



**Mental Health
Carers NSW**



Guidelines for organisations seeking to engage consumers with lived experience of mental health challenges, and their families, carers & kin.

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Purpose of this document

This document outlines the principles and procedures of BEING Mental Health Consumers and Mental Health Carers NSW for the guidance of policy makers and service providers seeking to engage directly with mental health consumers and carers.

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Contents

Purpose of this document.....	1
Summary	3
Background	4
General Principles for the engagement of consumers and carers	4
Our 2x2 model of engagement	5
Guidelines for organisations	5
Engaging Aboriginal and Torres Strait people.....	5
When inviting consumers and carers to an event	6
Promotion	6
Lead time.....	6
When a participant must pay.....	6
Availability of a quiet space	6
Recognition of lived experience.....	6
Focus groups, consultations, co-creation (co-design + co-production) and research.....	7
Payment for Participants	7
Recognition of lived experience.....	7
Support person available	7
Peer workers in attendance	7
Separate consumers and carers when necessary	7
Keeping everyone informed.....	7
Committee meetings.....	8
Payment as committee member	8
Payment as experts.....	8
Meeting papers	8
Requesting a person tell their story/experience	9
Finding someone to tell their story.....	9
Support for consumers/carers telling stories	9
Payment for someone to tell their story.....	9
Publication of stories	9
Expert comment on the story	9
After the engagement.....	9
Acknowledgement and follow up	9

Summary

BEING Mental Health Consumers (BEING) and Mental Health Carers NSW (MHCN):

- Are the NSW peak advocacy organisations for mental health consumers, and their families, carers and kin
- Both organisations encourage policy makers and service providers to engage and collaborate with consumers and carers in focus groups, research activities, committees and other consultative bodies, and other forms of involvement
- These guidelines assist organisations seeking to work directly with consumers and families/carers/kin through our two organisations

BEING and MHCN are committed to the underlying principles that

- Consumers and carers should be paid when formally engaged by organisations to participate in
- Ideally consumers and carers should not be expected to participate in formal activities alone but should always be accompanied by another consumer or carer (ideally both), or a member of BEING and/or MHCN
- The 2x2 model of engagement is recommended when appropriate

When inviting consumers and/or carers to participate in an event we recommend that organisations follow the guidelines below in relation to:

- Promotion and lead time
- Meeting the costs to consumers or carers for participation
- Providing a quiet place and suitable recognition for their lived experience.

These guidelines also provide advice on

- Payment for participation
- When to recognise consumers and carers
- Providing support
- The involvement of peer workers
- Engaging aboriginal and Torres Strait Islander persons in activities
- Engaging consumers and carers in committee meetings and research

There are separate guidelines when consumers and carers are invited to 'tell their story' and acknowledgement of their participation after the engagement.

Background

BEING Mental Health Consumers (BEING) and Mental Health Carers NSW (MHCN) are the NSW peak advocacy organisations for mental health consumers, and their families, carers and kin. Collectively we have a wide reach across NSW through our membership, public forums, education offerings, weekly newsletters, webpages and social media postings.

As part of our work, BEING and MHCN:

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

These guidelines assist organisations seeking to work directly with consumers and families/carers/kin through our two organisations. 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, and that engagement takes place in an ethical and acceptable way that avoids or minimises trauma.

While we endeavour to respond constructively, and to take every opportunity to ensure the voices of lived experience 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, available funding, the alignment of the activity with our strategic priorities and consistency of the issue to be discussed with our established policies.¹

General Principles for the engagement of consumers and carers

BEING and MHCN are committed to the following principles.

- Consumers and carers 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
 - always be engaged in a manner that provides support and allows them to withdraw if necessary
 - included in report backs on the completion and outputs of projects.
- Co-creation (co-design and co-production) methods should be used whenever possible when engaging consumers and carers. Their expertise should be acknowledged, listened to, and implemented.
- Activities and events involving consumers and carers should follow Recovery principles.
- Activities and events should be Trauma Informed.

