



Australian Government

Department of Health

Mental Health Lived Experience Peak Bodies – Consultation Summary

February 2024

DRAFT

Acknowledgements

This consultation summary is based entirely on feedback received from people with lived and/or living experiences of mental ill-health and/or suicide, who were consulted in relation to mental health lived experience peak bodies between 2022-23.

We would like to specifically acknowledge the following individuals or communities who contributed their time and expertise to this work and to the broader movement:

- All people in Australia with lived and/or living experiences of mental ill-health and/or suicide, and their communities
- First Nations Peoples and communities with lived and/or living experience of mental ill-health, social and emotional wellbeing, and intergenerational trauma
- All participants in the three consultation processes outlined in this summary, and all those who volunteered to contribute via the Expression of Interest process
- Long-term leaders of the lived experience movement who have developed and shared lived experience expertise
- Emerging leaders of the lived experience movement including younger, diverse and intersectional voices
- Project Advisors who provided their input to support the Department of Health and Aged Care's (the Department) consultation process
- All individual and organisational participants in previous consultation processes who have informed this work.

The feedback captured in this consultation summary builds upon and is informed by decades of work by people with lived and/or living experience, working with governments and health services to improve mental health outcomes. We acknowledge the challenges of sharing personal stories and the stories of loved ones, and deeply appreciate the impact it has had on improving how the national mental health system supports all Australians.

Overview

This consultation summary is an outline of the outcomes of three separate consultation processes aimed at considering the role/function and supporting the establishment of two national mental health lived experience peak bodies: one for consumers, and one for carers, family and kin.

The consultation processes include:

- Consultation undertaken by the NMHC – August-September 2022
- Workshops and Additional Voices conversations facilitated by TACSI – September-November 2023
- Public open submission process and online survey hosted by the Department – September-November 2023.

Outcomes of the three consultation processes have been translated into two separate Grant Opportunity Guidelines which potential supplier/s for the two peak bodies must apply against. This Consultation Summary aims to provide insight into the broad and diverse views shared through the consultation processes to support potential supplier/s in developing their application across the Grant Opportunity Guidelines' assessment criteria.

All three consultation processes were based on decades of tireless work from mental health consumer and family/carer/kin advocates. The establishment of the new peak bodies would not have been possible without the contributions and the momentum generated by early leaders who bravely shared their personal stories and views to initiate the Australian mental health lived experience movement.

Who was consulted?

NMHC Consultation

Two online surveys were run to seek feedback on:

- How to refine and build on previous work to represent the breadth and diversity of the needs and wants of people with lived experience and their communities
- The principles that should guide the scope and operation of the peak bodies
- Membership and leadership structures and sensitivities.

A two-day in-person summit was then held to discuss key operational features, such as membership, governance, how the peaks should interact with each other and other relevant organisations. Approximately **100** established and emerging lived experience leaders attended the summit.

Workshops and Additional Voices

Following the NMHC Consultation, the Government announced funding of \$7.5 million over three years to establish the two new peak bodies: one for consumers and the other for carers, family and kin. TACSI was subsequently engaged by the Department to facilitate a consultation process to support the establishment of the two peak bodies.

The process consisted of two workshops series (five workshops per peak body), followed by a range of Additional Voices conversations to test findings from the workshops. An Expression of Interest was run to identify interested participants, with over 300 individuals applying across both processes. A small group of individuals was selected to participate in the workshops who represented the breadth of the lived experience movement, with consideration given to individual expertise as well as group balance and composition.

In total, TACSI consulted with **42** people throughout the workshops and Additional Voices conversations. This included **15** consumers and **15** carers/family/kin who participated in the workshops; and **12** individuals who were part of the Additional Voices conversations.

Public Submissions

A discussion paper for each peak body was published on the Department's Consultation Hub, which is open to the public. Each discussion paper was accompanied by an online survey to allow individuals and organisations to submit feedback on the discussion paper. The questions in the survey were framed based on the NMHC process and feedback from key stakeholders. Email submissions were also accepted.

A total of **244** submissions were received. This included **148** submissions from consumers; **78** from carers/family/kin; and **18** via email that often spoke to both consumer and carer/family/kin elements.

Key Findings

The NMHC consultation informed:

- 12 recommendations regarding operational arrangements for membership and governance of both peaks
- a set of 7 foundational principles to guide the scope and operation of both peaks.

