived experience, and recognizing where gaps may exist now so that they can be addressed in the future.

HBGI EXAMPLE



HBGI was lucky enough to have several resources that enabled the formation and maintenance of the LEC.

First, HBGI had the available finances to recruit for a paid LEC, with independent budget set aside for the LEC's use.

In addition, HBGI had valuable human resources. First, through its Interim Board of Directors, HBGI had access to a wide variety of experts, many of whom also had or worked with people with lived experience; many of them served in an advisory role to HBGI in setting up the LEC.

HBGI also had members of both the Board and the Management team willing to serve in a liaison role and support the LEC within HBGI. This took dedicated time and could, especially on the Management side, have filled a full-time role.

When thinking about integrating lived experience, organizations should consider both the financial and human resources needed, being careful not to underestimate either. Organizations should consider hiring a staff, dedicated to lived experience and ensuring they have set aside sufficient budget to compensate members with lived experience.

The value and impact of the LEC in HBGI

The LEC's purpose is to increase HBGI's impact: delivering truly meaningful outcomes to as many people as possible. Even at this early stage, the LEC has changed HBGI's ways of working and brought immense value. While this impact cannot be fully captured in one page, below we share a few examples below to show how lived experience can transform your organization.

First, the LEC has shaped HBGI's ways of working and helped HBGI become a more inclusive organization. Internally, LEC has influenced HBGI's governance structures: the permanent Board is mostly composed of people with lived experience, including one former LEC member and the current LEC Chair.

In addition, the LEC has brought a form of accountability through its evaluation reports ([Appendices 7](#) and [8](#)). HBGI has endeavored to take these recommendations on board. This includes both the shift in Board governance to more directly link to the LEC, as well as the fact HBGI now covers data costs for members and held a physical meeting to discuss ways of working and the way forward.

When recruiting and working with external partners, the LEC ensured that HBGI worked with people who shared the values of lived experience integration. Members of the LEC served on the interview committee for HBGI's former scientific lead as well as the consultant

selection committee for the research work on research priorities.

LEC input has helped shape HBGI's external products as well. For example, a previous piece of HBGI work, conducted with the I.G. Advisors and MQ Mental Health team, assessed research priorities in anxiety and depression. LEC members were involved as full team members, helping the team stay focused on the demographic HBGI most wants to impact. The results from this work, including a LEC specific reflection, can be found [here](#).

The LEC has attracted increased funding to the organization. A variety of external stakeholders have referred to the LEC as the unique selling point of HBGI, recognizing how unusual it is to integrate people with lived experience at such an early stage of the organization. Indeed, the LEC has resulted in HBGI being able to mobilize USD75,000 of additional funding solely for the purposes of lived experience integration (on top of the greater amounts of startup funding received, part of which was also allocated for lived experience integration).

Finally, equally important though less tangible, the effect of the LEC on HBGI's culture and understanding of lived experience has been incredible.

These are just a few examples of how the LEC has impacted HBGI and we look forward to adding to these in the future.



Shomsia Ali
Management Team



Spending three days with our much-valued LEC in Morocco was an insightful time for many reasons. One particular reason was appreciating just how much more the LEC members brought to HBGI. We benefit not just from the personal lived experience insight but also from all of the other wealth of experience, skills and knowledge they generously bring, from other walks of their lives, including their day job. The LEC members openly share their contacts and networks with HBGI, making introductions and connections as required. Another valuable insight was, on hearing the different members' personal stories, appreciating how we all, to some degree, have a lived experience of poor mental health, as we do of poor physical health. Tuning into that experience, even if it was a single episode with a known trigger, can be both powerful and helpful.



Mariel Sander
Management Team



Learning from and with my LEC colleagues has been the absolute highlight of my time with HBGI. Having shepherded the LEC's development from its inception, I have seen firsthand how their input and insights have shaped HBGI into what it is today: an organization focused on doing good for as many people as possible, committed not just to making an impact but making an impact the right way.

Without exception, our LEC members are incredible advocates who live their principles throughout every aspect of their lives, and I have been inspired both as a professional and as a person through working with them.

As a young person who grew up with family affected by mental health conditions as well as her own experiences of mental ill-health, recognizing the irreplaceable value of lived experience has been empowering and illuminating. More than anything, it's helped me reflect that we're composed of more experiences than anyone else can ever fully understand, but that, in order to make the world better, we must always try.

I hope, whoever you are, that this report has helped you think about lived experience a little bit differently.



THE WAY FORWARD



Introduction to this section

This report comes from reflections over the past two years of working with the LEC and the in-person workshop in Morocco. This reflection process showed the importance of lived experience integration and the LEC to HBGI more broadly and reaffirmed HBGI's commitment to continuing to support lived experience integration as the organization

grows in its role as an Outcomes Funder of mental health programs.

This section outlines the next steps for the LEC, as well as the topics that remain under discussion. It concludes with an expression of gratitude to you, the reader, for your time and attention.

Future of the LEC

The LEC will continue to be a key part of HBGI. Coming out of the in-person workshop, the LEC has created an initial workplan for next six months ([Appendix 11](#)). Internally, LEC has undergone several structural changes in the way it will work going forward to ensure best fit with HBGI's new operating model:

- **LEC workstreams streamlined to three:**
 - Communications,
 - Governance, and Monitoring,
 - Evaluation, and Learning (MEAL).
- **Board integration:** the Chair of the LEC is now a full member of the HBGI Board with full voting rights.
- **Management integration:** members of the Management team serve as part of both the Governance and Communications workstreams to ensure an operational integration of lived experience and HBGI's activities.

- **Terms of Reference:** the LEC is currently undertaking a comprehensive review of its Terms of Reference, including thinking about the LEC's future needs for recruitment, honorariums, and links to Management team and Board. In addition, the new operating model contains many touchpoints to incorporate lived experience and LEC input. Some possible areas of joint working between LEC and the rest of HBGI include (with skill building as necessary to support engagement):
- **HBGI policies:** feeding into the development of a number of HBGI policies including sustainability, diversity, data management and human resources.
- **Human Resources:** participating in recruitment of senior staff members.
- **Data system:** supporting the appropriate selection of relevant data management system managing the various outcomes contracts.



An overview of the LEC structure in 2023

The three workstreams (Governance, MEAL, and Communications):

- Each consist of two coordinators and varying numbers of workstream members;
- Are supported by Management team, who are part of Governance and Communications workstreams (with future staff member to support MEAL);
- Meet every two-three weeks for 1-1.5 hours.

The Executive team

- Consists of Chair of the LEC and workstream coordinators;
- Invites Management team to join the meetings;
- Meets for one hour each month.

Full Council

- Meets every quarter for two hours;
- Invites Management team to join the meetings.

- **Investment Committee:** serving as full members of future Investment Committees, which will consider and approve proposals for programs to be funded via the Outcomes Funds. The Investment Committee will include the CEO, future CFO and Regional Director and key senior colleagues from local stakeholders.
- **Quality assurance:** participating in quality assurance processes, including in reviewing proposals for funding during Request for Proposal rounds, ahead of recommendations being made to an Investment Committee.
- **Communication and events:** representing the lived experience voice at various conferences, workshops and seminars on behalf of HBGI, as well as supporting HBGI in facilitating and hosting our own events.
- **Fundraising:** supporting HBGI raise funds through access to their networks.

Ongoing conversations

Of course, there remain ongoing topics of discussion between the HBGI LEC and the rest of the organization. We remain cognizant of those and are committed to keeping lines of

communication open to ensure absolute transparency and that we are not just open to but encouraging feedback and continued conversation.

FOR YOUR INFORMATION



Several ongoing topics of discussion include:

- The long term future of the LEC (will it be necessary? Or will people with lived experience be fully integrated at all parts of the organization?)
- Is it better to have one central LEC or regionally specific LECs as HBGI grows?
- How should the LEC and HBGI more broadly work with pharmaceutical companies?

Conclusion

We hope that whoever you are—funder, service provider, person with lived experience, or any other—that this report has provided useful insights for you. We hope that if you already integrate lived experience, the recommendations and insights from our LEC work will provide scaffolding to reflect upon your own practices. If you are considering integrating lived experience systematically, we hope the report provides guidance on why and how to do so in an inclusive and mutually beneficial way.

Many of us in the mental health field are here because of our own lived experience, even if we haven't thought of it that way before or recognized it as its own form of expertise. For you personally, we hope this report helps you reflect on what it means to have lived experience and how purposefully integrating lived experience perspectives can help your work deliver greater impact.

