



Australian Government
Department of Health and Aged Care

Discussion Paper – Mental Health Lived Experience Peak Bodies – Family/Carer/Kin Peak Body

The Department of Health and Aged Care acknowledges the Traditional Owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to First Nations Peoples and cultures, and to Elders past and present.

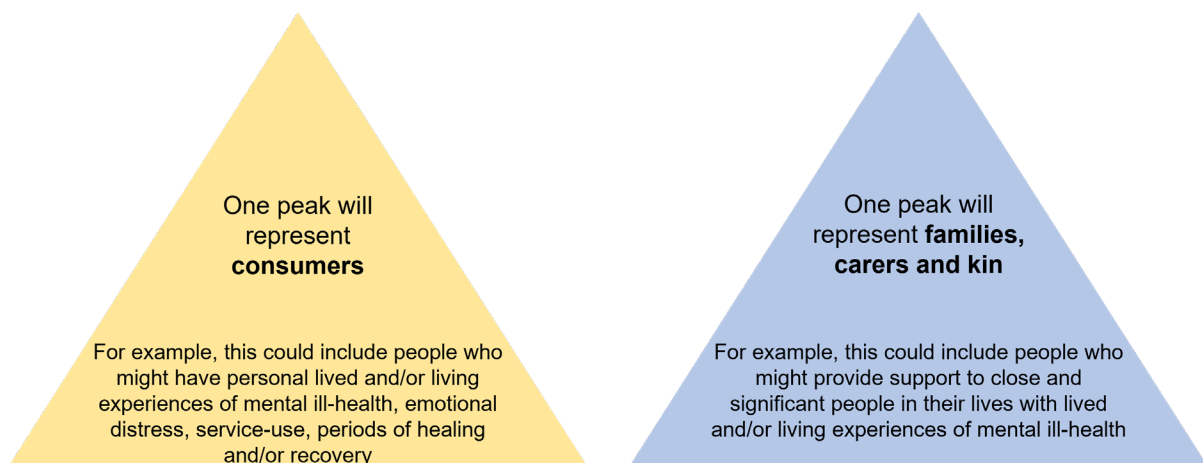
Overview

The Department of Health and Aged Care recognises the unique and powerful expertise that comes with lived and living experiences of mental ill-health as family members (including chosen family), carers and kin, who provide essential support to others on their mental health recovery journey. This includes young people and children who might provide support to family members, chosen family, friends and/or kin. We are deeply grateful to the generosity and bravery of people who continue to share their stories to inspire improvements to the mental health system and services. We also recognise that families, carers and kin experience unique challenges, needs and concerns. Their distinct perspectives should be considered in any reforms to the mental health system and services.

The Australian Government is dedicated to ensuring diverse consumer and carer voices are central to, and actively involved in, mental health reform and decision-making processes moving forward. On 30 January 2023, the Government announced \$7.5 million in funding to create and operate two new independent mental health lived experience peak bodies. One peak body will represent families, carers and kin, the other will represent consumers.

These peak bodies will help to ensure people with lived and/or living experiences of mental ill-health can help shape the policies and programs that affect them.

Figure 1. Visual representation of two mental health lived experience peak bodies



Although consumers and families, carers and kin may align on some issues, we recognise their lived and/or living experiences are **different**. It is important to represent both voices distinctly through these peak bodies.

The Department invites people with lived and/or living experiences of mental ill-health as families, carers and kin to share your thoughts on what the **family/carers/kin peak body** could look like and how it could best represent you and your communities.



