



**GLOBAL
MENTAL
HEALTH**
PEER NETWORK

*Unapologetically,
Experts By Experience*



2024

Project

**From Recognition to Realization:
An evidence-based model for equitable
compensation of Lived Experience expertise
in Global Mental Health**

Supported by:

kokoro

and

Vitol Foundation

GMHPN Background

GMHPN began with a clear and compelling vision: to empower individuals with lived experience of mental health conditions worldwide. This vision was anchored by a mission to develop leadership among people with lived experience and to advocate for their integration in discussion and decision-making process, and to be colleagues in service delivery. A strong, unifying vision is fundamental in galvanising support and action in the mental health landscape.

GMHPN

Our Vision

Empowering persons with lived experience through leadership development, peer-to-peer mentorship and support.



Our Mission

01

Embedding the expertise of persons with lived experience in the development and reform of mental health policies, research, community-based care and global mental health initiatives

02

Collaborating with stakeholders to continue revolutionising the world of mental health to better reflect the needs of mental health care service users and their extended communities

03

Leading and co-leading mental health initiatives and collectively advocating calls for action in a meaningful and authentic manner

Our Reach

Member Representation



49 Countries

68% Low-Middle Income Countries

160 Experts By Experience

50% Young People

64% Women

Across 4 Quarters of the World

Americas

Anguilla; Antigua and Barbuda; Argentina; Aruba; The Bahamas; Barbados; Belize; Bermuda; Bolivia; Bonaire; **Brazil**; British Virgin Islands; **Canada**; Cayman Islands; **Chile**; Colombia; Costa Rica; Cuba; Curacao; Dominica; Dominican Republic; Ecuador; El Salvador; Falkland; Islands; French Guiana; Greenland; Grenada; Guadeloupe; Guatemala; Guyana; **Haiti**; Honduras; Jamaica; Martinique; Mexico; Montserrat; Nicaragua; Panama; Paraguay; **Peru**; Puerto Rico; Saba; Saint Barthelemy; Saint Kitts and Nevis; Saint Lucia; Saint Martin; Saint Vincent and the Grenadines; Sint Eustatius; Sint Maarten; South Georgia and South Sandwich Islands; Suriname; **Trinidad and Tobago**; Turks and Caicos Islands; **United States of America**; U.S Virgin Islands; Uruguay; Venezuela

Northern Africa

Algeria; Benin; Burkina Faso; Burundi; Cabo Verde; **Cameroon**; Central African Republic; Chad; Comoros; Congo, DRC; Congo, Republic of Cote d'Ivoire; Djibouti; **Egypt**; Equatorial Guinea; Eritrea; **Ethiopia**; Gabon; Gambia; **Ghana**; Guinea; Guinea-Bissau; **Kenya**; Liberia; Libya; Mali; Mauritania; Mauritius; Morocco; Niger; **Nigeria**; **Rwanda**; Sao Tome and Principe; Senegal; Sierra Leone; Somalia; **Sudan**; **Tanzania**; Togo; Tunisia; **Uganda**

Southern Africa

Angola; **Botswana**; Eswatini; Lesotho; Madagascar; **Malawi**; Mozambique; **Namibia**; Seychelles; **South Africa**; **Zambia**; **Zimbabwe**

Europe

Albania; Andorra; Armenia; **Austria**; Azerbaijan; Belarus; **Belgium**; Bosnia and Herzegovina; Bulgaria; Croatia; Cyprus; **Czech Republic**; **Denmark**; Estonia; Finland; **France**; Georgia; **Germany**; Greece; Hungary; Iceland; **Ireland**; **Israel**; Italy; Kazakhstan; Latvia; Liechtenstein; **Lithuania**; Luxembourg; Malta; Moldova; Monaco; Montenegro; **Netherlands**; Macedonia; Norway; **Poland**; **Portugal**; Romania; Russia; San Marino; Serbia; Slovakia; Slovenia; **Spain**; Sweden; Switzerland; Turkey; **Ukraine**; **United Kingdom**; Vatican City

Asia & Oceania

Australia; Afghanistan; Armenia; Azerbaijan; Bahrain; **Bangladesh**; Bhutan; Brunei; Cambodia; **China**; **Hong Kong**; East Timor; Fiji; Kiribati; **India**; **Indonesia**; Iran; Iraq; Japan; Jordan; Kuwait; Kyrgyzstan; Laos; Lebanon; **Malaysia**; Maldives; Micronesia; Mongolia; Myanmar; **New Zealand**; Nauru; Nepal; North Korea; Oman; Pakistan; Palau; Palestine; **Papua New Guinea**; Philippines; Qatar; Samoa; Saudi Arabia; **Singapore**; Solomon Islands; South Korea; Sri Lanka; Syria; Tajikistan; Thailand; Tonga; Turkmenistan; Tuvalu; United Arab Emirates; Uzbekistan; Vanuatu; Vietnam; Yemen