From all of us at HBGI, thank you for reading this report.

ACKNOWLEDGEMENTS

This report was authored by the HBGI Management team in collaboration with the Lived Experience Council of HBGI. Questions and comments can be directed to info@hbgi.org with the subject line “Lived Experience Council Report”.

Thank you to the many who generously gave their time and advice in setting up the LEC. Your genuine passion and thoughtful insights was essential to making the idea reality.

Support for this report came from the Lundbeck Foundation, as well as HBGI’s other supporters, including the Wellcome Trust, Otsuka Pharmaceuticals, and Johnson&Johnson.

Thank you to Daria Mukhina for designing this report (for more information, please refer to her [portfolio](#) here).

Thank you finally to Brandon Staglin for bringing in the first lived experience advocates to the HBGI Working Groups in 2020.



APPENDIX

[Appendix 0](#): Studies showing link between mental health and other challenges

[Appendix 1](#): An overview of outcomes contracting in fragile contexts

[Appendix 2](#): HBGI framework for lived experience integration, Sept 2020

[Appendix 3](#): Current diversity breakdown of LEC

[Appendix 4](#): Selection process for LEC, fall 2020

[Appendix 5](#): LEC workstreams and workplan, 2021

[Appendix 6](#): List of LEC accomplishments from 2021-2022

[Appendix 7](#): Summary Report 2021

[Appendix 8](#): LEC Report Card 2022

[Appendix 9](#): Reflections from the October 2022 Marrakech workshop

[Appendix 10](#): Dos and Don'ts for lived experience integration, by LEC, Nov 2022

[Appendix 11](#): LEC initial workplan, Oct 2022

Appendix 0

Studies showing link between mental health and other challenges

Please note that this list is non-exhaustive and should be used only as a starting point in understanding how mental healthcare is essential to making progress in a number of other socioeconomic challenges.

1. Rooks-Peck et al, 2018. [URL](#).
2. Collins et al, 2021. Intervening for HIV prevention and mental health: a review of global literature. [URL](#).
3. Culhane, Metraux, and Hadley, 2002. Public Service Reductions Associated with Placement of Homeless Persons with Severe Mental Illness in Supportive Housing.
4. Mondello et al, 2007. Supportive Housing in Maine: Cost Analysis of Permanent Supportive Housing. Pearson, Carol, Gretchen Locke, Ann Elizabeth Montgomery, and Larry Buron." The Applicability of Housing First Models to people with Serious Mental Illness."
5. Seligson et al, 2013. New York/New York III Supportive Housing Evaluation: Interim Utilization and Cost Analysis. A report from the New York City Department of Health and Mental Hygiene in collaboration with the New York City Human Resources Administration and the New York State Office of Mental Health.
6. Public Health England, 2017. Commissioning Cost-Effective Services for Promotion of Mental Health and Wellbeing and Prevention of Mental Ill-Health.

Appendix 1

An overview of outcomes contracting in fragile contexts

WHY TO CONTRACT FOR OUTCOMES, NOT INPUTS

The following short paper sets out the characteristics of outcome-based contracting and contrasts these with the more common form of contracting – ‘fee for service’. Outcomes-based contracting has the potential, when designed and managed well, to increase the efficiency and effectiveness of contracted services in many contexts. This paper further describes those characteristics which make this form of contracting also particularly suited to low resource or fragile country contexts.

THE CHARACTERISTICS OF OUTCOME-BASED CONTRACTING

If services are being contracted out to be delivered by another organization, the most common form of contracting model – in terms of how the service is paid for/funded – is a ‘fee for service’ model. Under this model, the purchaser (the organization who is contracting out the program, for example, a government department or a donor) carefully pre-defines the service – its content and how it will be delivered. The purchaser then may run a competitive tendering process to select a provider to deliver the service. Through this process, the provider is selected, often (usually in large part) on price, with those quoting a cheaper price winning the tender. Once selected, the provider is then paid for the achievement of the prescribed inputs or activities. In some instances, payments are also linked to outputs.

For example, in a training context: the purchaser defines the curriculum and assessment tools, the number of hours to be taught, and possibly the class size and the qualifications of the trainer; the would-be provider submits a proposal describing their capability to fulfil this requirement, and setting out their price; the selected provider is then paid for each trainee enrolled, each hour taught, each trainee completing the program, and possibly each examination passed.

Under an outcome-based model, the purchaser focuses on the desired outcome of the service, as opposed to its content. What are the results or impact that is being sought? The purchaser defines the outcome and determines a price for it. The provider is selected (at least principally) on the quality of their delivery proposal, not on price. They are paid for the number or magnitude of their outcomes or impact.

For example, in an employment context: the purchaser defines the outcome(s) as a job that is secured and that is sustained by someone who was previously unemployed; the purchaser stipulates the characteristics of this employment, possibly in terms of salary, hours of work and length of contract; the purchaser sets a ‘unit price’ to be paid for each job started and for each job sustained for the stipulated period; the would-be provider submits a proposal describing how many job starts and sustained employment outcomes they can deliver at that price, and how they will achieve this; the provider is selected on the technical strength of their proposal (and maybe the quantity of outcomes they commit to deliver); the provider is then paid every time they achieve one of these outcomes (each time a person secures a job, and for staying in work).

Outcome-based contracts are sometimes described as ‘risk-reward’. The provider takes on the (financial) risk of delivery. The provider is rewarded for taking on that risk, and making upfront investments, with payments linked to performance. The level of the payments (the ‘unit prices’) must be set high enough to incentivise that investment, without allowing unreasonable profits/surplus. The purchaser setting the price in advance for an outcome-based contract is advised to think carefully about the relationship between cost and delivery, and arrive at the ‘unit prices’ on the basis of a commercially-informed costing of the potential service.

In a fee-for-service model the level of payments are left to the market to decide. It is argued that the use of price competition will mean the price settles at the most cost-efficient level. However, this does not take into consideration the possible perverse incentive for the provider simply to win the competition at any cost. The ‘winner’s curse’ describes the instances when a provider secures a contract because they were cheapest, but at a price that is not actually deliverable.

Because of the transfer of (financial) risk to the provider in an outcome-based contract, it is argued that providers must be given control of the content of the service in order to manage that risk. The extent to which this control is handed over varies between contracts. In the most extreme variant, a ‘black box’ procurement model is followed.

In a ‘black box’ model the purchaser does not define any of the detail of the service content at all. In fact, even after contract award, the provider is allowed to vary their delivery as they choose, with little or no audit or quality assurance. The focus is purely on the outcomes. This creates a number of risks for the purchaser.

It is advisable for the purchaser to maintain some control and oversight of content of the service. In most cases the purchaser has a duty of care (i.e. an ongoing responsibility) for the service users (e.g. the trainees or jobseekers). The purchaser must, for example, ensure that no service users are discriminated against on the basis of gender or ethnicity. The purchaser may also want to define a baseline of basic service delivery that all service users must receive, and prescribe health and safety or security or complaints procedure requirements. In this case, a ‘grey box’ model is used, in which the provider has a large degree of control but the purchaser specifies service parameters and minimum standards, and then actively audits and quality assures during delivery.

Just as the box might be grey rather than black, most applications of outcome-based contracting actually use hybrid payment mechanisms. Not all of the money is attached to the outcomes. Under an employment program, for example, the provider might be paid for enrolments onto the service as well as for job outcomes.

Weighting payments on outcomes obviously creates an upfront cash requirement. The provider must take on premises, hire staff, purchase resources etc. prior to receiving enough income (from the outcomes payments) to cover these costs.

There are a number of ways to fill this cash gap. The provider could use their own reserves, but only larger organisations are likely to carry such sums, and NGOs may not be allowed to touch any reserves they hold. The provider could borrow from a bank, though this comes at a cost and NGOs are often limited in the debt they are allowed or are willing to take on.

The purchaser could choose to remove the upfront cash requirement or could find ways to facilitate external investment. An upfront 'mobilisation allowance' could cover the providers' early costs and then be repaid once outcomes start to be delivered, though this may leave too much risk with the purchaser if the services are large scale. Or a 'prime contractor' model could be used, in which the purchaser contracts with large 'primes' (with the necessary reserves or the borrowing capacity), who then subcontract to smaller, local providers, either using 'softer' payment terms down their supply chain or easing the cash requirement through breaking it into more manageable chunks. Alternatively, the purchaser could structure the deal such that third party investors bring the investment, with their repayments tied to the outcomes.