Following extensive analysis of the outcomes of this consultation, four key priorities for implementation guided the Workshops, Additional Voices conversations and discussion paper process. The identified priorities were:

1. Creating peak bodies that privilege the voices of those most affected and centralise mental health lived experience leadership
2. Valuing diversity and promoting inclusive approaches to membership and operations
3. Ensuring the peak bodies are sustainable, viable and responsive to evolving needs of diverse lived experience communities
4. Creating opportunities for the two peak bodies to work together, while recognising the distinct voices, needs and experiences of mental health consumers and of families, carers and kin.

The three processes provided insight into a number of key issues relating to the peak bodies. On other issues, there was either less exploration or a lack of consensus.

Overall, the findings had key consistent themes for the two peak bodies, with an emphasis on:

- needing to build on the work of lived experience voices that have come before
- ensuring a lived experience led approach
- embracing and promoting diversity and inclusion
- balancing innovation and viability, and
- working together with key stakeholders.

This summary highlights five key themes for consideration in the design of the two peak bodies. These principles were developed by the Department based on the themes that were consistently raised across the three consultation processes. These themes are designed to assist potential supplier/s in preparing responses to the Grant Opportunity Guidelines. They intended to be a guide only and potential supplier/s are encouraged to draw on their own in-depth knowledge, understanding and expertise in their responses.

This summary also identifies some additional findings that may require further consideration throughout the establishment process of the two peak bodies.

DRAFT

Themes

Theme 1: The peak bodies should be grounded in the broader movements and a human rights approach.

It was broadly acknowledged that there were strong foundations on which to establish the peak bodies, leveraging the work and wisdom of the existing lived experience movements for consumers and carers, families and kin. A human rights approach was consistently considered important to guide the work of both peak bodies. Embedding self-determination in the work of the consumer peak was also seen to be critical.

Table 1: Theme 1 summary

Theme 1: Summary of feedback	
Public Submissions	<u>Consumers</u>
	<ul style="list-style-type: none">• The need to adopt a human rights approach was raised in multiple responses, consistent with the existing consumer movement.• It was also emphasised that the peak body would need to work collaboratively with and align with the values of the broader consumer movement.• There was a general preference to focus on systemic advocacy (advocating on behalf of diverse lived experience voices to contribute to system-wide mental health policies, programs and reform processes), however the importance of ensuring components of individual advocacy was also called out.• It was also noted that the peak body needed to maintain its connections with the consumer/survivor movement, and seek to elevate, enrich and support the efforts of the movement.
	<u>Carers, families and kin</u>
	<ul style="list-style-type: none">• The view of some respondents was that there are already existing associations and the benefit of establishing a new peak body needs to be clearly articulated.• This indicates that there is a need to tap into and build upon the work of existing organisations.
Workshops and Additional Voices	<u>Consumers</u>
	<ul style="list-style-type: none">• Participants noted the peak body will need to maintain its connection to the consumer movement and where possible seek to enrich and support the efforts of the movement.• The peak body will be expected to uphold and protect the human rights of those it represents especially those at the greatest risk of human rights violations.• The peak body should include individuals who relate to mental health challenges but describe their experiences differently, and those who may not be aware of support options because the system is not reaching them.

Theme 1: Summary of feedback

Carers, families and kin

- Participants noted the peak body needs to be informed by the mental health carer, family and kin movement at large, and leverage previous work and momentum in this space.
- The lived experience of mental health carers, family, kin and supporters should be recognised as a specific and unique context of caring.
- The need to ensure the peak body is grounded in an evidence-based human rights approach, including transparency and ethical compliance, was also raised.
- It was also noted that the peak body would need to work with partners and other peak bodies to leverage external expertise.

NMHC Consultation

- Allowing individuals to self-determine which peak bodies represent them upholds the human rights principles of self-determination and inclusion.
 - Lived and living experience is rich, complex and diverse and individuals understand their experiences in different ways.
-

Theme 2: The peak bodies should be lived experience-led as much as possible, and incorporate lived experience across a range of roles.

All three processes overwhelmingly supported the need for the peak bodies to be lived experience-led as much as possible. This includes at Board and leadership level. Where specialised skills are required that available people with lived/living experience may not possess, it was considered appropriate to appoint individuals without lived/living experience to specific positions (for example financial management) in the short- to medium-term. However, the peak bodies should plan for how to support people with lived/living experience to develop these broader skillsets.

