African Population and Health Research Center

Mental Health Data Prize - Africa

POLICY BRIEF

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FROM PARTICIPATION TO POWER

Embedding lived experience, mental health data capacity and emerging lessons from the Mental Health Data Prize - Africa

PRIMARY AUDIENCE *Lived experience experts and networks, Ministries of health, government officials, policy experts, African Union health bodies, universities and researchers, research funders, ethics committees, Regional and National mental health programmes, and implementation partners*

Executive Summary

The Mental Health Data Prize - Africa (MHDP-A) shows that mental health data innovation is strongest when it is built with people with lived experience of mental health. It should not merely be about them. The Prize championed ten multidisciplinary teams tasked with delivery of data-driven solutions for anxiety, depression and psychosis in African contexts. The awardees implementation processes integrated mental health data science, ethics, open science and responsible innovation framework rooted deeply with lived experience engagement. By fostering a secure and inclusive environment, the post-award workshop successfully bridged perspectives across data science, clinical expertise, and lived experience to collaboratively address critical data gaps, measurement barriers, and research-to-practice translation. To address systemic gaps identified in a recent MHDP literature review, future initiatives must standardize lived-experience engagement in African mental health research, specifically by resolving power imbalances, guaranteeing fair compensation, and instituting trauma-informed partnership practices.[1]

This brief emphasizes that the research ecosystem, including funders and institutions must shift from project-by-project inclusion to a structured model that embeds lived experience expertise across the research lifecycle. To ensure impactful, ethical, and equitable research outcomes, future initiatives must prioritize three core pillars:

1. **Research readiness must be reciprocal:** we must empower lived-experience participants to engage, and train researchers to collaborate
2. **Sensitive mental health data requires co-creation:** data scientists and lived-experience experts must integrate to design ethical protocols
3. **Collaboration requires trust, shared decision-making, and mutual respect.** The prize's learning ecosystem successfully accelerated team concepts into policy-ready, implemented solutions.

Core Policy Message

Lived experience should be recognized as a distinct form of expertise that drives the relevance, quality, ethics, interpretation of meaningful research and shapes program and policy value of mental health data

Key Messages

- **Capacity building must be two-sided:** people with lived experience need support to participate confidently in research, while technical teams need support to work respectfully, safely and productively with experienced experts.

1 https://wellcomeopenresearch.org/articles/10-667

- **Mental health data is sensitive:** data science, artificial intelligence and dashboards must be designed with ethics, safeguarding, consent and stigma reduction from the outset. Lived experience expertise should be meaningfully engaged in co-creating these aspects.
- **Equitable partnerships and respectful collaboration:** People with lived experience need to be treated as equal partners in research, actively engaged from the start of the study with clearly defined roles. Their contribution is meaningful and should not be taken as the occasional addition.
- **The MHDP-A prize model created a learning ecosystem:** webinars, workshops, virtual and localised technical sessions, peer learning, project presentations and mentorship helped teams transition from ideas to more responsible and policy-relevant solutions and implementation sites.
- **The next policy step is institutionalization:** lived experience engagement should be budgeted for, managed with clear guidelines, evaluated and embedded in mental health research systems. It should not be left to individual goodwill or end with the research project that was supporting it.

111	10	5 Days	3 Months
Applications received during the call	Teams selected for implementation	Post-award workshop in Kampala	Open science and data upscaling support

1. What Policy Problem Does this Brief Address?

Mental health research and service planning in Africa are constrained by weak data systems, limited resources, stigma, low translation of evidence into practice and insufficient inclusion of people who live with mental health conditions. While depression and anxiety cause the highest global health burdens, ranking second and eighth in years lived with disability, psychosis is exceptionally debilitating. Policy planning is critical yet currently stalled by delayed care, stigma, fragmented records, and weak community support. A rapid review of literature, done under the Mental Health Data Prize Africa (MHDP-A) notes that although mental health research is growing, people with lived experience are rarely engaged as partners. This is despite their first-hand insights into priorities, harms, service barriers and realistic pathways for change.