In a public service delivery context, the first application of such an outcome-based model may have been in Wisconsin in the 1990s. It was applied there as authorities looked to address endemic unemployment with a switch from input-based training programs to a 'work-first' approach. This was heavily influential in the subsequent development of employment programs in the UK (notably the Employment Zones) and Holland. In Australia, around the same time, the whole of the public employment service was outsourced on this basis.

The uptake in low resource country contexts has been slower. Possibly with a perception of risk, both by purchasers and providers, as well as an emphasis on external 'expert' advisors, there has been a preference for prescribed, paid-for inputs. This has possibly come at the cost of reduced service impact.

The use of Development Impact Bonds (DIBs) is also slowly increasing. These are not really 'bonds' in any true sense but are a variant of outcome-based contracting. In a DIB, the purchaser contracts a 'social' investor who provides the upfront financing needed by the provider and subcontracts the service provision to local providers. Payments to the investor by the purchaser are tied to achievement of predetermined/priced outcomes or impact. The advantages of this model are that: the investors relieve the upfront cash requirement, and; they bring an additional focus on performance (to protect their investment) which further strengthens service delivery and increases the chances of outcomes/impact being achieved. Examples include: diabetes prevention in Israel; maternal and neonatal maternity rates in Rajasthan; eye care in Cameroon; disability rehabilitation centres in Mali, Nigeria and the Congo, and; employment for highly vulnerable jobseekers in Columbia.

One of the reasons that outcome-based models have not had wider application is the inflexibility of institutional budgets. Most public institutions (as well as most donors) manage with annual budgets and find it hard, if not impossible, to budget across years. It is much easier for them to manage input-based payments against a fairly rigid timetable in which inputs are achieved within the given financial year, than plan for payments in future years linked to performance. This performance link also means that the final cost may vary up or down. It is actually easier to contract and manage a service that delivers poor social outcomes, but has a simple fixed cost, than a service that has the potential to deliver more but could exceed forecasts. This inflexibility in budgets is one of the reasons why such institutions have rigid procurement rules which further limit outcome-based models.

THE APPLICABILITY OF THE MODEL IN A FRAGILE ENVIRONMENT

The applicability of outcome-based contracting in fragile or conflict-affected countries is sometimes questioned, but it may be that certain characteristics of the model make it particularly suited to such fragile or simply low resource environments. Indeed, it may address a number of the weaknesses inherent in fee-for-service models.

Attaching money to outcomes, rather than multiple inputs, is potentially very attractive to government and to donors in these contexts. First of all, it demonstrates greater accountability, with payments tied direct to impact. This can increase the credibility of the government and contribute to social cohesion. It may also go some way to addressing 'donor fatigue'.

Secondly, it reduces the opportunity for corruption. The multiple payment points along the chain of a service paid according to inputs each represent an opportunity for fraudulent activity. The multiple points are replaced with just one or two payment triggers under an outcome-based model.

Far from being a model from London or Washington that is imposed on the distant country, an outcome-based contract shifts the contracting from the 'what' to the 'how'. The 'what' of the service content is not defined or imposed 'top down' as it is under a fee-for-service model. The contracting model becomes the tool that answers the question: how do we facilitate a 'bottom-up' design that is locally responsive and appropriate.

Because of the focus on outcomes, the service design and delivery are more likely to be demand-led. In order to achieve the outcomes, the provider must listen to the service users (e.g. jobseekers and employers) and adapt to meet their local, personal needs. The service cannot be 'one size fits all', with all service users pushed through the prescribed content. It must be individualized and is more likely to innovate.

A feature of a fragile or low resource context is that it may be subject to change. Under an outcome-based contract, the provider has the ability to flex delivery, whilst maintaining a focus on the outcomes. Under a fee-for-service contract, the provider must continue delivery of the prescribed content, even if the environment has shifted.

A fee-for-service contract may appear to be cheaper but this does not mean it is more cost-effective. The outcome-based contract is usually more cost-effective because it increases value for money through maximising the results. Indeed, the money is not paid if there are no results.

Appendix 2

HBGI framework for LE integration, Sept 2020

(N.B please note that this was during the first two years of HBGI when the organisation was thinking through how to deliver an increase in global research, without considering delivery as the gateway to that learning)

Engagement Depth	Governance Level	Organizational Level	Research Level
Most to least	Management and leadership	Within the organization itself	Systems for research projects
Partnership Creation or co-creation	Integration of lived experience members into Working Groups and Board Co-creation of lived experience-specific governance structure (Lived Experience Council)	Co-creation of accountability mechanisms around lived experience Co-creation of organizational structures around lived experience	Council to determine principles and recommendations for lived experience engagement in research <i>More project-specific strategies developed later</i>
Involvement Input and collaboration	Design of policies and structure of LEC	LEC and Board liaisons to provide input on HBGI core materials (e.g. scientific strategy, website, mission statement)	LEC to provide input on HBGI's strategies for incorporating lived experience into projects <i>More project-specific strategies developed later</i>
Consultation Feedback or approval	Engagement with Management team as relevant	Engagement with Management team as relevant	Engagement with Management team as relevant

Appendix 3

Current diversity breakdown of the LEC

The current LEC members are diverse, representing a number of different countries including: Uganda, Kenya, Thailand, the UK, the USA and South Africa. Age ranges from 25 years old to 60+ with a range of lived experience of psychiatric conditions represented, from depression to schizophrenia to bi-polar. As well as being active members of the LEC, many of the LEC members are also involved in other mental health organizations or professions, both in professional and voluntary capacity.

The below are demographic charts showing age, location, and ethnicity breakdowns of the LEC.

Count of Age



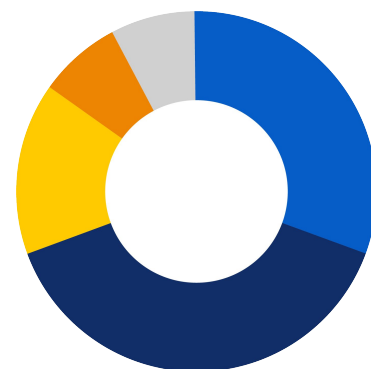
- 18-25 | 23.1%
- 26-30 | 15.4%
- 30-40 | 30.8%
- 40-50 | 15.4%
- Over 50 | 15.4%

Count of Location



- North America | 30.8%
- Europe + UK | 23.1%
- Africa | 38.5%
- Asia + Pacific | 7.7%

Count of Ethnicity



- Black | 38.5%
- White | 30.8%
- Asian | 15.4%
- Hispanic or Latin | 7.7%
- Native American | 7.7%

Appendix 4

Selection process for the LEC, fall 2020

A member of the Management team first reviewed all applications and removed any who did not fit the LEC criteria listed in the application. For evaluation of qualified applicants, HBGI convened a Nomination Committee of experts in lived experience integration.

To evaluate the applications, the HBGI team created a framework based on consultations with the Committee and a spreadsheet used by Black Dog in evaluating its lived experience consultants. This framework asked evaluators three things: 1) to rate each applicant according to five different axes, 2) to give the applicant a 1-5 rating as a whole, and 3) to give a recommendation on whether or not to interview the candidate (an answer of “yes”, “no”, or “maybe”).

The five axes approved by the Nomination Committee and Interim CEO are listed here in order of importance with the percentages representing the relative weight of each axis:

1. Strategic mindset (30%) *(ability to use individual experience to inform broader scope of work, thoughtful about the role of lived experiences in an organization, interest in making systemic change, takes initiative to do work that is needed or fills a gap in a field, interest in holistic approach (not just biomedical) and awareness of external factors like social determinants of health)*
2. Collaborative mindset (25%) *(experience working in teams, experience working with other people with lived experiences, considerate of others' perspectives and voices, empathetic approach)*
3. Motivations (25%) *(interest in making a global impact in research field and culture around brain health, interest in creating better outcomes (both primary, e.g. improving treatments, and secondary, e.g. decreasing stigma), interest in building capacity and research infrastructure in low resource settings, interest in a more holistic approach to research that includes social determinants of health [SDOH])*
4. Understanding of research (14%) *(previous experience or interest in brain health research, understanding of research process and landscape, understanding of external factors that affect research (e.g. SDOH), interest in research innovations or setting a new research agenda)*
5. Understanding of HBGI (6%) *((understanding that HBGI's impact will not be immediate, understanding that HBGI is a research organization (not focused on advocacy or service delivery), understanding that LEC role will be strategic, not necessarily specific to research projects)*

This weighting system allowed applicants to each be given an overall score between 1-5 based on agreed upon priorities, instead of just relying on each individual evaluator's assessment of the applicant as a whole to minimize any bias. By averaging that weighted score with the evaluator's score for the applicant as a whole, we generated one “overall score” which was then taken forward in the evaluations. Every application was anonymized and reviewed by two members of the Nomination Committee.