¹ Terminology guide: In this document, we use the term “lived experience” to encapsulate the experiences, both past and present, of consumers and family/carers/kin. The term “consumer” refers to someone with a lived experience of mental illness either in the past or continuing. “Carer” may include family members, friends, community members, or kin, where they are engaged in providing care for a person with a lived experience of mental illness.

Our 2x2 model of engagement

When consumers and carers participate in both one-off events and continuing commitments it is important they have the support they need.

Some consultation activities may engage several consumers and/or carers, such as focus groups, 'town hall' meetings, research activities etc where they can provide each other support. BEING and MHCN are committed to the principle that individual consumers and carers should not be engaged in consultative activities alone; they should always be supported in the activity by at least one other consumer and carer. Where numbers are constrained, and/or the activity is continuing, such as committees or working parties etc, BEING and MHCN follow a 2x2 model of engagement. This model of engagement provides support for the consumers and carers with lived experience and helps to address power imbalances.

Support to consumers and carers is also provided by a BEING or MHCN policy officer, (most of whom have their own lived experience). Policy officers 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. A policy officer is a suitable support to the lived experience consumer or carer as part of a 2x2 pair.

The 2x2 model involves the following features.

Unless it is not appropriate or practical to do so:

- both consumers and carers should be invited to participate
- both organisations should be invited to participate in project governance or consultation activities
- a consumer or carer should be accompanied by either
 - a second consumer or carer, or
 - a policy officer volunteer of the relevant organisation.

For a strategic consultative activity, the 2X2 model may look like one of these combinations:

- one consumer and one person representing BEING, and one carer and one person representing MHCN
- two consumers, one carer and one person representing MHCN
- two carers, one consumer and one person representing BEING
- two consumers and two carers.

Guidelines for organisations

The following guidelines provide advice for organisations seeking to engage directly with consumers and carers through BEING and MHCN. We strongly encourage organisations who do not use BEING and MHCN to engage with consumers and carers to also operate within these guidelines.

Engaging Aboriginal and Torres Strait people

MHCN has developed guidelines on the involvement of Aboriginal and Torres Strait Islander people in events and these guidelines are available by contacting MHCN.

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

When inviting consumers and carers to an event

Actions	Notes
<p>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 NSW Mental Health Coordinating Council's language guide. See - MHCC's Language Guide.</p>	<p>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 consumer/carer movements, or not promote your opportunity.</p>
<p>Lead time If your activity requires a registration, allow at least 3 weeks between the date we agree to promote the opportunity and the final date for consumers and carers to apply or register for your opportunity.</p>	<p>Many consumers/carers are busy and need time to fully consider your opportunity.</p>
<p>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.</p>	<p>We strongly recommend offering bursaries for people with lived experience due to the financial impacts of caring for a loved one, unemployment or underemployment etc.</p>
<p>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.</p>	<p>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.</p>
<p>Recognition of lived experience Best practice is to recognise consumers and family, carers and kin at the start of your meeting.</p>	<p>A recognition speaks to the consumer and carer movements 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.</p>

Focus groups, consultations, co-creation (co-design + co-production) and research

Actions	Notes
<p>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 is that is likely to be significant.</p> <p>Both BEING and MHCN have a list of suggested hourly rates for different activities, such as participant, chair, expert etc. These are adjusted regularly to allow for inflation. Please contact either BEING or MHCN for the current rate per hour that they recommend.</p>	<p>Alternatively, an organisation can choose to pay participants, as a minimum, the standard rate for consumers and carers published by the Ministry of Health NSW on their website.</p> <p>When the participation calls for additional skills or experience, increase the payment on a case-by-case basis. BEING and MHCN can provide advice on this issue if you need it.</p> <p>When policy officers and other staff participate in activities, they will be covered by their wages and will not require payment for participation.</p>
<p>Recognition of lived experience A recognition speaks to the consumer and carer movements 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.</p>	<p>Best practice is to recognise consumers and family, carers and kin at the start of your meeting.</p>
<p>Support person available Some meetings contain content that may re-traumatise an individual. Consider the need for a peer worker to be on-call to support consumer/carer participants throughout the meeting and for one hour afterwards.</p>	<p>We recommend that peer worker/s, 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.</p>
<p>Peer workers in attendance When peer workers are attending the meeting as participants, it is important to clearly identify if they are attending in their capacity as a consumer/carer or as a peer worker to avoid any conflicts of interest.</p>	<p>The direct involvement of peer workers may not be appropriate in all focus groups, consultations or co-creation sessions, if they are to participate in their role as peer workers and not as a consumer or carer.</p> <p>A decision should be made on a case-by-case basis about the appropriateness of peer worker involvement.</p> <p>Peer workers may be helpful in some engagements to facilitate sessions consistent with their role.</p>
<p>Separate consumers and carers when necessary Consider the use of separate meetings and consultations for consumers and carers where participation in the same room may not be appropriate</p>	<p>For some engagement or activities, the participation of consumers only, or carers only, would be appropriate. In these situations, the 2x2 policy is not appropriate.</p>
<p>Keeping everyone informed We prefer that you have a plan in place to keep all applicants for an event (including unsuccessful applicants) up to date on the process prior to and outcomes after the event.</p>	<p>This is particularly important for research, which has a history of extracting information without giving back to the community.</p>

