

Creating Inclusive Spaces: Engaging Individuals with Lived Experience of Mental Health Challenges

Purpose of this document

This document outlines the principles and procedures of the National Mental Health Consumer Alliance (Alliance) for engaging directly with people with lived experience of mental health challenges.

Contact: please contact policy@nmhca.org.au to discuss any engagement opportunities and to obtain copies of the documents identified in the Guidelines.

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Summary

The National Mental Health Consumer Alliance (Alliance) is the National peak advocacy organisation for people with lived experience of mental health challenges.

The Alliance encourages policy makers and service providers to engage and collaborate with people with lived experience of mental health challenges in focus groups, research activities, committees and other consultative bodies, and other forms of involvement. These guidelines will assist organisations seeking to work directly with people with lived experience of mental health challenges through the Alliance.

The Alliance is committed to the underlying principles that:

- People with lived experience of mental health challenges will be paid when formally engaged by organisations
- The 2x2 model of engagement is recommended when appropriate. That is, people with lived experience of mental health challenges should not be expected to participate in formal activities alone but should always be accompanied by another consumer (which in some cases may be an employee of the Alliance)

When inviting people with lived experience of mental health challenges to participate in an event we recommend that organisations follow the guidelines below in relation to:

- promotion and lead time,
- meeting the costs for people with lived experience of mental health challenges to participate,
- providing a quiet place, and
- suitable recognition of their lived experience.

These guidelines also provide advice on

- payment for participation and Alliance fee structure for consultations,
- when to recognise people with lived experience of mental health challenges,
- providing support,
- engaging people with lived experience of mental health challenges in committee meetings and research,

- the involvement of peer workers, and
- engaging Aboriginal and Torres Strait Islander people in activities.

Background

The National Mental Health Consumer Alliance (the Alliance) is the peak advocacy organisation for people with lived experience of mental health challenges. We have a wide reach across Australia through our members (the State and Territory mental health consumer Peak bodies (STPs)), our membership, public forums, newsletters, webpages and social media postings.

As part of its work, the Alliance will:

- promote and provide opportunities for policy makers and service providers to collaborate with people with lived experience of mental health challenges
- find suitable people with lived experience of mental health challenges to participate in focus groups, research activities, committees and other consultative bodies, and other forms of engagement
- encourage organisations to seek the involvement of people with lived experience of mental health challenges in co-design, co-creation, and co-development activities
- provide advice directly to other organisations about consumer views on systemic issues.

These guidelines are to assist organisations seeking to work directly with people with lived experience of mental health challenges through the Alliance. In providing opportunities for organisations to engage with people with lived experience of mental health challenges we are conscious of the need to ensure that they, and our employees, are well-supported throughout these activities. Engagements need to be trauma informed and take place in an ethical way to ensure this safety.

While we endeavour to respond constructively, and to take every opportunity to ensure the voices of people with lived experience of mental health challenges are heard, we reserve the right to determine our level of engagement and not to participate in some requests. We will determine our ability to assist based on the nature of the consultation, our availability, time provided to consult, available funding, the alignment of the activity with our strategic priorities and consistency of the issue to be discussed with our established policies.

We use the term “people with lived experience of mental health challenges” or “mental health consumers” throughout these guidelines as a catchall term due to its connection with our movement’s history but we acknowledge that different people identify with different terms. We do not include family, carers, kin or the bereaved in our definition of lived experience in this document.

General Principles for the engagement of mental health consumers

Ideally, all mental health projects and policies should be consumer-led under the principle of “nothing about us without us”.

The Alliance is committed to the following principles to ensure safe and effective engagement with people with mental health challenges.

- People with lived experience of mental health challenges should be:
 - provided the opportunity to influence policy development and service design from the beginning of projects
 - paid for their participation and input in formal activities and events
 - engaged in a manner that provides support and allows them to withdraw if necessary
 - at the end of the project, are included in communications about how the project went.
- [Co-creation](#)¹ (co-design and co-production) methods should be used whenever possible when engaging people with lived experience of mental health challenges. Their expertise should be acknowledged, listened to, and implemented.
- Activities and events involving people with lived experience of mental health challenges should be purposeful and trauma informed.