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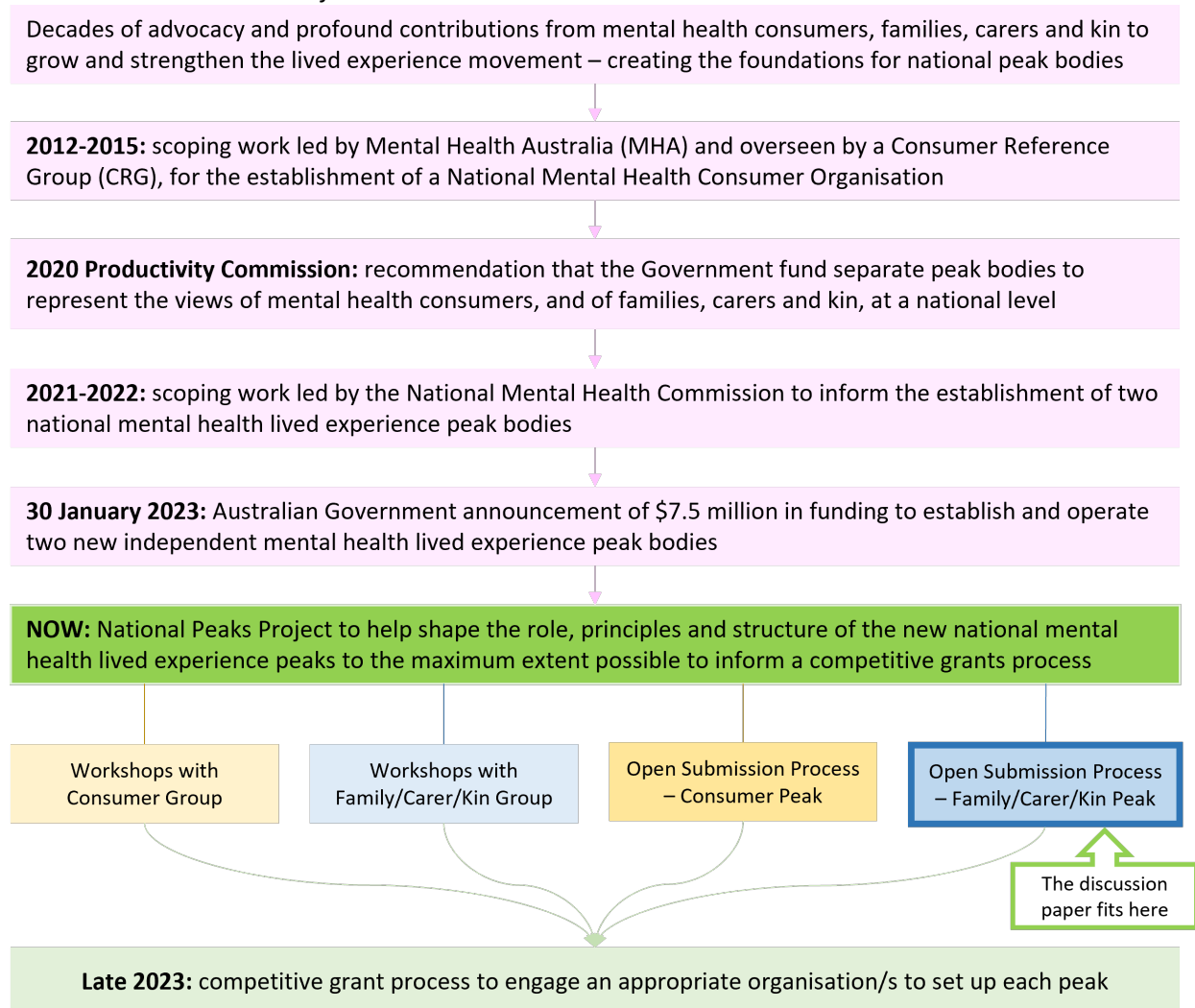
A note on language: please see [Appendix A](#) for additional guidance on how we understand the terms ‘family/carer/kin’ and ‘peak bodies’ throughout the process.

There is a separate open submission process inviting people with lived and/or living experiences of mental ill-health as consumers to share their thoughts on what a consumer peak body could look like. We invite you to contribute to either or both submission processes depending on what resonates most with you.

About the open submission and National Peaks Project process

This open submission process is one part of a broader project designed to shape the role, principles and structures of the peak bodies in partnership with people with lived and/or living experiences of mental ill-health.

Figure 2. Visual representation of where this discussion paper and open submission process fits in the broader National Peaks Project





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As figure 2 illustrates, the creation of a family/carer/kin peak body builds on extensive previous work undertaken by the sector and years of advocacy efforts from individuals and organisations representing mental health consumers, families, carers and kin.