Table 2: Theme 2 summary

Theme 2: Summary of feedback	
Public Submissions	<u>Consumers</u> <ul style="list-style-type: none"> • Responses reinforced the importance of the peak body being lived/living experience-led, with general support for prioritising people with direct lived and/or living experiences of mental ill-health in any leadership, Board or paid positions. • In response to a question about whether the consumer peak body should be lived experience led, 72.97% responded 'completely meets my expectations'. • Responses emphasised the nuances in definitions of lived and/or living experience and 'consumer' voices, including to consider the distinction between 'lived' and 'living' experience. • The need to be flexible and balance lived/living experience expertise with desired skills in other areas was also raised, for example finance, risk management, governance.
	<u>Carers, families and kin</u> <ul style="list-style-type: none"> • The majority of respondents agreed that the peak body should be lived experience-led, representing family, carers, kin and supporters of those with lived/living experience of mental ill-health and/or suicide. • Attention was called to ensuring consideration of how different caring responsibilities can significantly impact the mental health of families, carers and kin.
Workshops and Additional Voices	<u>Consumers</u> <ul style="list-style-type: none"> • Participants emphasised that the peak body should be uncompromisingly lived experience-led, with a diversity of lived/living experience roles, such as membership, volunteering and paid roles.
	<u>Carers, families and kin</u> <ul style="list-style-type: none"> • Participants strongly advocated that lived/living experience of specific and profound mental health caring was a non-negotiable and should be a part of every role, including at the Board level.

Theme 2: Summary of feedback

- Lived/living experience was considered to include those who don't formally identify as carers and people who don't see the carers system as something to support them.
- The need for learnt lived/living experience expertise was raised, meaning the ability to see beyond an individual's personal experience and be able to represent experiences more broadly.

NMHC Consultation

- Priority should always be given to individuals with lived/living experience for all positions within the peak bodies.
 - There was strong agreement through the consultation process that all positions within the peaks, including Board positions, should be filled by people with relevant lived/living experience, except where requisite other skills aren't able to be covered. Where needed, there would be the option to 'buy-in' additional expertise as needed.
 - There was also strong support for developing the governance skills of Board members with lived experience through training, educational and mentoring opportunities, and for the Board to actively recruit, train, and mentor diverse and emerging leaders into Board positions to strengthen the leadership pipeline.
-

Theme 3: The peak bodies should demonstrate diversity and inclusion across leadership, membership, and operations.

Diversity and inclusion emerged as a strong and consistent theme. While it was clearly acknowledged that the peak bodies should represent a range of lived/living experience perspectives and ensure a safe and inclusive environment, participants also suggested this must be balanced with the need to function effectively and within the resources provided. Based on this feedback, the peak bodies will need to continue to evolve and actively seek to include and represent diverse and intersectional voices, including through partnerships with organisations that represent and support particular cohorts who may not be adequately represented.

Table 3: Theme 3 Summary

Theme 3: Summary of feedback	
Public Submissions	<u>Consumers</u> <ul style="list-style-type: none"> • Responses reiterated the importance of representing diverse voices and considering intersectionality, often noting specific cohorts. • A number of respondents suggested certain experiences or cohorts of people need to be specifically prioritised, such as to uplift those who have been most impacted by the mental health system. • It was considered that inclusivity should be evident across membership, staffing, volunteering, Board representations and delegations. • Some responses also noted the importance of tailoring communications and taking into consideration different communication styles and abilities, including offering materials in different languages and providing easy read resources. • Conversely, several respondents raised concerns around balancing the need to represent diverse perspectives while also ensuring the scope of the consumer peak body remains manageable and that it is best structured to deliver targeted, mental health-focused advocacy. • Other responses noted that, at the Board level, a model with representation from states and territories with current existing peak bodies would be appropriate to provide a collective voice that represents the regional diversity of consumers. • It was also noted that the peak body would need to recognise that diverse voices may at times be in conflict.
	<u>Carers, families and kin</u> <ul style="list-style-type: none"> • There was an emphasis on equity and inclusivity among the responses, particularly in recognising the unique needs of young carers with diverse backgrounds, including First Nations Peoples and communities, people from culturally and linguistically diverse backgrounds, and LGBTIQ+ communities.

Theme 3: Summary of feedback

- This was balanced by concerns about the need to avoid 'scope-creep' and ensure the focus was kept on the needs and wants of mental health carers, families and kin.
- Participants also raised the need to address overlaps in or dual identities for those that identify as both carer and consumer, with some noting that the current terms imply binary experiences.

Workshops and Additional Voices

Consumers

- Participants in workshops noted that the consumer peak needs to consider the diversity of needs and priorities of different groups, and represent all people with unique and varied lived and/or living experiences of mental health challenges and distress, including those experiencing suicidality.
- This includes ensuring people with intersectional identities and experiences are embraced, and that their presence and contributions are valued and evident in the work of the peak body.
- It was also clear that there should be a commitment to foregrounding Aboriginal and Torres Strait Islander ways of knowing and wisdom, with permission from and in partnership with First Nations Peoples and organisations.
- The need for dedicated Aboriginal and Torres Strait Islander roles was also raised.