Finally, the framework also included coding demographic information such as: geography (coded by regions based on WHO classifications), ethnicity (based on the variety of responses, as well as the American and UK census systems), gender, experience with specific conditions, age, and type of lived experience (personal, care partner encompassing parent or friend, or professional), though this information was not shared with evaluators as they were reviewing the applications.

Interviews (Nov 2020)

Interviews were automatically offered to applicants that had received a “Yes” from both evaluators in response to the “Should this applicant be interviewed?” question. For applicants that had received a “Yes” and a “Maybe” or a “Yes” and a “No”, the team gave them an interview if they had a high “overall score” (see Section C “Evaluation process” for how that overall score was calculated) compared to other applicants (with priority given to those who had received a “Yes” and a “Maybe” rather than a “Yes” and a “No”). The team also took into account demographic and diversity considerations at this stage in the process.

Overall, based on these evaluations, the team invited 30 applicants to be interviewed for the LEC and asked Nomination Committee members to lead those interviews alongside a member of the HBGI Management team. The interviewers from the committee were Hussein Manji, Shuranjeet Takhar, and Kimberly Allen alongside Mariel Sander from the Management team.

The interviews were blocked off to be up to 30 minutes each with the following flow: self-introductions and icebreaker, introduction to HBGI (emphasizing HBGI’s role as a research funder, early stages, defining lived experience broadly), one question from a given list, and any follow-up questions based on the interviewee’s application. Finally, the applicant was given time to ask any of their own questions.

Nomination Committee members were then asked to fill out a simple evaluation after each interview rating the applicant’s answer and leaving any comments on their impression of the applicant.

Selection process (Nov-Dec 2020)

Interview scores from Nomination Committee members were averaged with the written application scores to yield one outstanding score for each applicant. The top 15 scorers were automatically accepted into the LEC.

The remaining 15 were reviewed and together, the group eliminated applicants who did not seem like a good fit (e.g. several had skills that seemed more fit for Working Groups). In addition, when there was no significant difference in scores or impressions from the interviews, the group took into account demographic and diversity considerations. Finally, the group chose to include four of the original HBGI members with lived experience from the Working Groups who had volunteered to be a part of the first LEC.

Appendix 5

LEC workstreams and workplan, 2021

(N.B please note that this was during the first two years of HBGI when the organisation was thinking through how to deliver an increase in global research, without considering delivery as the gateway to that learning)

OBJECTIVES INITIAL WORKSTREAMS

1. Changing how research is done	1. Scientific strategy
2. Accountability within HBGI to lived experience leadership	2. Evaluation
3. Sustainable self-governance and accountability to principles	3. Council governance
4. Building a movement and network around HBGI's work	4. Advocacy and communications
5. Upskilling and capacity building	5A. Sharing skills 5B. Team building

Associated LEC workstream	How it supports HBGI's mission	Work program	Will this need additional funding?
1. Scientific strategy	Lived experience integration in HBGI workstreams	a. Support IG/MQ work	Yes
	Lived experience integration in HBGI workstreams	b. Develop process for consulting with non-Council lived experiences on HBGI workstreams	No
	Lived experience integration in HBGI workstreams	c. Produce report outlining barriers to meaningful engagement of lived experiences in brain health research	No
	Lived experience integration in HBGI workstreams	d. Ad hoc consultation of the LEC members with HBGI on specific workstreams (e.g. data-sharing workstream)	Yes

Associated LEC workstream	How it supports HBGI's mission	Work program	Will this need additional funding?
2. Evaluation	Sustainability of the LEC	a. Quarterly survey of the LEC members	No
	Lived experience integration in HBGI workstreams	b. Develop process for evaluation of the LEC within HBGI	No
3. Governance	Sustainability of the LEC	a. Develop LEC member recruitment process	No
	Sustainability of the LEC	b. Develop LEC new member application	No
	Sustainability of the LEC	c. Develop LEC member role descriptions	No
4. Advocacy and communications	Lived experience integration in HBGI workstreams	a. Produce social media campaigns to grow HBGI's audience	Yes
	Lived experience integration in HBGI workstreams	b. Advise HBGI regarding messaging around lived experience	No
	Lived experience integration in HBGI workstreams	c. Represent HBGI at conferences or advocacy events	Yes
5. Sharing skills	Upskilling to ensure meaningful lived experience engagement	a. Create and execute opportunities for internal skills development	No
	Capacity building to ensure meaningful lived experience engagement	b. Create and execute opportunities for skills development of lived experience communities	Yes
	Capacity building to ensure meaningful lived experience engagement	c. Build capacity for people with lived experience to engage in brain health research (<i>with input from 1. Scientific strategy</i>)	Yes
6. Council leadership	Sustainability of the LEC	a. Budgeting for LEC members	No
	Sustainability of the LEC	b. Plan quarterly full Council meetings	No
	Lived experience integration in HBGI workstreams	c. Ad hoc consultations with HBGI not linked to specific workstream	Yes

Associated LEC workstream	How it supports HBGI's mission	Work program	Will this need additional funding?
Additional budget		In person meeting	
		HBGI swag (t-shirt)	
		Technical support	

Appendix 6

List of LEC accomplishments from 2021-2022

Please note this list is not exhaustive and that tasks were facilitated by Management and Board liaison support.

- **Governance**

- Created admin systems such as Google Drive, project proposal templates, workplan, objectives and workstreams (with associated workstream meeting patterns, agendas, and minutes), a LEC governance policy approved by the Interim Board, budget, holiday schedule (including August and December holidays).
- Terms of Reference, including policies around honoraria, the election process, organizational chart, mental health break notification process, resignation process, inactive member policy, definition of term length and roles for leaders.
- Election process with online voting tool and motivational statement submission, and formal appointment letters.
- Partnered with Evaluation workstream to inform lessons learned and engagement recommendations survey.
- Conducted a skills assessment of LEC members, drafted a diversity pledge, and designed the recruitment process.

- **Advocacy and communications**

- Produced awareness days and events calendar, spearheaded accompanying social media campaigns (Read a Book Day, Mental Health in Art and Research event, Movember).
- Provided lived experience representatives to UN consultations on neurological conditions.
- Assisted with website updates.

- **Scientific strategy**

- Developed a set of guidelines based on literature in field and experiences.
- Worked as part of HBGI team working with IG Advisors /MQ Mental Health to set priorities in anxiety and depression (including leading engagement of a third of the LEC members).

- **Evaluation**

- Conducted initial survey of the LEC members on their engagement (in mid 2021).
- Conducted another survey on lessons learned and recommendations and presented findings in report to Interim Board and CEO.
- Developed report card on request from Interim CEO to evaluate HBGI's adherence to lived experience engagement

- **Skills sharing** (focus on internal upskilling, creating events for whole LEC, participation in external events)
 - Conducted internal upskilling on mental health research and anti-racism.
 - Ran a workshop on storytelling in mental health advocacy at the Generation Mental Health conference.
 - Conducted skills sharing sessions on activating your own lived experience, story-telling, etc.
- **Team building** (please note: this was not a formal workstream)
 - Built a community, including birthday wishes, recipe exchange around winter holiday season, sharing accomplishments via Slack and inviting members to other events.
- **External**
 - Participated in external consultations (e.g. with McKinsey on their brain health dashboard).
- **Other parts of HBGI**
 - Served as team members on consultations with consultants (IG/MQ, Camber, and McKinsey).
 - Participated as team members in interview committee for scientific lead and selection committee for consultants IG/MQ.
 - Gave keynote speech at HBGI Global Leadership Meeting.
 - Contributed to white paper, Board meetings, social media planning, and staff recruitment.

It is important to note that LEC members served in different roles for many of these tasks. Some projects were LEC-led (e.g. the drafting of the Terms of Reference, skills-sharing workshops), whereas some involved LEC working in partnership with Management (e.g. serving as a full team member on IG/MQ project) or providing input in a more limited way (e.g. having a representative at every Board meeting).