Our preferred model of engagement

When people with lived experience of mental health challenges participate in one-off events and continuing commitments it is important they have the support they need.

The Alliance is committed to the principle that individual people with lived experience of mental health challenges should not be engaged in consultative activities alone; they should always be supported in the activity by at least one other consumer. Some activities may engage several people with lived experience of mental health challenges, such as focus groups, ‘town hall’ meetings, research activities etc. where consumers can support each other.

Where numbers are constrained, and/or the activity is continuing, such as committees or working parties, the Alliance follows a 2x2 model of engagement. This model of engagement provides support for people with lived experience of mental health challenges and helps to address power imbalances.

¹ [Co-creation, co-design, co-production for public health – a perspective on definitions and distinctions - June 2022, Volume 32, Issue 2 | PHRP](#)

The 2x2 model involves the following features:

- two people with lived experience of mental health challenges should be invited to participate. If this is not possible then the consumer should be accompanied by, in order of preference, either
 1. a policy officer organised by the Alliance, or
 2. a paid peer support person, or
 3. a family/carer/kin representative (only where family/carer/kin have also been invited to contribute in the event).
- the Alliance should be invited to participate in project governance or consultation activities

For a strategic consultative activity, the 2x2 model may look like one of these combinations, in order of preference:

1. one mental health consumer and one person representing Alliance, or
2. two people with lived experience of mental health challenges, or
3. one mental health consumer and a carer/family member/kin representative

The Alliance staff, all of whom have mental health challenges, can also provide support. Alliance staff are familiar with the experience of a wide range of stakeholders. They can frame issues and experiences into a context which is usable by policy makers and service providers seeking direct lived experience input.

Guidelines for organisations

The following guidelines provide advice for organisations seeking to engage directly with people with mental health challenges through the Alliance. However we encourage all organisations looking for national policy or services consultations or advice to use these guidelines.

We recognise that each State and Territory mental health consumer peak body has their own Guidelines and paid participation rates. If you are engaging directly with people on a State/Territory basis, we recommend you contact each consumer mental health peak body to understand their requirements.

The Alliance has an Engaging Safely policy that outlines how the Alliance will carry out any engagement with people with lived experience of mental health challenges. All organisations that want to engage

consumers through the Alliance must have an Engaging Safely policy and this must be shared with the Alliance prior to any engagement. If your organisation does not have an Engaging Safely policy you will be required to either write one or adopt the Alliance's policy in its entirety to ensure that the engagement is conducted in a safe and supportive way.

Fee Structure

The Alliance charges a fee to coordinate consultations with people living with mental health challenges. Our fee structure is at the end of the Guidelines.

Engaging Aboriginal and Torres Strait Islander people

We strongly recommend that organisations planning to involve Aboriginal and Torres Strait Islander people in their work consult and use the [IALEC organisation readiness framework](#).

When inviting people with lived experience of mental health challenges to an event

Actions	Notes
Promotion When providing us with text to promote your opportunities in our newsletters please ensure the language in any material you want to promote through our newsletters complies with the Alliance's language guide. The Alliance's Language Guide continues to grow, so please contact the Alliance for our latest version.	There are some terms we will not publish, and so we reserve the right to either edit your language where we feel it is inappropriate to the mental health consumer movement, or not promote your opportunity.
Lead Time If your activity requires registration, allow at least 6 weeks between the date we start to promote the opportunity, and the final date for people with lived experience of mental health challenges to apply or register for your opportunity.	Many people with lived experience of mental health challenges are busy and need time to fully consider your opportunity.
When a participant must pay Where your opportunity requires payment by the participant (e.g. a registration fee), please indicate if bursaries are available for people with lived experience.	We strongly recommend offering bursaries for people with lived experience of mental health challenges due to underemployment, low waged, unemployment etc.
Availability of a quiet space A quiet room/space should be available if you are holding a conference or public event, involving people with psychosocial disability.	Some people with mental health challenges also experience sensory challenges, and/or may feel upset by some content discussed at the event. Providing a quiet space is a reasonable adjustment to ensure everyone can participate.
Recognition of lived experience Best practice is to recognise people with lived experience of mental health challenges at the end of your meeting. Recognition of clinicians should not be included.	Recognition speaks to the consumer movement, those we have lost from the movement, and the ongoing struggle for our collective human rights. For this reason, it should not be blended with Acknowledgement of Country.
Engaging Consumers Safely All people with lived experience of mental health challenges engaged by you to participate on a committee must be provided with a copy of your Engaging Safely policy.	If the organisation does not have an Engaging Safely policy they must apply the Alliance's policy in full. Please contact the Alliance for more information.