Carers, families and kin

- Participants raised a specific need to ensure inclusion and representation of past and bereaved carers, young carers, older carers and other cohorts more likely to experience loneliness; those currently not supported or seen; and those with experiences of transitional and episodic care.
- This included understanding family and caring holistically to recognise the diversity of experiences, identities and realities.
- The peak body was seen to be a group of 'national voices' that come from multiple connections, and have a role in systematically advocating on behalf of its members to ensure that policies, services and programs are responsive to the diversity and intersectionality of identities and experience.
- The need for dedicated Aboriginal and Torres Strait Islander roles was also raised.

NMHC Consultation

- There was strong support for establishing identified Board positions to promote inclusion of a range of groups reflecting a diversity of experiences, identities and geographic regions.
- There was also strong support for an intersectional approach to recruitment of Board members to ensure a broad diversity of experiences, identities and cultures are represented.
- It was considered that embedding priority population group participation at all levels from the outset would be essential to ensuring effective representation of the diversity of lived/living experiences, and to ensure the organisation was set up in a way that was free from stigma and discrimination.

Theme 4: The peak bodies will need to balance innovation with financial sustainability and viability.

There was support for the peak bodies to embody innovative approaches, including co-leadership and non-hierarchical ways of working to ensure a safe and inclusive organisation. Conversely, there were concerns that the peak bodies needed to balance this with operating in a way that would succeed and meet the expected engagement methods of governments, key stakeholders and other peak bodies. There was a focus on how to ensure the sustainability of the peak bodies while maintaining equity and access for members. The peak bodies will need to consider how to address these issues in their proposed approach to governance and financial viability, including through identifying potential extra revenue streams.

Table 4: Theme 4 Summary

Theme 4: Summary of feedback	
Public Submissions	<p><u>Consumers</u></p> <ul style="list-style-type: none"> • Responses indicated that innovation was key to the work of the consumer peak body, and that there was a need for ongoing co-design and co-production. • Only 33.78% of respondents indicated 'completely meets my expectations' to a statement about considering different models of generating revenue to ensure financial viability. • There were concerns that paid membership would limit representation, particularly for those experiencing financial instability. • It was suggested that consideration could be given to paid membership only for organisational members and/or individuals over a certain income threshold, with the option of low or no-cost membership and other supports as needed. • There were also suggestions to consider accreditation with professional bodies, workplace education programs and sponsorship opportunities to generate revenue. <p><u>Carers, families, and kin</u></p> <ul style="list-style-type: none"> • Responses noted there were a range of different ways the peak body could challenge traditional organisational and membership structures. • A number of responses also noted that financial sustainability was critical to the peak body's success and that this should be prioritised, and additional means of revenue would need to be sourced.
Workshops and Additional Voices	<p><u>Consumers</u></p> <ul style="list-style-type: none"> • There were positive reflections on innovative models of governance and leadership, with participants encouraging the consideration of shared leadership (for example Co-Board Chairs, shared CEO responsibilities) and non-hierarchical approaches. • However, it was acknowledged that this needed to be balanced with pragmatic and strategic foundations to support interactions with the broader system, such as working with governments in

Theme 4: Summary of feedback

ways that are familiar and proven to be effective in other sectors.

Carers, families, and kin

- The peak body was considered to have a role in challenging traditional operational and governance models, for example refreshing, sharing and rotating roles periodically.
- This was balanced by views that the peak body needed to be able to interact with the broader system in a way that makes sense to other organisations (for example a clear spokesperson or engagement point on specific topics).

NMHC Consultation

- Mental health consumers who were consulted emphasised the need for the peak bodies to operate differently to the conventional, hierarchical structures and systems that have disempowered them and served to reinforce power imbalances.
- It was largely agreed that membership should be free. A tiered membership was proposed, with a view to ensuring that the interests of individual members remain the core focus of the peaks and their decision-making is embedded into the peaks' operational structures.

Theme 5: The peak bodies will need to work with each other and other relevant organisations, including jurisdictional and First Nations peak bodies, to identify and advocate on common issues.

The need for two separate peak bodies – one for consumers, and one for family, carers and kin – has emerged strongly. This will allow the distinct interests and needs of both groups to be considered and represented, and ensure safety for individuals. However, both peak bodies will need to establish ways of working together and with other organisations, including jurisdictional peak bodies, First Nations peak bodies and peak bodies representing specific populations, interests or intersections with mental health.