Appendix 7

Summary Report 2021

HEALTHY BRAINS GLOBAL INITIATIVE LIVED EXPERIENCE COUNCIL

For attention of: HBGI CEO and HBGI Interim Board of Directors

Date: 20th February 2022

1. Introduction

1.1 Background and purpose of the report

The Lived Experience Council (LEC) of Health Brains Global Initiative (HBGI) exists to ensure the voices, perspectives and expertise of people with “lived experience”^a mental and neurological health challenges are embedded within HBGI. This annual summary report presents key achievements, summarizes LEC members’ reflections and lessons learned and formulates recommendations for putting lived experiences at the centre of HBGI’s work in 2022 and beyond. The report is based on individual workstream progress updates and an online survey conducted in Q4 2021.

1.2 LEC membership

Following an application and interview process in 2020, 21 applicants were selected to form the inaugural LEC. In the first six months of 2021, LEC developed detailed terms of reference (TOR)^b and held a self-organized election process between July-September 2021. As of December 2021, LEC counted with a total of 15 active members^c. Overall, LEC is composed of people with a wide variety of lived experiences from diverse backgrounds across geography, gender, age, race, ethnicity, education, and professional experience.

2. Key achievements and highlights per workstream

The full LEC determined five priority workstreams which are governed and executed by LEC members. Workstream Co-Chairs were elected in September 2021 and each workstream determined its own activities and frequency of meetings. LEC members actively contribute to one or more workstreams, with most members having contributed to Governance (8), followed by Evaluation (5), Scientific Strategy (4), Skills Sharing (3) and Advocacy and Communication (2) in 2021. Most turnover was experienced in the Advocacy and Communications workstream.

2.1 Advocacy and communications

In the first quarter of 2021 (Q1), the workstream focused on setting objectives to help in directing the workstream. These objectives include: **(1) Producing social media campaigns to grow HBGI's audience, (2) Advising HBGI on messaging around lived experience and (3) Representing HBGI at conferences or advocacy events.** The workstream members then proceeded to work together to come up with a calendar of events to guide implementation of workstream activities. In Q2, the workstream was at the forefront of designing and implementing some social media campaigns. This included an Instagram engagement on ‘Read A Book Day’ which involved sharing of recommendations about global experiences of mental health challenges.

In October, the workstream hosted an Instagram live session on ‘Mental Health in Art and Research,’ where different guests were invited to share their thoughts and experiences. In November, some members of the workstream led a social media engagement which involved a chat on men’s mental health in recognition of ‘Movember.’

2.2 Evaluation

In the first half of 2021, workstream members focused on sharing experiences around monitoring and evaluation and defining the workstreams’ objectives. Since monitoring and evaluation is a relevant process across all workstreams, activities in 2021 were cutting across LEC. The workstream designed, analyzed and presented **two surveys** – one to assess the level of engagement of LEC members whose results were presented during the 3rd full LEC meeting in September 2021 (n = 18) and one survey to capture lessons learned and recommendations whose results were presented during the 4th full LEC meeting in January 2022 (n = 10)^d. Beyond that, the workstream initiated discussions internally and with the CEO which led to two key agreements. Firstly, the evaluation workstream leads the development of this brief **report on lessons learned and recommendations** which will be shared with the new CEO and Board prior to its first Board meeting in 2022. Secondly, the workstream will lead a process to develop criteria and a framework for a **report card** to assess if HBGI lives up to its promise to put people with lived experience at the centre of everything it does.

2.3 Governance

In Q1, workstream members agreed on a monthly meeting schedule (Zoom and call-in option) and scheduled routine preparatory meetings, inviting partnering workstream members for selected agenda items and meetings. Co-Coordinator created and organized a google drive folder for workstream agendas, minutes and communications and workstream members created a **LEC Terms of Reference**^e, a “living document” to articulate why the LEC exists, what it is, what it does, how it is structured, and how it interacts with the HBGI. It includes an **organizational chart** and the description of the **voting process for LEC leadership**. In Q3, the Terms of Reference were updated to include a **member health break notification process, a Co-Coordinator/member resignation process, an inactive member policy, a definition of the Co-Chair role as well as definition of a two-year term length for LEC members**. In Q2, the governance workstream created and initiated an Executive Committee and workstream Co-Coordinator nomination, voting and election process, and put an online voting tool and a motivational statement submission process in place. In Q4, formal appointment letters were sent to the newly elected Executive Committee and Workstream Co-Coordinator. The governance workstream partnered with the evaluation workstream to inform the design of the Q4 survey on lessons learned and recommendations for engagement.

2.4 Scientific strategy

The focus for the scientific strategy workstream is to work closely and in **alignment with the consulting group IG/MQ** to make sure their research meets HBGI strategic objectives. The leadership for the workstream changed in Q2, resulting in more time spent learning how the consultants planned to achieve HBGI's goals. During this time, some back and forth resulted in a shared understanding about the creation, flow, and implementation of the research needed, including the survey instrument, focus groups, and literature review. During the data collection phase, there was concern about IG/MQ’s ability to reach HBGI’s initial focus on people's developing brains from ages 10-29.

LEC members and HBGI members stepped up to address this need by providing more respondents whose inclusion would ensure broader representation from youth, particularly from low and middle income countries.

2.5 Skills sharing

The skills sharing workstream first met to define the frequency of meetings and the general direction of the workstream. It was decided that the workstream would focus on **LEC internal upskilling**, **creating events for the whole LEC**, and finding opportunities to **participate in external events**. On the internal upskilling side, we watched several lectures from leading academics from the UK discussing the importance of ensuring that mental health research becomes anti-racist. This led to a lively discussion amongst workstream members. On the creating events front, the workstream is in the planning stage of setting up a series of events which will take place in Q1 2022. With regards to external events, the workstream was able to take part in the Generation Mental Health (GenMH) conference where it delivered a workshop on storytelling for mental health advocacy.

3. Reflections and lessons learned from 2021

3.1 Engagement in HBGI processes

Beyond advancing the constitution of LEC itself, members contributed to a range of important HBGI processes in 2021 (see figure 1). One third of active LEC members contributed to the IG/MQ work on refining the scientific research agenda, starting with anxiety and depression. Between two and three members contributed to Board meetings, HBGI’s social media planning and content production as well as the White paper. The LEC participated in one HBGI staff recruitment process, namely for the position of Scientific Strategy Lead.

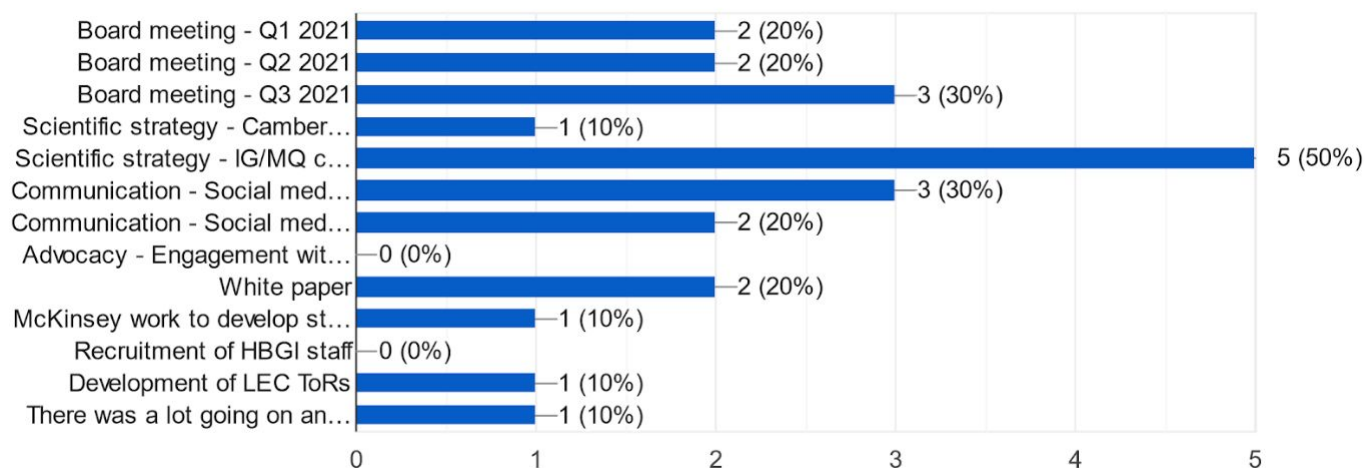


Figure 1: Overview of LEC member engagement in key HBGI processes in 2021.

When engaged in these processes, 80% of LEC members saw their feedback fully valued and 20% partly valued. Furthermore, most members mentioned that their feedback was fully (40%) or partly (30%) taken on board, whereas the remaining respondents lacked feedback from HBGI if their feedback was taken on board.