From Recognition to Realization:

An evidence-based model for equitable compensation of Lived Experience expertise in Global Mental Health

Contributors & Team:

Project Leads:

- Charlene Sunkel (Founder/CEO: GMHPN - South Africa)
- Sumaiyah Docrat (Health Economist - Ethiopia)

GMHPN Support Staff:

- Claudia Sartor (Deputy CEO: GMHPN - South Africa)
- Sandra Ferreira (Global Manager: GMHPN South Africa)
- Edwin Mutura (Communications & Services Officer - Kenya)
- Zak Martah (Project Assistant: GMHPN - South Africa)

International Lived Experience Advisory Committee:

- Kriti Vashisht (GMHPN US/ India)
- Mujtaba Hussain (GMHPN India)
- Fahmida Akter (GMHPN Bangladesh)
- Anto Sugianto (GMHPN Indonesia)
- Julieann Cullen (GMHPN Ireland)
- Hilda Chinoko (SUCCEED Malawi)
- Mayowa Olusamni (SUCCEED Nigeria)

Supported by:

- Kokoro
- Vitol Foundation



From Recognition to Realization:

An evidence-based model for equitable compensation of Lived Experience expertise in Global Mental Health

Collaborating with Health Economics experts, the Global Mental Health Peer Network (GMHPN) is leading an initiative to accelerate progress in the equitable compensation of lived experience expertise in global mental health, with funding support generously provided by Kokoro and Vitol Foundation.

To achieve this objective, an inclusive, mixed-methods approach is being employed to develop a fair, appropriate, and evidence-based model to guide global remuneration practices for lived experience expertise across various stakeholders and sectors involved in mental health. This model aims to consider the diversity of contexts, complexities, and expertise required for the authentic engagement of experts by experience in mental health advocacy, policy, planning, legislation, practice, and research.

Context

Today, the value of lived experience expertise in driving policy, practice and procedural change in global mental health is accepted without contention. Grounded by a well-established evidence-base, international human rights instruments, global frameworks and commitments in health and development underscore the imperative and value of meaningful and authentic involvement and participation of people with lived experience of mental health conditions and psychosocial disabilities in the design, implementation, and evaluation of health interventions and programs, research and health systems design and in decision-making and policy (refer to page 6).

Further, this position has resonated across multilateral and bilateral agencies, research bodies and funding agencies, academic institutions, the private-sector and philanthropy. This recognition and the growing inclusion of lived experience expertise in mental health advocacy, policy, planning, legislation, practice and research has encouraged the momentum for fair and transparent compensation, recognizing the time and expertise that people living with mental health conditions and psychosocial disabilities offer across the domains of global health and development, and as an instrument for reducing the range of financial barriers to participation that induce the disproportionate exclusion of those that are economically marginalized and reinforce inequality. Providing compensation, not only ensures active, equitable, meaningful and authentic peer engagement but further shows that individuals' contributions and expertise are valued and acknowledged.



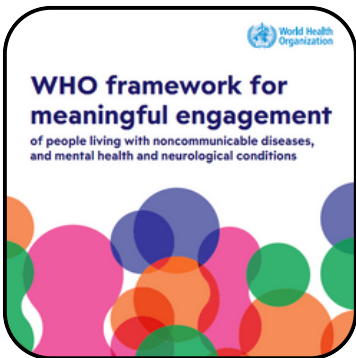
UN Convention on the Rights of Persons with Disabilities

“recognizing the **valued existing and potential contributions** made by persons with disabilities **to the overall well-being and diversity of their communities**, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of **full participation** by persons with disabilities will result in their **enhanced sense of belonging and in significant advances** in the human, social and economic development of society and the eradication of poverty”.



United Nations Sustainable Development Goals (SDGs):

The SDGs, particularly Goal 3 (Good Health and Well-being), emphasize the need for inclusive mental health policies and services **that consider the perspectives and experiences of people with mental health conditions**.



WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions - Meaningful **engagement of individuals with lived experience**, including their caregivers, families and communities, can also **catalyse political action** and **commitments for the prevention and control of NCDs** and the **promotion, protection and care of mental health**.



WHO World Mental Health Report: Transforming mental health for all

“People with lived experience **are crucial stakeholders** in mental health. Their participation is **vital to improve mental health systems, services and outcomes**. Such participation includes **full empowerment and involvement** in mental health advocacy, policy, planning, legislation, programme design, service provision, monitoring, research and evaluation”.