We acknowledge and thank the many people who have already shared their stories, insights and feedback to inform the creation of mental health lived experience peak bodies. Thanks to the tireless work to date, there is strong evidence on the need for and benefit of establishing formal mechanisms that enable consumers and families, carers and kin to influence mental health policies, programs and reform at the national level.

We also appreciate there may be people who do not feel their voices have been heard in previous work or who might be new to the carer movement.

Our intention and aim is to build on previous work and invite new, emergent and diverse perspectives. This will enable us to create peak bodies that can respond to current and future lived and living experience contexts.

Foregrounding First Nations wisdom

This project will be conducted in a way that prioritises active collaboration and partnership with Aboriginal and Torres Strait Islander Peoples and ways of being, knowing and doing. We are committed to a do-no-harm and listen-first approach to working with First Nations Peoples and communities, and focus on equity principles to ensure to the best of our ability that all voices are heard equally, and that the peak bodies are designed in a way that will be grounded in cultural responsiveness and anti-racism once established.

Why your views matter

We want to know how the family/carer/kin peak body could best serve you and your communities and ensure that your lived experience voice is heard throughout mental health reform moving forward.

How your views will be considered

All feedback provided through this open submission process, and the concurrent co-design workshops led by The Australian Centre for Social Innovation (TACSI), will inform a competitive grant process to engage an appropriate organisation/s to set up each peak body. The competitive grant process is expected to open later in 2023.

Feedback will inform the contents of Grant Opportunity Guidelines (GOGs) to support the grant process. The GOGs will outline key elements of a grant/s for the initial establishment and operation of each peak body, such as:

- eligibility criteria
- specific objectives; and
- intended outcomes.

The GOGs will also provide details on exactly what grant money can and can't be used for. A Departmental delegate will ultimately award the grant to the applicant/s who can best demonstrate their ability to deliver the peak bodies in line with the GOGs.



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For further information about Commonwealth grants and how they are used, please visit: www.finance.gov.au/government/commonwealth-grants/commonwealth-grants-rules-and-guidelines.

Note on framing and aligning ‘co-design’ in this project

This project is an opportunity to collaborate and shape the family/carer/kin peak body’s role, principles and structure together.

This work seeks to demonstrate how the Department can work alongside the people at the heart of the family/carer/kin peak body in better and more transparent ways.

We recognise there are many ways individuals, groups, organisations and institutions are seeking to ‘co-design’ across the mental health system, and this project is also part of that. In this project’s context and scope, ‘co-design’ is aligned with the ‘Collaborate’ level in the International Association for Public Participation (IAP2) Public Participation Spectrum, available at: iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf.

Through this project, we will strive to ‘Collaborate’ as follows:

We (the Department) will look to you (the lived and living experience community and leaders) for advice and innovation in formulating solutions. We will incorporate your advice and recommendations into the decisions to the maximum extent possible.

How to share your views

We recognise that through previous work, several operational resources and underlying principles have already been developed to guide the establishment of a national consumer peak body. People and organisations representing families, carers and kin have since adapted some of these resources to suit a potential family/carer/kin peak body. We have taken these resources and guiding principles to inform a series of priority next steps for implementation. These will inform how the Department engages an appropriate organisation/s to receive funding for the initial establishment and operation of each peak body.

We invite you to share your thoughts on these implementation priorities, and to provide any feedback on how they might be achieved. We also invite you to share with us anything you suggest may be missing.

To share your views, please complete the ‘Online Survey’ via the link available through the Consultation Hub, noting:

- For **each** implementation priority below, you will be invited to select from multiple choice options to indicate whether a collection of statements linked to achieving the priority meet your expectations of the family/carer/kin peak body.
- Please use free-text fields throughout the survey if you would like to expand on your responses, and/or to provide any additional thoughts, comments or feedback that you suggest we should also take into consideration when progressing this work.

Please note any responses to these survey questions will be considered as part of the broader project outlined in Figure 2. Where possible, this could include drawing on points raised through the



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open submission process to inform further discussions during workshops facilitated by TACSI with the Family/Carer/Kin Group.