3.2 Enablers and barriers of engagement

The safe space created within LEC gives its members meaning and motivation. The opportunity to share opinions and perspectives freely, the sense of community created by members, the diversity of LEC membership, a shared strong belief in the councils' mission and the connection and support from peers were mentioned as enabling factors for active participation in the council. The clarity of LEC and workstream leadership was furthermore mentioned as a supportive factor for active participation. Several barriers to participation were identified that lie within how LEC organizes itself. One challenge is to find meeting times and modalities that favor everyone.

Unstable internet connection remains a barrier for several members. Not having access to key information about HBGI (e.g. clarity on what LEC is contributing to within HBGI, overview of planned HBGI activities) was mentioned as a barrier for successful participation.

4. Recommendations for 2022

4.1 To LEC

- **Cutting across workstreams:** Find alternative opportunities for participation such as members contributing offline; work towards better delineation of work responsibilities and duties of LEC members; consider developing a deliverables plan for each workstream with individual responsibilities and roles assigned; explore options for physical meetings and other enhanced ways of interaction; plan more fun and team building activities at the end of meetings.
- **Governance workstream:** Discuss the option to withdraw membership benefits (e.g. honorarium) for non-participation; lead the recruitment of new members; make sure that expectations for new LEC members are set from the outset.
- **Skills sharing workstream:** Contribute to the creation of an atmosphere of learning (e.g. invite each of the LEC members to present on a topic of their choice to the rest of the group).

4.2 To HBGI Interim Board of Directors

- LEC would appreciate receiving Board meeting agendas and summaries in writing.
- LEC would like to be more strongly involved with and represented at the HBGI Board. Approaches for integrated governance (e.g. 1 LEC member becoming a full Board member) should be discussed further between LEC Governance workstream and HBGI governance sub-committee.
- LEC hopes for continued participation of HBGI Board liaisons in LEC.

4.3 To HBGI CEO

- LEC would welcome the continued participation of the CEO in full LEC meetings to share updates on HBGI and provide opportunities for discussion. This will help LEC to feel more connected with HBGI overall.
- LEC would like to see the CEO be available for communication with sub-groups (e.g. individual workstreams, LEC Executive Committee) on a needs basis and exemplify an "open door policy".
- Additional guidance from the CEO on how LEC work feeds into HBGI overall strategy would be appreciated ("we need to be sure that what we are doing in workstreams matters to the organization").

4.4 To HBGI Management and its workstreams

- LEC would like to be engaged in networking opportunities and social events with HBGI Management.
- LEC would like to continue working with Mariel as liaison between HBGI management and LEC.
- LEC would appreciate receiving HBGI Management's workplan and objectives for 2022 to identify concrete opportunities for engagement and workload planning.
- LEC would welcome stronger involvement in key HBGI Management work, particularly the following processes: social media work, recruitment of HBGI staff and McKinsey work on HBGI Strategy development.

4.5 Potential areas for assessment in the Report Card

The Report Card that is currently being developed by LEC shall assess if HBGI lives up to its promise to put people with lived experiences at the center. It shall be a qualitative assessment prepared by LEC and presented in a table format, potentially including visuals, on a maximum of two-three pages. The audience of the Report Card is the HBGI CEO, with the Board being copied in its submission. It shall help the CEO to take decisions towards strengthening lived experience leadership within HBGI. The Report Card is aimed to be developed bi-annually in 2022 (e.g. June and December) and annually afterwards. Potential areas for assessment could be:

- Assessment of LEC workstream performance (output level);
- Lived experience in HBGI policy and strategy (e.g. Is LEC actively contributing to strategy development?; Do key policies and strategies reflect the centrality of lived experience?);
- Lived experience in HBGI governance (e.g. How is LEC represented at the HBGI Board?);
- Lived experience in HBGI processes (e.g. Is LEC involved in awards of large contracts and recruitment of senior staff?);
- Valuing lived experience (e.g. Is LEC feedback valued?; Is LEC feedback taken on board?).

^a HBGI defines lived experience as someone having personal experience with mental ill-health or neurological health issues themselves, or with people close to them

^b [Source](#)

^c [Source](#)

^d [Survey](#)

^e [Source](#)

Appendix 8

LEC Report Card 2022

Date: October 4, 2022

Aware that...

One of HBGI's central tenets is to fully embed the perspectives of people most affected by mental and neurological health in both our strategy and action.

To get started, in 2021 the LEC was formed bringing together people with lived experience across a wide variety of ages, locations, conditions, and ethnicities to help build HBGI from the bottom up.

We ask..

- How involved does LEC need to be in everyday decisions?
- Does HBGI value LEC feedback and is it taken on board?
- Does HBGI Board take steps to include lived experience in major policy decisions?
- How might we promote successful engagement between the HBGI and the LEC?
- Does HBGI lives up to its promise to put people with lived experience at the centre?

And so...

We developed the LEC Report Card to help us answer some of these questions!

LEC Report Card process

September 2021	October 2021	May 2022	June –July 2022	August 2022	September 2022
Brainstorming 'report card' (template and process)	Meeting with the HBGI CEO & Board Liaison to discuss the report card idea	Survey Design	Data collection	Data Analysis	Draft report card for comments from LEC

Areas assessed

- LEC membership;
- LEC workstream performance;
- Lived experience in HBGI's policy and strategy;
- Lived experience in HBGI governance;
- Lived experience in HBGI Human Resource processes;
- Valuing lived experience;
- Ideas to strengthen the overall LEC engagement in the HBGI's work.

LEC membership

January 2021	December 2021	September 2022
25 applicants were selected to form the inaugural LEC.	A total of 15 LEC members were active.	Only 12 LEC members, and only 10 are active.

LEC workstream performance

(% of Completed work plan activities)

- **67%** – Communication and advocacy;
- **56.7%** – Governance;
- **75%** – Evaluations;
- **50%** – Scientific strategy;
- **67%** – Skills building.

Lived experience in HBGI's policy and strategy

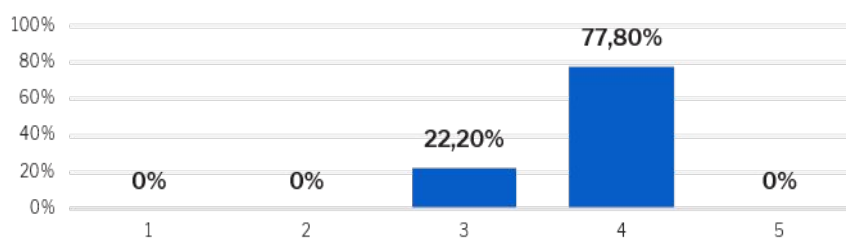
HBGI strategies and policies that LEC contributed to in 2021 and 2022

1. IG/MQ Report;
2. HBGI communication strategy;
3. Mind the Gap Report;
4. HBGI Operating Plan;
5. LEC Nominating Committee review of the application and interviewing process (Inaugural LEC);
6. LEC Terms of Reference (LEC internal).

The degree to which lived experience is reflected in key strategies and policies

[on a scale from 1 = not reflected, 5 = fully reflected]

If you contributed to key HBGI strategies and policies in 2021 and 2022, to which degree do they reflect lived experience.
(9 responses)



Recommendations to increase LEC engagement in HBGI strategy and policy development in the future:

1. The LEC would welcome stronger involvement in key HBGI Management work, particularly reviewing the progress on the implementation of the Operating Plan.
2. Increased collaboration between the LEC, HBGI management, and the Board, not operating as separate entities.
3. The LEC would appreciate receiving HBGI Management's work plan and objectives for each quarter to identify concrete opportunities for engagement and workload planning.

Lived experience in HBGI governance

So, how are things going?

Good governance:

- Transparent;
- Accountable;
- Follows Rule of Law;
- Responsive;
- Equitable and inclusive;
- Consensus oriented.

LEC has observer status only, with limited participation in selected HBGI Board sessions.

Recommendations to increase LEC representation on HBGI Board:

1. The LEC would appreciate receiving Board meeting agendas and summaries in writing.
2. The LEC would like to be more strongly involved with and represented at the HBGI Board. Approaches for integrated governance (e.g. one LEC member becoming a full Board member) should be discussed further between the LEC Governance workstream and HBGI governance subcommittee.
3. The LEC hopes for the continued participation of HBGI Board liaisons in LEC.
4. Establish clear board accountability for diversity.

Lived Experience in HBGI Human Resource processes

- **LEC engagement in contract award processes for services:** no contract award processes conducted.
- **LEC engagement in senior staff recruitment:** one senior staff recruited but without the LEC's participation.