The problem is therefore not simply a lack of data. It is also a question of whose knowledge counts, who interprets the data, who defines the problem, and whether data-driven tools are safe, meaningful and usable in real mental health systems. Without lived experience leadership, mental health data can become technically sophisticated but socially disconnected.

Definition in Practice

For this brief, **lived experience expertise** refers to the knowledge, insights and perspectives that come from first-hand experience of mental health challenges. This includes but is not limited to formal diagnosis or formal service use. Lived experience expertise can strengthen research questions, tool design, data interpretation, ethics, communication and policy uptake. Lived experience experts are also referred to as people with lived experience.

2. What did MHDP-A do differently?

The Mental Health Data Prize - Africa was designed as more than a competitive award. It created a cohort-based learning process around mental health research, data science, lived experience, ethics, open science and responsible innovation. The ten selected teams brought together researchers, data scientists, programmers, policy actors and people with lived experience. The implementation phase combined technical support, surveys, stakeholder meetings, project presentations and documentation of learning. The initiative also featured upskilling sessions to advance data solutions, open science practice and lived experience integration.

MHDP-A Component	What it Enabled	Why it Matters for Policy
Foundational Learning	Webinars, workshops and shared platforms built a common understanding of mental health data, ethics, lived experience and open science.	Created a base for responsible innovation before teams moved deeper into solution development.
Post-Award Workshop	A five-day convening in Kampala combined keynote inputs, technical talks, project presentations, shared resources, cross-team collaboration and reflection.	Allowed teams to stress-test ideas, receive feedback and build trust across disciplines.
Lived Experience Integration	People with lived experience were integral to team structures and discussions on stigma, storytelling, design, interpretation and dissemination.	Shifted lived experience from beneficiary status towards knowledge, leadership and accountability.

MHDP-A Component	What it Enabled	Why it Matters for Policy
Mental Health Data Science	Teams explored artificial intelligence, machine learning, measurement, causal insight, dashboards, clinical interfaces and digitization of mental health data.	Connected data science to real service, policy and implementation problems.
Open Science Upscaling	Teams received support on approaches to make tools available for wider use and public access via platforms like OSF, GitHub, Zenodo, data description, licensing, metadata, reproducible workflows and dissemination.	Prepared tools and documentation for reuse, adaptation and public-good value.

3. The most critical emerging lessons for meaningful lived experience integration and capacity building center on the following pillars

1. Engagement must begin before tools are built

People with lived experience (PLE) should help shape the problem definition, data priorities, consent processes, indicators, language and dissemination routes. This engagement should be maintained across the research cycle as a strong partnership. Power imbalances and stigma should be avoided, with clear roles, plus leadership opportunities for PLE. Inviting lived experience contributors only after a dashboard, model or database has been built risks tokenism and weakens trust.

2. Capacity building is an ethical requirement

The rapid review emphasizes that both lived experience experts and research teams require capacity building on roles, expectations, research processes and safe collaboration. The MHDP-A reinforced this through technical sessions, peer learning and mentorship.

3. Lived experience improves the interpretation of data

Dashboards, predictive models and digitized clinical data can show patterns, but they cannot automatically explain meaning. People with lived experience can help interpret why people delay care, why service data may under count need, and how stigma shapes reporting and participation.

4. Safe spaces matter

The in-person workshop was intentionally designed to go beyond formal presentations and create a supportive environment for cross-sector learning and well-being checks. This is critical, where discussion of mental health including psychosis may involve stigma, distress or emotional labour.

5. Storytelling can humanize data if it is consented and protected

Digital storytelling, podcasts, blogs, videos and community conversations can make mental health evidence accessible. However, storytelling must be grounded in informed consent, wellbeing support, control over personal narratives and clear boundaries around public exposure.

6. Research readiness requires role-sensitive training

The MHDP-A cohort included data scientists, researchers, programmers, policy experts and people with lived experience. Capacity building therefore needed to be flexible and inclusive, recognizing that teams had different levels of technical expertise, research experience, and familiarity with open science and lived experience approaches. Training should combine foundational materials, practical exercises, peer pairing, tailored mentorship, and clear non-technical pathways for meaningful participation. It should include foundational materials, practical exercises, peer pairing, tailored mentorship and clear non-technical pathways for participation.