If you have any questions or concerns about completing this survey or wish to suggest a different format for sharing your thoughts, please contact the team via: LivedExperience@health.gov.au for further advice. Please also let us know if there is anything that might make this process more accessible to you.

Priorities for implementation – establishing the family/carer/kin peak body [for consideration]:

1. *Creating a family/carer/kin peak body that privileges the voices of those most affected and centres mental health lived experience leadership*

Does each statement below meet your expectations of a family/carer/kin peak body? Please use the free text field in the survey if you would like to expand on your answer.

- A mental health family/carer/kin peak body should represent people and communities supporting close and significant people in their lives with lived and/or living experience of mental ill-health, while remaining inclusive of broader or intersecting lived experiences. For example, you might consider how the family/carer/kin peak body could also include and represent people and communities with lived and/or living experiences of suicide or bereavement due to suicide, neurodivergence, alcohol and other drug dependence, homelessness, trauma, disabilities including psychosocial disabilities, or survivors of violence, who may not have a self-identified lived and/or living experience of mental ill-health specifically.
- Membership should include people with lived and/or living experience as family members, carers, supporters and kin of a person(s) with, or who has experienced, mental ill-health. This includes young people and children who might provide support to family members, chosen family, friends and/or kin.
- Membership should also include organisations representing families, carers and kin, state/territory representatives and other organisations (including those intersecting with but non-specific to mental health).
- The family/carer/kin peak body should adopt an inclusive and open approach to membership that honours each person's right to determine whether one or both peak bodies represent their interests and those of their communities.
- The family/carer/kin peak body should be lived experience-led, with lived experience voices prioritised in membership structures, staffing and governance arrangements. This includes prioritising individual members' voting rights in relation to Board appointments.
- People in leadership positions, Board members and appointed staff member positions within the family/carer/kin peak body should have a lived or living experience of mental ill-health as family members, carers and kin.



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2. Valuing diversity and promoting inclusive approaches to membership and operations

Does each statement below meet your expectations of a family/carer/kin peak body? Please use the free text field in the survey if you would like to expand on your answer.

- The family/carer/kin peak body should be representative of people with diverse lived experience, including through targeted membership and identified Board positions to ensure appropriate representation of specific cohorts such as:
 - Aboriginal and Torres Strait Islander Peoples and communities
 - people from culturally and linguistically diverse backgrounds
 - people who identify as LGBTIQ+
 - people from rural, regional and remote areas
 - older Australians
 - children, youth and/or young people
 - people with complex and/or severe mental ill-health
 - people with disabilities
 - people with unstable living arrangements
 - people with complex care arrangements.
- The principle of valuing diversity and promoting inclusion should be built-in to the operational policies, processes and procedures for the family/carer/kin peak body (for example, through the peak body's approach to Human Resourcing, Board recruitment, cultural responsiveness, leadership and governance arrangements, strategic direction etc.)

3. Ensuring the family/carer/kin peak body is sustainable, viable and responsive to evolving needs of diverse lived experience communities

Does each statement below meet your expectations of a family/carer/kin peak body? Please use the free text field in the survey if you would like to expand on your answer.

- The family/carer/kin peak body should focus on systemic advocacy (advocating on behalf of diverse lived experience voices to contribute to system-wide mental health policies, programs and reform processes), rather than on individual advocacy and/or individual services.
- An existing organisation/s with understanding of the mental health sector and lived experience movements should be initially funded on a time limited basis to establish the new family/carer/kin peak body, before transitioning to independent governance arrangements.
- As a priority, an organisation funded to establish the family/carer/kin peak body should work with the lived experience sector and communities to develop and refine an appropriate governance model and key operational documents, such as a/an:
 - Organisational Constitution (a document that sets out how an organisation should operate, such as how it is structured, who has the power to make decisions and what their roles and responsibilities are, and what the core activities might be)
 - Guide to the Organisation
 - Operational Policies and Procedures (for example: an Employee Handbook)



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- To ensure that the family/carer/kin peak body remains financially viable, different models for generating revenue will need to be considered (for example: paid membership for some or all members, offering training programs etc.).