Problem:

Global acknowledgement for the experiential value of people with lived experience has been established, however the problem remains to translate this experiential value into fair and transparent compensation that is commensurate with the level of effort, goals, objectives and cultural, economic, and legal contexts of involvement and participation.



Although recent years have witnessed the emergence of various repositories of best practices, principles and paid participation policies across numerous sectors, little consensus on appropriate models of compensation have been reached or investigated globally, particularly in relation to fair compensation for the involvement and participation of people with lived experience living in Low and Middle Income Country contexts.

In these settings, it is of critical importance to pursue equitable remuneration for lived experience inputs. This is in light of the capacity for remuneration to encourage greater participation and engagement of lived experience stakeholders, leading to more inclusive and representative policy, research, and development initiatives; whilst addressing inequalities in settings where mental health is a low priority, and those with lived experience face additional barriers to accessing support and opportunities. Providing remuneration can also help to address these inequalities and; ensuring that lived experience stakeholders are able to sustain their involvement in mental health initiatives, allowing for ongoing contributions.

Numerous global stakeholders deserve due acknowledgement for their active commitment to recognizing the specialized knowledge of experts by experience, and compensating their contributions despite the challenges imposed by policies and procedures that are yet to comprehensively recognize and integrate this distinct form of expertise into formalized structures. Equally, if the experiential value is not met with adoption of equitable remuneration practices, the recognition of the core value of participation is arguably no value at all.

To the best of our knowledge, **no guidance exist that provides an evidence-based structure for the compensation and remuneration of the impact and value of lived experience expertise in mental health policy, research and practice.**

This means that **global stakeholders have little guidance as to how to incorporate the involvement of lived experience engagement and consultation that is fairly remunerated into their initiatives and projects.**

Formative Conceptualization of Our Approach:

During the formative conceptualisation of this initiative, the team established a priori assumptions that broadly characterised eight methodological phases, envisioned to take place between January and September 2024, to derive a fair, reasonable and standardized model to support equitable remuneration for lived experience expertise, reflecting the range of services and consultancy roles that are increasingly necessitated in global health and development.

Phase 1: Establishing the Value of Lived Experience in Mental Health Policy and Practice

To form a consensus based on evidence regarding the significance of lived experiences in enhancing mental health policy, practice, advocacy, and research.

Phase 2: Reviewing Best Practices for Remunerating Lived Experience Contributors

To analyze the existing literature and evidence base concerning best practices for compensating lived experience stakeholders in the sectors of global health, development, and policy.

Phase 3: Survey Instrument Design and Distribution

To design and disseminate a survey tool among GMHPN members worldwide.

Phase 4: Data Analysis and Preliminary Model Design

To analyse survey data and synthesize best practices to inform the design of a preliminary model for compensating lived experience stakeholders employing data triangulation, to inform model across stakeholder groups.

Phase 5: Formative Compensation Framework Development

To establish a compensation framework based on the formative model, considering the value of lived experience, consultation costs, and market rates.

Phase 6: Pilot Testing and Model Validation

To pilot test the costing model with a subset of GMHPN members, validate its efficiency, and gather feedback for enhancing cultural sensitivity, and identifying potential facilitators and barriers to model institutionalisation.

Phase 7: Model Revision and Integration of Feedback

To refine and adjust the compensation model by integrating feedback and learnings from the pilot to testing phase.

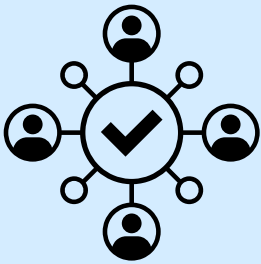
Phase 8: Model Implementation Narrative and Recommendations

Co-creation of an implementation narrative with strategic recommendations for ensuring its long-term sustainability and future efforts to maintain the model's applicability and effectiveness.

An Inclusive Mixed-Methods Approach:

Building on the formative conceptualisation of our approach, an inclusive, mixed-methods approach has been adopted in the development of a standardised model to inform fair, appropriate, and evidence-based remuneration practices for the involvement and participation of lived experience expertise, across a broad ecosystem of global stakeholders, in the area of mental health. The methodological approach reflects a dedication to enhancing global relevance and inclusivity.

In an effort to ensure methodological rigour and comprehensiveness, the model development process commenced by subjecting the *a priori methodological approach* to an iterative process of consultation and triangulation. The aim was to refine and achieve transparency across all constituent research phases and processes, adapting our initial methods, analytical techniques and research design to ensure the validity and reliability of development .



The expertise of **an International Lived Experience Advisory Committee, composed** of 7 GMHPN members and external experts by experience selected via nomination based on the relevance on their experience and to achieve an optimal balance in geographical representation, was established to guide the complete development approach. This platform facilitates the representation of a diverse range of content, opinions, and perspectives internationally.