7. Responsible innovation requires shared governance

Artificial intelligence and large language model tools for speech-to-text, clinical notes or narratives must be validated with people who understand the language, context, stigma and lived realities of mental health conditions. Lived experience should meaningfully inform model review, user testing and risk assessment, and ensure their perspectives genuinely drive decisions.

4. What the Ten Awardee Solutions Make Possible

The ten awardee teams in the MHDP-A have developed a diverse set of data-driven solutions. These include dashboards for planning and visualization, interfaces that support clinical care, tools that support causal insight across youth mental health and school domains, streamlining speech or narratives-to- structured data pipelines using natural language processing and large language model workflows, and building scalable platforms to digitize high volume clinical notes of psychosis patient information into structured databases. Instead of isolated pilots, these solutions are built as open scalable public-good building blocks.

Solution Family	Potential Lived Experience Contribution	PolicyValue
Dashboards and visualization tools	Validate whether indicators reflect real needs and avoid stigmatizing labels.	Make service gaps, patient pathways and inequities visible for planning.
Clinical-care interfaces	Co-design workflows that are acceptable to patients, clinicians and caregivers.	Improve documentation, referral, follow-up and continuity of care.
Causal insight tools	Help interpret school, family, community and service factors that shape mental health, including that of the youth.	Support better targeting of interventions and prevention strategies.
Natural language processing and large language model tools	Review language, meaning, context, consent and potential harms in automated transcription or classification.	Convert unstructured narratives into analyzable data while maintaining human oversight.
Digitized psychosis data platforms	Advise on safeguards, privacy, stigma and how data is communicated back to communities.	Create a foundation for research, monitoring, quality improvement and accountability.

5. Policy Recommendations

1. **Adopt a lived experience engagement standard for mental health data projects.** This should define roles across the research cycle, from design, to data collection, interpretation, governance, dissemination and evaluation.

2. **Budget for compensation, preparation and wellbeing support.** Funders and ethics committees should require clear lines for remuneration, transport, accessibility, psychosocial support, and contingency costs for lived experience experts.

3. **Create safeguarding and consent protocols for lived experience work.** Protocols should address role clarity, emotional labour, confidentiality, public storytelling, withdrawal, escalation pathways and safe participation.

4. **Embed lived experience in data governance and artificial intelligence validation.** People with lived experience should inform how sensitive data is captured, labelled, anonymized, interpreted, visualized and shared.

5. **Invest in practical capacity building for all roles.** Training should cover mental health research basics, data ethics, open science (GitHub/OSF/Zenodo), research translation, communication and rights-based engagement.

6. **Establish a Monitoring and evaluation framework for lived experience engagement.** Indicators should track measurable influence on research questions, design decisions, data interpretation, dissemination, policy uptake and participant wellbeing.

Policy Options

Option	What it Means	Policy Implication
Option 1: Basic inclusion	Require each project to include at least one person with lived mental health experience.	This is better than exclusion, but risks tokenism if roles, power, compensation and safeguards are undefined.
Option 2: Structured engagement	Use a common lived experience framework with role descriptions, budgets, safeguarding, training and evaluation.	Most feasible short-term option. It creates consistency across teams and reduces ethical risk.
Option 3: Institutionalized leadership	Establish lived experience advisory panels, ethics review expectations, fellowship pathways and national guidance.	Most transformative option. It embeds lived experience into the mental health research and policy ecosystem.

Conclusion

The Mental Health Data Prize - Africa demonstrates that mental health data innovation must be both technically strong and socially grounded. The strongest value of the Prize is not only that it selected ten promising teams, but that it created a space where data science, ethics, lived experience, open science and policy translation could be co-developed. The next phase should consolidate this learning by institutionalizing lived experience leadership across mental health research and data systems. Integrating Lived experience into these processes is an absolute requirement for all mental health conditions, not an optional addition. It is central to generating evidence that is ethical, credible, usable and responsive to the people most affected.