Focus groups, consultations, co-creation and research

Actions	Notes
Payment for Participants Participants should be paid for their participation in the event and for any significant time spent in preparation, reading, travel time and cost of travel when travel is likely to be significant. The Alliance has a participation payment policy that sets out the rates payable for people with lived experience of mental health challenges participation. The rate is based on the Remuneration Tribunal (Remuneration and Allowances of Part Time Office) Determination and is reviewed every 12 months. Please contact the Alliance for a copy of this policy.	When the participation calls for additional skills or experience, the payment should be increased on a case-by-case basis. The Alliance can provide advice on this issue if you need it. When policy officers and other staff participate in activities, they will be covered by their wages and will not require payment for participation.
Recognition of lived experience A recognition speaks to the consumer movement and the ongoing struggle for our collective human rights. For this reason, it should not be blended with Acknowledgement of Country, nor should recognition of clinicians be included.	Recognition speaks to the consumer movement, those we have lost from the movement, and the ongoing struggle for our collective human rights. For this reason, it should not be blended with Acknowledgement of Country. Current best practice is to recognise people with lived experience of mental health challenges at the end of your meeting.
Engaging Consumers Safely All people with lived experience of mental health challenges engaged by you to participate on a committee must be provided with a copy of your Engaging Consumers Safely policy.	If the organisation does not have an Engaging Consumers Safely policy they must use the Alliance's and put into practice everything it states. Please contact the Alliance for more information.
Support person available Some meetings contain content that may re-traumatise a mental health consumer. Consider the need for a peer worker to be on-call to support mental health consumer participants throughout the meeting and for one hour afterwards.	We recommend that peer workers, when engaged in a paid support role, are paid at a SCHADS 5.1 casual rate at a minimum. Please note, this amount increases from year to year.
Separate consultation for people with lived experience of mental health challenges when necessary	For some engagement or activities, the participation of people with lived experience of

Consider the use of separate meetings and consultations for people with lived experience of mental health challenges where participation in the same room may not be appropriate (for example, power imbalance between one consumer at a meeting of psychiatrists)	mental health challenges only would be appropriate.
Keeping everyone informed We prefer that you have a plan in place to keep all applicants, including unsuccessful applicants, for the event up to date on the process prior to, and outcomes after, the event.	This is particularly important for research, which has a history of extracting information without giving back to the community.

Committee meetings

Actions	Notes
Payment as committee member All people with lived experience of mental health challenges should be paid to attend a committee meeting unless they are attending in their paid employment role. The Alliance has a participation payment policy that sets out the rates payable for mental health consumer participation. The rate is based on the Remunerational Tribunal and is reviewed every 12 months. Please contact the Alliance for a copy of this policy.	Please see the Alliance's Paid Participation Policy. The minimum fee will be based on a minimum of 2 hours participation.
Payment as a Chairperson The Alliance has a participation payment rate for Chairpersons. The Alliance has a participation payment policy that sets out the rates payable for people with lived experience of mental health challenges participation. The rate is based on the Remunerational Tribunal and is reviewed every 12 months. Please contact the Alliance for a copy of this policy.	Please see the Alliance's Paid Participation Policy. The minimum fee will be based on a minimum of 2 hours participation.
Meeting papers People with lived experience of mental health challenges should be provided with meeting papers at least one week prior to the meeting. Consider providing people with lived experience of mental health challenges with a plain English version of technical papers where they form part of the committee papers.	People with lived experience of mental health challenges may need longer than other committee members to read and process the material.
Engaging Consumers Safely All people with lived experience of mental health challenges engaged by you to participate on a committee must be provided with a copy of your Engaging Safely policy.	If the organisation does not have an Engaging Safely Policy they must use the Alliance's policy and put into practice everything it states. Please contact the Alliance for more information.