A **content analysis of existing frameworks, guidelines, policies and best practices** relating to the remuneration and compensation for the involvement and participation of lived experience expertise, across a broad ecosystem of global stakeholders, in the areas of health and development, broadly, and, specifically focused on mental health was performed in order to characterise the principal themes and topics emerging from existing evidence globally. The structured evidence review also provided an overview of approaches and associated challenges articulated based on prior efforts to accelerate equitable compensation models of lived experience expertise and identify the main gaps for the purpose of the aims of the initiative.



The **development of initial survey instruments** were iteratively refined based on International Lived Experience Advisory Committee inputs, evidence review outcomes and priority inputs identified for model development, recognising the availability of secondary and experiential sources.

Framing the Focus of our Approach:

International human rights standards and directives, alongside global, regional and sector specific frameworks, commitments and guidelines are founded on the fundamental premise of *'equal pay for equal work'* - necessitating the remuneration for engagements with individuals with lived experience at levels equivalent to all specialist expertise.

In moving from **Recognition to Realisation**, the operationalisation of equitable compensation of lived experience expertise in Global Mental Health is constrained by:

- The lack of **transparency** in remuneration practices for specialist expertise across International Agencies, the Corporate Sector, Academia, Research, the Non-Profit Sector and Government, and standardisation of typologies of specialist expert levels of participation and expertise.
- The **authentic** representation and clarity in lived experience involvement and engagement, in relation to the scope of roles, levels of participation, nature of specialisation of expertise and taxonomies of experience, particularly in LMICs.



The model will establish a single framework that:

- Encapsulates an authentic representation of the roles, levels of participation, nature of expertise and a taxonomy of experience and skills in lived experience involvement and engagement;
- Achieves coherence with remuneration practices and typologies of technical expert engagement across the ecosystem of global health actors.

Surveys:

Two separate survey instruments have been designed:

1. For **global GMHPN members and fellow peer experts by experience** to obtain views and experiences related to their involvement in engagement and consultation.

This survey ask questions about roles performed that have specific requirement for lived experience expertise. For each role, the survey ask about the range of activities performed, the duration of involvement, the characteristics of the organisation that sourced and/or requested involvement. The survey also includes questions that ask the individual to indicate the country that they live, age, gender, education and/or other training, and occupation/ employment history in health and/or development.

Access the Survey here:

[Experts By Experience](#)

2. For **organisations and entities in mental health** to obtain perspectives on their practices of involving lived experience expertise.

This survey will ask about approaches considered and/or adopted by the organisation/entity in the compensation and remuneration of lived experience expertise, challenges/barriers that hinder full participation, and lessons learned from the process. Further questions ask to provide general attributes of the organisational/ entity (structure, governance, core areas of work, geographic reach and mission/ mandate) however, to enable organisations to be candid in their responses, all survey responses are anonymised.

Access the Survey here:

[Organisations/ Entities](#)

Launch Plans:

International Equal Pay Day, celebrated on 18 September, represents the longstanding efforts towards the achievement of equal pay for work of equal value. It further builds on the United Nations' commitment to human rights and against all forms of discrimination.

GMHPN plan to host a webinar on **International Equal Pay Day** to present **From Recognition to Realization: An evidence-based model for equitable compensation of Lived Experience expertise in Global Mental Health**

The launch will **call for action** to ensure that individuals with lived experience receive fair and equitable compensation for their expertise and contributions, and acknowledgement for the value of the unique insights of experts by experience. Through inclusion and recognition lies the power of empowerment that helps shape the future of global mental health.

This **International Equal Pay Day**, GMHPN calls on all stakeholders and sectors to commit to creating a more equitable and inclusive mental health landscape where people with lived experience are equally valued for their expertise as their fellow experts without lived experience.

Dissemination Plans:

The GMHPN is committed to ensuring widespread access to its developed costing model for lived experience expertise. Through a dedicated page on the GMHPN website, we aim to provide easy access to this valuable resource for stakeholders worldwide. Additionally, we plan to leverage various media channels to disseminate information about the model, including conference presentations and stakeholder meetings. By utilising multiple avenues for dissemination, we hope to encourage widespread adoption and implementation of the costing model, empowering organisations and entities across all major sectors in global mental health to accurately value and integrate lived experience expertise into their mental health initiatives.

Implementation Plans:

The GMHPN will apply the costing model to its Experts By Experience Consultancy Services provided to clients within the broad mental health and human rights landscape. Going forward, all GMHPN services will be costed based on the remuneration model.



**GLOBAL
MENTAL
HEALTH**
PEER NETWORK



Address

Lemoenkloof, Paarl 7646 Western Cape, South Africa



Email

Charlene.Sunkel@gmhpn.org



Website

www.gmhpn.org