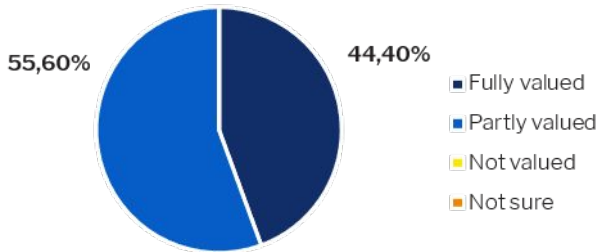
Recommendations to increase LEC engagement in CONTRACT AWARD and SENIOR STAFF RECRUITMENT processes in the future:

1. To have LEC representation in the contracts award and staff recruitment processes (should have at least one person with lived experience assist with contract awards and senior staff recruitment as a matter of best practice). Then, this should be accompanied by streamlining the role of the LEC in these processes.
2. Build the capacity of the LEC members to ably participate in the above processes through skills based training.
3. Any form of agreement with LEC members be related to a basic job description and agreed number of hours.
4. Be consistent and avoid any confusion, and to engage in a way that is clear.

Valuing Lived Experience

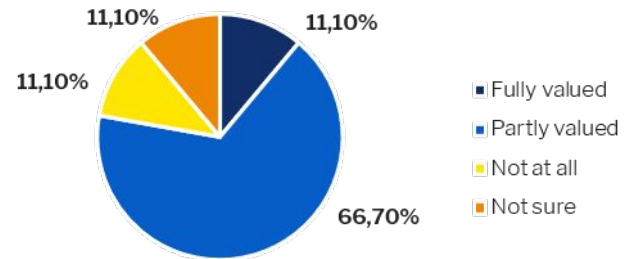
LEC feedback valued

When you were engaged in HBGI Management processes, to what degree did you feel your feedback was valued?



LEC feedback is taken on board

When you were engaged in HBGI Management processes, to what degree was your feedback taken on board?



Recommendations to ensure LEC feedback is valued and taken on board:

1. Streamline communication between the LEC, the Board, and the Management by receiving written feedback on issues raised by the LEC.
2. Allowing the LEC to have seats at Board meetings and feel more fully integrated with HBGI.

Ideas to strengthen the overall LEC engagement in the HBGI's work

To HBGI's Acting CEO:

1. The LEC would welcome the continued participation of the CEO in full LEC meetings to share updates on HBGI and provide opportunities for discussion.
2. The LEC would like to see the CEO be available for communication with sub groups (e.g. individual workstreams, LEC Executive Committee) on a needs basis and exemplify an "open door policy".
3. Additional guidance from the CEO on how the LEC work feeds into HBGI overall strategy would be appreciated.

To HBGI's Senior Advisor:

1. More collaboration between LEC and the HBGI senior advisor in key decision making processes to reflect lived experience perspectives.

HBGI Management and its workstreams:

1. Continue engaging the LEC in networking opportunities and social events with HBGI Management.
2. Integrate lived experience in HBGI Management work.
3. Mariel to continue working with the LEC as the liaison between HBGI Management and LEC.
4. Review LEC's work commitment and remuneration.
5. Ensure frequent communication with Management, and cross workstream learning.

The power of measuring results

- If you do not measure results, you cannot tell success from failure;
- If you cannot see success, you cannot reward it;
- If you cannot reward success, you are probably rewarding failure;
- If you cannot see success, you cannot learn from it.

Appendix 9

Reflections from the October 2022 Marrakech workshop

Theme	Operations
What went well?	<p>The LEC comprises a truly diverse group of people.</p> <p>LEC Members self-selecting the workstream they wished to be a part of.</p>
What didn't go so well?	<p>Unclarity of the role and function of the LEC at the start - until a workplan was developed.</p> <p>LEC and HBGI (Management) remain relatively siloed.</p>
What do we continue to do?	<p>More involvement (integration) between the LEC and Management. This will facilitate greater buy-in from the LEC members and possibly lead to less members attrition.</p> <p>More support from Management for the LEC e.g. professional development opportunities, and; opportunities to network, in order to capitalize on individual LEC members' willingness to network and develop professional/personal relationships which will benefit the work of HBGI.</p> <p>Improve cultural competence and expertise so that HBGI's programs can be implemented in a culturally sensitive manner.</p>
What do we stop doing entirely?	<p>Recruitment of new LEC members - not stop, but pause for a while. Recruitment is important, but the existing capacities of current members should be prioritized for development.</p> <p>Recruitment should also be paused until HBGI's new operating plan is fully clear and adopted.</p>
What do we need to change?	<p>Creating more opportunities for asynchronous work as getting the LEC members together at the same time is challenging given geographical spread.</p> <p>Less hierarchy and more reciprocity between the different entities of HBGI: Board, Management and the LEC</p>

Theme	Workstreams
What went well?	<p>Workstream as a structure for the LEC's working was preferred. However, workstreams need to remain flexible, re-evaluated regularly and able to pivot accordingly.</p> <p>The evaluation workstream clarified expectations and the governance workstream created the foundation for success moving forward.</p>
What didn't go so well?	<p>The advocacy workstream shouldn't be developing social media posts or graphics (this should be the role of Management, with the LEC advising on cultural competency, language etc).</p> <p>Workstreams meetings need to be structured with an agenda and better organized to make them more effective.</p> <p>Due to LEC member attrition, some workstreams have been more robust whilst others struggle to complete their workplan.</p>

What do we continue to do?	
What do we stop doing entirely?	Less social media posts by advocacy and communications workstream
What do we need to change?	When recruiting new LEC members, current workstream needs should be taken into consideration. Bring in formal exit interviews for departing LEC members to understand factors behind high attrition rate.

Theme	People and culture
What went well?	<p>Good representation and diversity within the LEC relative to other global mental health spaces.</p> <p>Opportunities to connect with people from around the world and sharing information and experiences from different cultures (LEC's diverse membership).</p> <p>Mutual support through uncertainty and creating a space where people could connect and build community beyond the work despite challenges of working remotely via video conference.</p>
What didn't go so well?	<p>Timezone differences was particularly hard to navigate – people could not engage at a time that was helpful to their wellbeing.</p> <p>Ability to retain the full number of original LEC members - moving from 25 to 12 active LEC members.</p> <p>Cultural clash - the LEC has developed its own and unique culture, which means at times, it could clash with some areas of HBGI's work, making engagement difficult. For example, working with external consultants who have been commissioned by the Management team. The culture of the consultancy firm was particularly different to the LEC's which led to misunderstandings and friction.</p>
What do we continue to do?	<p>Seize on the great ethnic and cultural diversity of the LEC to ensure it positively impacts on ensuring cultural sensitivities within the different work and decision making structure of overall HBGI work.</p> <p>Continue creating a communal space within the LEC which can work hard towards improving the organization as well as supporting one another.</p>
What do we stop doing entirely?	
What do we need to change?	<p>Review and edit the LEC Terms of Reference (ToR), reflecting well the diversity of the LEC.</p> <p>Create a 'playbook', which is different to the ToRs, of working effectively within and with a LEC, which can be shared with partners and other organizations wishing to work with people with lived experience.</p> <p>In-person connection - need to explore more opportunities for this.</p>

Theme

Governance and internal communication

What went well?

Regular, quarterly LEC meetings, which also ensured regular communication between the LEC members, who were otherwise remote.

Formal structure to the LEC, including written updates in between meetings. Ensured fluid and regular communication.

Despite geographical barriers, Covid 19, and different time zones, the LEC members managed to maintain communication and produce extensive amount of work.

Ownership - The LEC was decidedly involved in developing the ToR for the LEC and its own scope of work, aligned to wider HBGI's objectives and workplans.

What didn't go so well?

Onboarding - after the initial onboarding of LEC members, some members were unclear of their role and purpose. Possibly led to initial drop-outs?

Amongst some workstreams, internal communication and collaboration was limited. Possibly due to difficulties with working in different time zones.

The communication channels like Slack could have had more participation.

Consideration of using different platforms such as Whatsapp could have been made.

What do we continue to do?

Quarterly full LEC meetings should continue.

Leadership of the workstreams (co-ordinators) should continue.

LEC members should continue to put in the same level of commitment and energy that they have so far.

What do we stop doing entirely?

Refigure the communication process between Board, Management, and the LEC. It would be nice to have access to the same information across all entities of HBGI so that everyone feels as connected to the overall project and work of HBGI.

What do we need to change?

Have better communication that includes everyone involved in HBGI.