Requesting a mental health consumer to tell their story/experience

Actions	Notes
Finding someone to tell their story A request to Alliance to find a mental health consumer to share their lived experience of mental health challenges should be made at least 6 weeks and preferably 8 weeks prior to the date of the event.	We will charge a fee if a request requires considerable time to fulfill. Please see Fee Structure later in this document.
Engaging Consumers Safely All people with lived experience of mental health challenges engaged by you to tell their story/experience is provided with a copy of your Engaging Safely policy.	If the organisation does not have an Engaging Safely policy they must use the Alliance's and put into practice everything it states. Please contact the Alliance for more information.
Support for people with lived experience of mental health challenges/telling stories When a consumer is invited to tell their story, they may need assistance or coaching to prepare for the event. They should also be fully supported at the event either by a co-consumer or a consumer peer worker.	The mental health consumer may need coaching on how to best tell their story, and what to expect from telling their story, so they can be fully prepared.
Payment for someone to tell their story The storyteller should be paid at the Alliance participation rate identified earlier and paid for additional costs such as preparation time and travel costs.	Please see the Alliance's Paid Participation Policy.
Publication of stories Prior to agreeing to participate in storytelling, people with lived experience of mental health challenges should be - asked to consent to their story being recorded and reused - given information on how their stories will be used - provided with the opportunity to place restrictions or limitation of the distribution of their story if that is important to them - provided with the opportunity to not include their name or other identifying traits - asked if they would like a support person present (at your expense)	The mental health consumer telling their story must provide written authorisation for any videos, websites or other means capturing their story/self. The mental health consumer must be given the opportunity to provide complete direction to where and for what period their story is made publicly available and reserves the right to withdraw consent at any time.
Expert comment on the story Care is needed when there is expert commentary on the story after it is told. The Alliance should be consulted where there is the intention to include a commentary or review of the story at the event.	It is important that care is taken to ensure that "expert" comments do not negate the story's impact. The Alliance can provide a broader consumer lens to the story, rather than a clinical view.

After the engagement

Actions	Notes
Acknowledgement and follow up Ensure that you message people with lived experience of mental health challenges with an expression of acknowledgement, thanks and appreciation. This is more important than simple politeness.	People with lived experience of mental health challenges are likely to find engagements around mental health challenges stressful and challenging. Expressing acknowledgement and thanks when their engagement is finished, may be particularly important for their self esteem and wellbeing.

Fee Structure for Consultations

Task	Notes
Paid participation The minimum fee will be based on a minimum of 2 hours participation. Please refer to the Participation Payment Policy for up to date rates. The Alliance generally recruits 1 person from each State/Territory to participate in consultations.	Consultations generally run for a maximum of two hours. If you require a longer consultation please contact the Alliance to discuss.
Peer worker/support person The minimum fee is \$300 for up to 2 hours.	All consultations coordinated by the Alliance will have a peer worker to support participants.
Notetaking and report writing The minimum fee is \$200 per hour.	If required, the Alliance can take notes and draft a report on the consultation.
Facilitator The minimum fee starts at \$505 for up to 2 hour consultation (this includes preparation work).	If required, the Alliance can organise an appropriate facilitator that has lived experience of mental health challenges.
Finding specific speakers/additional participants The minimum fee is \$200 per hour.	If the Alliance is tasked with finding more than one person per state/territory or finding a specific speaker a cost may be incurred. Please contact the Alliance to discuss.
** All costs may increase each year with inflation. Please contact the Alliance for current fee structure.	