Table 5: Theme 5 Summary

Theme 5: Summary of feedback	
Public Submissions	<p><u>Consumers</u></p> <ul style="list-style-type: none"> • Responses emphasised the importance of collaboration with other organisations, including existing state and territory peak bodies, and drawing on existing resources. • A suggestion was also raised about a rotating stand-in representative from each peak body within the other, to ensure that the two peak bodies are working cohesively and are aligned in their directives. • It was also noted that the role of ‘allies’ would need to be considered. <p><u>Carers, families and kin</u></p> <ul style="list-style-type: none"> • There was a firm expectation that the peak bodies should work together, especially to advocate on common issues. • This included the need to engage collaboratively with governments, external organisations and particularly Aboriginal and Torres Strait Islander Peoples. • Some responses were in opposition to relying too strongly on gathering experience and expertise from other organisations, indicating that existing organisations seem to be ‘out of touch with the real issues’.
Workshops and Additional Voices	<p><u>Consumers</u></p> <ul style="list-style-type: none"> • The peak body should support making connections, capability building and mobilisation of existing advocates to develop specific lived/living experience expertise and advocacy skills. • The peak body will need to work alongside national, state and territory peak bodies; jurisdictions that do not have existing lived/living experience representation; those working in designated lived experience/peer roles and workforces; and existing and emerging lived/living experience communities. • Partnerships with other parts of the system that are fundamentally connected to the challenges that members may be experiencing will also be critical, such as housing/homelessness and interfaces with the National Disability Insurance Scheme.

Theme 5: Summary of feedback

- It was also acknowledged that non-consumer perspectives may at times need to be invited, but that this should be balanced with principles of self-determination and at the discretion of the peak body.

Carers, families, and kin

- Participants indicated that the peak body needs to work with existing organisations, groups and movements.
- It was noted that collaboration principles between the two peak bodies should be considered, with an emphasis on consistency in design and developing shared solutions.
- The potential for some roles to represent the 'dual perspectives' of carer and consumer was also raised, and was seen to be a way to embed a partnership approach between the two peak bodies.

NMHC Consultation

- Formal agreements between the two peak bodies, and between the peak bodies and other organisations, should be developed during the establishment phase to guide working relationships.
- Memoranda of Understanding should be used to formalise agreements, where appropriate.
- There was strong support for state and territory peak membership of the national peak bodies, and recognition of the need for national and jurisdictional peak bodies to develop good working relationships.

Cross-Cutting Elements

Some views were consistent across the consultation processes for both peak bodies, but do not fit into the key themes outlined above. These views are summarised here.

Auspicing arrangements

Questions and concerns were raised by both consumers and carers, families and kin in relation to potential 'auspicing' arrangements for the peak bodies. For example, some respondents queried how long 'time-limited' funding would be provided to establish the peak bodies, while others asked why the peak bodies would not be independent bodies to begin with. Others raised concerns about how an existing organisation may unduly influence the identity and funding decisions of the peak bodies. Some respondents suggested state/territory peak bodies could be engaged to set up the peak bodies, rather than an existing organisation; and others noted that there were benefits to leveraging the resources, capabilities and experience of existing organisations. Concerns in relation to auspicing will be mitigated by allowing flexibility in how the peak bodies will be established, including encouraging consortia and partnership arrangements.

Approach to membership

Membership structures and ideas ranged from advocating for 'a balance between organisational and individual voices' to prioritising individual members as the focus and decision-makers of the peak bodies. There was support for membership to be as inclusive as possible and for individuals to be able to identify with one or both peak bodies depending on their experiences. This may mean the peak bodies will need to take an approach to membership that supports self-identification, considers individuals with a range of lived/living experiences, and is guided by further co-design.

National Logistics

Some respondents raised questions in relation to the logistics of operating peak bodies at the national level, including asking about where each peak body will be located and whether the two peak bodies will be located in the same area. The location of the peak bodies should be considered alongside strategies for engagement with members and broader stakeholders, to mitigate concerns about some geographic areas having a stronger voice than others. Consideration should also be given to ensuring equitable and effective representation of regional/remote voices.

Paid engagement with lived experience

Remuneration was raised consistently in both processes, and particularly by family, carer and kin representatives. Mental health lived experience can have considerable financial impacts and without remuneration for time and contributions, it was considered that consumers and family, carers and kin would face barriers to engagement. Several of the discussion paper responses also outlined that communication on this front would be vital to the peaks bodies' reception and ability to build membership. Specifically, it was noted that without a clear approach to remuneration, the range of different and diverse lived/living voices would not be fully represented.