

CONSULT Guidelines:

Lived Experience Engagement and
Consultation for Policymakers



**GLOBAL
MENTAL
HEALTH**
PEER NETWORK

The Global Mental Health Peer Network (GMHPN) is an international organisation that builds capacity among people with lived experience of a mental health condition through empowerment, mentorship and support. The organisation has an established Experts by Experience Consultancy Services unit that is unique in that it involves ONLY persons with lived experience in the delivery of services, and ensures diverse perspectives within different contexts. Our impact is across policy, services, development, implementation, and evaluation of mental health issues and services. We exist within an international framework of 6 world regions and 140 peer representatives.

[Our stance on the value of lived experience expertise](#)

International human rights instruments call for equality and recognition of the value of all people, including people with psychosocial disabilities/or mental health conditions, in advancing socio-economic and sustainable development.

International strategies and related documents emphasise the same by acknowledging the importance of placing people with lived experience of mental health conditions at the centre of policy and practice, thereby ensuring that people with lived experience and their representative organisations are **meaningfully and authentically included** in engagement and decision-making processes.

The UN Convention on the Rights of Persons with Disabilities (2006) notes the commitment to “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”.

WHO World Mental Health Report: Transforming Mental Health for All (2022) notes that “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”.

Evidence on the value of lived experience integration into research, policy, service development and delivery, stigma reduction, and training of healthcare professionals have been well documented. The benefits are evident on multiple levels.

[Perspectives: involving persons with lived experience of mental health conditions in service delivery, development and leadership \(Sunkel, Sartor 2022\)](#)

[A New Normal: Integrating Lived Experience Into Scientific Data Syntheses \(Beames et al 2021\)](#)

[Embedding lived experience into mental health academic research organizations: Critical reflections \(Hawke et al 2022\)](#)

[Promoting Lived Experience Perspective: Discussion paper prepared for the Queensland Mental Health Commission \(Byrne 2017\)](#)

In spite of the above advances and the growing inclusion of lived experience expertise into engagement and decision-making processes to guide positive change, there still remains limited recognition of its **monetary value**. This further undermines the lived experiences and expertise of people with mental health conditions and their representative organisations, and **jeopardises collaborative and inclusive approaches** to positive change.

GMHPN Recommendations

GMHPN hopes to see governments and policymakers adopting a collaborative approach to policy review/reform that recognises people with lived experience of mental health conditions as key partners.

GMHPN encourages governments and policymakers to review their stance on unpaid/underpaid work provided by individuals with lived experience and their representative organisations in policy review/reform. This would entail lived experience engagement and consultation included and budgeted for in planning public consultations, with expenses related to participation, for example, travel and accommodation costs.

The GMHPN developed its **CONSULT engagement and consultation guidelines** as a resource for governments and policymakers to help strengthen their partnerships with people with lived experience and their representative organisations. We appreciate governments and policymakers that are open to including our voices and therefore we would like to provide support and guidance on how best to work together and create the change we all envision.

C.O.N.S.U.L.T. engagement and consultation guidelines

Create an engaging, safe and supportive space for quality contributions.

- Some of us may experience certain difficulties related to our mental health condition or side-effects of medication, so we may need your flexibility in terms of considerations (reasonable accommodations) to allow us to meaningfully contribute.
- Reasonable accommodations are specific to each individual and therefore, to understand what adjustments or considerations are required, don't hesitate to ask us what these may be.
- Enable conditions such as reasonable engagement hours, frequent breaks, adequate rest, reduce stress, availability of emotional support and allow meaningful discussions to meet engagement goals that promotes wellness for all participants.

Obtain diverse representation of persons with lived experience to enhance equality and inclusion.

- Our lived experiences reflect a life course, a context that is specific to each of us, based on where we grew up, live, socialise, where and how we interact with our culture and the people around us, and how we identify as an individual.
- Lived experience inclusion should always ensure that our diverse voices are incorporated and that no one is left out of the constructs of policy and practice.

No to power imbalances, paternalistic approaches, tokenism, discrimination, and stigmatization.

- All engagement and consultation processes must align with basic human rights principles - Participation, Accountability, Non-discrimination, Equality, Empowerment and Authenticity.

Sustain a mutually respected partnership.

- Remain connected with lived experience organisations/movements and explore potential collaborations that are mutually beneficial.
- Ensure that opportunities to review/transform policy and practices are communicated in advance so that organisations/movements are able to consult with their members to provide collective feedback/inputs.
- We may not come from a legal background, so be cognisant of using legal terminology– but please do use this lingo, and define it , so we can become more empowered.

Uphold the principles of effective engagement and consultation.

- Include people with lived experience from the get-go and not as an afterthought.
- Ensure meaningful and authentic inclusion through empowerment, valued contributions, transparency and accountability.

- We intend to perform optimally – this means, we need governments and policymakers to create suitable conditions for engagement and consultation:
 - Be clear about the review process and expectations, our roles and responsibilities throughout the process,
 - Provide a pre-consultation orientation session to present an overview of the policy/legal document up for review, to ensure that participants are well-informed and clear about its content,
 - Provide reasonable deadlines and timeframes for the completion of the review,
 - Provide information, preparation documentation and engagement/consultation session dates at least a month in advance, if at all possible,
 - Provide feedback afterwards that indicates how lived experience contributions were incorporated, or provide rationale in instances where contributions were not accepted.

Leverage lived experience expertise through meaningful and authentic inclusion.

- Value our expertise and understand that our contributions derive from our lived experiences, and are complimented by our advocacy work in mental health – this is our role.
- Our adversities and struggles with mental health problems have positioned us to contribute towards influencing the future of mental health and at a larger scale, to help cultivate populations who can actively and productively impact positive socio-economic growth.
- People with lived experience have unique expertise, obtained throughout our own journeys of navigating mental health and other public systems in seeking best possible options that would lead to recovery. Through these experiences, we have obtained personal knowledge that is validated by shared knowledge, and this bring perspectives and solutions that are practical and cost-effective.
- There are thousands, if not millions, of people with lived experience who can and want to make a difference, they just need to be given the opportunity. Please do not limit engagement/consultation to one identified person continuously, it a disempowering approach that leads to inequality. When one person cannot be available, it does not mean that including other lived experience representatives is not possible.

Transform policy and practice that is an accurate reflection of lived experience voices.

- Authentic involvement specifically refers to non-tokenism, therefore involving people with lived experience for their expertise on an equal basis as other participants in their fields of expertise.
- Contributions made by persons with lived experience must be considered based on its merits and feasibility by which it should be incorporated into the development of policies and related documents, as it would be for any other professional or expert. Contributions should not be discarded merely because of its [non-clinical/ non-academic] source.
- Governments and policymakers should be transparent in regards to contributions that were accepted and rejected, by providing the rationale behind these decisions.

The overall elements within these guidelines are supported by international and local human rights instruments, country commitments to international strategic plans and guidelines related or relevant to mental health. Below are a few key references:

Universal Declaration of Human Rights (1948)

UN Convention on the Rights of Persons with Disabilities (2006)

WHO Comprehensive Mental Health Action Plan 2013-2030 (2013)

WHO World Mental Health Report: Transforming Mental Health for All (2022)