Committee meetings

Actions	Notes
<p>Payment as committee member Consumers and carers should be paid to attend a committee meeting unless they are attending in their paid employment role.</p>	<p>Payment should cover all time spent on the activity including prereading and post meeting activities.</p>
<p>Payment as experts Consumers and carers who act as a chairperson or “expert” in a committee, should be paid at a higher rate than for participants.</p>	<p>Both BEING and MHCN have a list of suggested hourly rates for different activities, such as participant, chair, expert etc. These are adjusted regularly to allow for inflation. Please contact either BEING or MHCN for the current rate per hour that they recommend.</p>
<p>Meeting papers Consumers and carers should be provided with meeting papers at least one week prior to the meeting. Consider providing consumers and carers with a plain English version of technical papers where they form part of the committee papers.</p>	<p>Unlike others on the committee, consumers and carers may need longer than other committee members to read and process the material.</p>

Requesting a person tell their story/experience

Actions	Notes
<p>Finding someone to tell their story A request to BEING or MHCN to find a consumer or carer to tell their story should be made at least 4 weeks and preferably 8 weeks prior to the date of the event.</p>	<p>Both organisations hold databases on consumers and carers that can be asked to participate in storytelling. We may need to charge a fee if a request for a specific consumer or carer requires considerable time to fulfill.</p>
<p>Support for consumers/carers telling stories When a consumer or carer 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/co-carer or a consumer peer worker/carer peer worker.</p>	<p>The person may need coaching on how to best tell their story, and what to expect from telling their story, so they can be fully prepared.</p>
<p>Payment for someone to tell their story The storyteller should be paid at the “expert” rate identified above and reimbursed for additional costs such as preparation time and travel costs. Where applicable consider a payment for travel time.</p>	
<p>Publication of stories Prior to agreeing to participate in storytelling, consumers and carers should be asked to consent to their story BEING recorded and reused. They should also be given information on how their stories will be used. They should be provided with the opportunity to place restrictions or limitation of the distribution of their story if that is important to them.</p>	<p>Written authorisation for any videos, websites or other means capturing the person telling their story is required. The participant can give full direction to where and for what period their story is made publicly available and reserves the right to withdraw consent at any time.</p>
<p>Expert comment on the story Care is needed when there is expert commentary on the story after it is told. BEING and/or MHCN should be consulted where there is the intention to include a commentary or review of the story at the event.</p>	<p>Care is needed to ensure that “expert” comments do not negate the story’s impact. BEING and MHCN can provide a broader consumer/carer lens to the story, rather than a clinical view.</p>

After the engagement

Action	Notes
<p>Acknowledgement and follow up Ensure that you message consumers and carers with an expression of acknowledgement, thanks and appreciation. This is more important than simple politeness.</p>	<p>Consumers and carers are likely to find engagements around mental health issues stressful and challenging. Expressing acknowledgement, thanks and understanding, when their engagement is finished, may be particularly important for their self esteem and wellbeing.</p>

Contact details are provided on the cover page of this document.