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*

Does each statement below meet your expectations of a family/carer/kin peak body? Please use the free text field in the survey if you would like to expand on your answer.

- Individuals who identify as both consumers and as families, carers and kin should be welcome to become members of both peak bodies.
- Formal agreements should be developed during the establishment phase to guide how the family/carer/kin peak body works with the consumer peak body, and with external organisations, including to identify and advocate on common issues.

5. *Additional information*

Please provide any other comments and/or attach any supporting information you think will assist with the design of the family/carer/kin peak body.

Next Steps

The Department will review feedback and recommendations from the open submission process, along with virtual co-design workshop sessions facilitated by TACSI. This will inform a competitive grants process to engage an appropriate organisation/s to set up each peak body. The competitive grant process is expected to open later in 2023.

For further information on the National Peaks Project process, please visit the TACSI National Peaks Project Hub (sites.google.com/tacsi.org.au/national-peaks/home) or the Department's website (www.health.gov.au/topics/mental-health-and-suicide-prevention/what-were-doing-about-mental-health/national-mental-health-lived-experience-peak-bodies).

Please do not hesitate to contact the team via LivedExperience@Health.gov.au if you have any questions about this open submission process.



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APPENDIX A

Note on Language

What do we (the Department) mean by ‘family/carer/kin’ throughout this paper

As noted in the Productivity Commission’s Final Report in its Inquiry into Mental Health, it is important that both consumer and carer voices are clearly heard in all aspects of mental health reform. However, many people who support close and significant people in their lives with lived and/or living experiences of mental ill-health do not think of themselves as ‘carers’, but their voices still need to be heard and valued.¹

The Department chooses to adopt a broad definition of mental health ‘family/carer/kin’ to encourage all people who self-identify as having relevant lived and/or living experiences of mental ill-health to share their views on how a mental health lived experience (family/carer/kin) peak could represent them.

We suggest ‘lived and/or living’ experiences of mental ill-health as a family member (including chosen family and nonbiological kinship bonds), carer or kin could include (but is not limited to):

- providing support to a family member, friend or loved one experiencing mental ill-health, including as a child or young person providing care and support to significant people in their lives
- providing emotional and practical support to a person living with mental ill-health within or outside your immediate household
- walking beside someone who is living with and/or experiencing the social and human rights impact of living with mental illness, including homelessness
- having experienced life-altering mental health challenges from the perspective of a family member, carer, supporter or kin.

These experiences may be short- or long-term, in the past or ongoing.

We recognise that ‘lived and/or living experience’ does not mean the same thing to everyone. Different people and communities may understand mental health and ill-health differently, and not all people in care-giving roles will identify themselves as being ‘carers’. Your preferred terminology may differ from the terms preferred by others or used throughout this document. We encourage you to use the words and phrases that are most meaningful to you throughout your submission.

We also acknowledge that Aboriginal and Torres Strait Islander lived experience of mental health is unique. We adopt the Black Dog Institute Aboriginal and Torres Strait Islander Lived Experience Centre’s definition that “a lived experience recognises the effects of ongoing negative historical impacts and or specific events on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. It encompasses the cultural, spiritual, physical, emotional and mental wellbeing of the individual, family or community”.²

¹ Australian Government Productivity Commission, 2020, *Mental Health Inquiry Report*, vol. 3, no. 95. p. 1101.

² Black Dog Institute, *Aboriginal and Torres Strait Islander Lived Experience Centre*, accessed 21 June 2023. <https://www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network/>



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What is a 'peak body'?

A peak body is a non-government organisation that represents the interests of a specific part of the population or sector at the state/territory and/or national level. A peak body's role is to develop and provide 'a voice' for its members, which is gained through consulting and engaging with people in the community. A peak body might provide advocacy or contribute to research and policy development on behalf of its members. A peak body also provides a point of contact for Government to access, engage with and listen to the collective voice of people most affected by policies and programs.

The creation of mental health lived experience peak bodies will enable Government to work better with people with lived and/or living experiences of mental ill-health to drive effective reforms and improve outcomes for the Australian community.