Leadership of HBGI needs to be stabilized (e.g. current Board is Interim, and current CEO is 'acting').

Bring in an exit process for members leaving.

Appendix 10

Dos and Don'ts for lived experience integration, by the LEC, Nov 2022

This appendix details the LEC members' advice on what to do and not to do for any organization that is looking to onboard lived experience as part of an advisory group or council or any other capacity similar to these. For simplicity, we refer to it in this appendix as a council. These recommendations are based on their work with different institutions including HBGI. Please be mindful that this is related to mental health lived experience.

DOS

1. Have clarity of purpose, vision and definition: be very clear on why you are seeking to integrate the lived experience voice. What purpose will it serve to your organization? What impact do you wish it to have? What does your organization mean by lived experience?
2. Collaborate: know what you want the LEC to achieve. Once the LEC is established, work with them to refine and agree on the desired impact and then develop and agree on what the clear, tangible and realistic deliverables are for the LEC,, aligned to the organizational vision and purpose.
3. Empower: linked to the above and below, empower your LEC to self-manage, whilst remaining aligned to the organization's overall vision, values and work. Support them in setting their own work schedule, pattern and goals. Support them to also have an independent voice, when required.
4. Integrate with thought: embed lived experience systematically within your organization, from the top down (starting at the highest level of leadership). Find ways to bring in the lived experience voice into your existing programs.

DON'TS

1. Waver from the vision/solutions by prioritizing a focus on problems when working with your LEC.
2. Deviate from clear and open communication that can strengthen collaboration.
3. Make plans for the LEC, or its members, without consulting them first.
4. Use the ideas and work generated by people with lived experience, whether by individual members or the LEC, whether in part or whole, without proper attribution to or permission from them.
5. Neglect partners and goals, and risk losing connection and collaboration.
6. Expect lived experience engagement without appropriate remuneration and support. And if engagement is required beyond what is the 'norm' as already established, communicate and request involvement with plenty of notice.

DOS

5. Establish fluid and two-way communication: between the LEC and the organization's management and Board. Create a culture where that communication can be open, honest and transparent. Linked to this, be willing to be challenged and probed knowing that this is part of the LEC's role.
6. Review and grow: be willing to pivot when necessary, particularly if the LEC is part of a startup. Regularly review the purpose and goals of the LEC. Do this jointly, and agree and change, if needed. LEC is unlikely to stay stagnant and will evolve and grow as the organization does.
7. Remain flexible: linked to the above, review regularly and change and adapt if needed.
8. Seek out diversity: ensure that your LEC is representative, particularly of the demographic you serve. Representation should avoid tokenism. Cast the net wide, looking beyond the usual places to ensure you recruit a diverse council.
9. See the assets: recognize the people with lived experience as experts. But also see the whole person and everything else they offer. Tap into their technical skills, knowledge and network, whether it is from their lived experience or elsewhere, such as paid employment.
10. Focus on progress, including the process of making progress.
11. Have a lived experience nominations committee.
12. Remunerate appropriately: your LEC members are unlikely to be employees. However, volunteering comes at a cost for the members; resources and time. Recognize and compensate accordingly, including for LEC related costs such as travel and data usage. If you have an honorarium system, or for expenses incurred, pay on time.

DON'TS

7. Assume that everyone is comfortable with corporate language and structures (e.g. long emails and lengthy reports, when some prefer verbal updates and talking through report contents).
8. Assume a one-size-fits-all approach when working with your LEC. Different members will learn, respond and work differently. Tailor your approach and communication, as required.
9. Assume understanding of the needs of the LEC and the members. Speak with them first!
10. Exclude LEC from decision making, whether at a Board or operational level unnecessarily, notwithstanding the need to recognize that at times, staff will need to make operational decisions, or immediate decisions that do not always warrant consultation with the LEC or Board.
11. Assume people with lived experience are unable to contribute to the organization professionally beyond their lived experience (see the Dos section for more detail!).

Appendix 11

The LEC's initial six-months workplan, developed during the in-person workshop, October 2022

Please note that the workplan, as a living document, may have been updated following the workshop.

Workstream	Activity	Timeline	
Communications	Updating LEC members' biography on HBGI's website	1 month	
	Developing communications structure between Management, the LEC and Board	1 month	
	Process established for managing and approving internal/external requests from the LEC	1 month	
	Developing and maintaining an events calendar (for LEC and Management)	1 month	
	Writing an OpEd (identifying theme, publications, drafting content etc)	3 month	
	Developing principle communications pack materials	3 month	
	Supporting with the communications plans and activities for the Calls for Expression of Interest response report	6 month	
	Connecting HBGI to the right mental health networks	Ongoing	
	Capturing the LEC members' own stories to share with wider audience (voluntary for lived experience members)	Ongoing	
	<i>Other activities for longer-term priority</i>		
	Newsletters (regular channel for updates for fundraisers)		
	More intentional lessons and learnings from others		
	Evaluation	Reviewing and reflecting on the in-person LEC meeting	1 month
LEC review of the Theory of Change		3 month	
Ensuring mental wellbeing learning activities for the LEC members to help avoid burnout		3 month	
Engagement Survey within the LEC		6 month	
More intentional with lessons and learnings from others (learning from work/other stakeholders out there)		6 month	
Engagement with HBGI's Risk and Assurance lead and Regional Director (when outcomes fund is established and people are in post)		6 month	

Workstream	Activity	Timeline
Governance	Meet with every LEC member interested in governance to debrief and discuss work and transition process	Immediate
	Detailed review of HBGI's new Operating Plan	1 month
	Establish governance for transition phase	1 month
	Update the LEC's Terms of Reference	3-6 month
	Develop the LEC's 'playbook'	6 month
	Review the LEC's skills and capacity building needs/gaps and what is required (building on work already done to map this)	6 month
	Review and finalize LEC members' reward/recognition and compensation for involvement with HBGI	6 month
	Interview and HR training for LEC members	6 month

References

- ¹ Global Burden of Disease, Institute for Health Metrics and Evaluation, 2019.
- ² McKinsey Health Institute, Prioritizing brain health: Scaling what works to add years to life and life to years, 2022. [URL](#).
- ³ Policy Brief: COVID-19 and the Need for Action on Mental Health, United Nations, 2020. [URL](#).
- ⁴ Mental health conditions have been linked to these challenges, whether as a cause or consequence, in a number of studies. References are included in Appendix O.
- ^{5 6} Mental Health Atlas Chisholm et al, 2016. Scaling up treatment of depression and anxiety: a global return on investment analysis. [URL](#).
2017, World Health Organization, 2018. [URL](#).
- ⁷ Mathers and Loncar, 2006. Projections of global mortality and burden of disease from 2002 to 2030. [URL](#).
- ⁸ Chandler and Munday, 2020. A Dictionary of Media and Communication, Oxford University Press. [URL](#).
- ⁹ Sandu, 2017. The value of lived experience in social change: The need for leadership and organisational development in the social sector. [URL](#).
- ¹⁰ National Survivor User Network & National Involvement Partnership. (2015, March). Involvement for influence. [URL](#).
- ¹¹ Perry et al, 2012. A systematic review of the evidence on service user involvement in interpersonal skills training of mental health students. [URL](#).
- ¹² Crawford et al, 2002. Systematic review of involving patients in the planning and development of health care. [URL](#).
- ¹³ Australian policy mandates participation of lived experience since early 1990s as essential to recovery-oriented service delivery. Source: Byrne et al, 2016. The stigma of identifying as having a lived experience runs before me: challenges for lived experience roles. [URL](#).
- ¹⁴ NHS states “involving patients leads to “more responsive services and better outcomes of care.” Source: NHS Executive, Leeds Department of Health, 1999. Patient and public involvement in the new NHS.
- ¹⁵ Johnson et al, 2008. Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System. [URL](#).
- ¹⁶ Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., & Chant, A. (2019). Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expectations*, 22(4), 785–801.
- ¹⁷ Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs (Project Hope)*, 32(2), 223–231.
- ¹⁸ Repper and Carter, 2011. A review of the literature on peer support in mental health services. [URL](#).
- ¹⁹ Trachtenberg et al, 2013. Peer support in mental health care: is it good value for money? [URL](#).
- ²⁰ LifeSpan Integrated Suicide Prevention and Black Dog Institute, 2020. LifeSpan Lived Experience Framework. [URL](#).
- ²¹ Please see the McKinsey brain health dashboard for more information. Coe et al, McKinsey Health Institute, 2022. Prioritizing brain health: Scaling what works to add years to life and life to years. [URL](#).