

Mental Health Carers Voice Engagement Framework

History of the program

In developing this Engagement Framework it came in response from feedback from carers, some internal concerns we had regarding the diversity of our representation program and increased external demands for consultation. In our program design previously, there was a strong focus on Mental Health Carer Representation on committees and working groups. This has been the standard for good consumer and carer engagement for many years and followed the partnering with consumers rhetoric of the '*Nothing about us, without us*'.

Many carer representatives involved in systemic advocacy felt that the role was highly important because being present in the room put carers needs in the forefront of peoples' minds. We also had people who had been mental health carers for a long time and really wanted to give some of their expertise to improve outcomes for future carers.

However, there were also hurdles in carer representation being the primary model for engagement. For many carers sitting on a committee was unappealing, intimidating and/or impractical. Even with training and support carers had experiences of the committee work being very slow, feeling unheard or 'out of the loop' and unsure of how they contributed. It was also mentioned that it felt prohibitive to many carers as their working role or their caring role made it difficult to commit to regular engagement with the committees.

We also received specific feedback from Aboriginal and Torres Strait Islander carers, Culturally and Linguistically Diverse carers and Young Carers that that model for carer engagement felt very exclusive and intimidating with elevated levels of bureaucratic processes that they did not understand and the use of jargon making it feel like they did not belong. We attempted to alleviate this by having focus groups with these carer cohorts to feedback to the carer representatives on the committees these other carer views, but carer representatives reported that the opportunities to contribute feedback such as this was limited by time and whether the comments were deemed relevant or were 'parked' within the meeting.

Because of these difficulties, carers who were interested and able to participate in carer representation were often similar in their background. They had been caring for many years, the person they cared for was generally more stable in their mental health or had passed away. They were predominately composed of white-Australian, retired public servants with a slight over representation of males (when considering most primary carers are female). Many of these carers have also been involved as representatives beyond their recommended term because no other carers have approached to nominate, which added stress and strain to these carers because they felt a duty to continue to advocate.

However, considering the many changes the sector has undertaken, many of these carers have not engaged with the current services or under the current legislation. This has meant that we had increased need to provide the carer representatives with more insight into other current carer experiences of services to keep their representation relevant. Due to the slow nature of systemic advocacy as well, many of our carer representatives were feeling disenchanted by the hope of improving mental health services and were feeling 'consultation fatigue'.

Our observations of carer engagement have been that there is a willingness to engage, but an uncertainty of how to do it purposefully. And it was clear to us that there were clear difficulties sustaining non-purposeful

advocacy activities in this model moving forward. Our experiences informed us that it was a necessary component but should not be the principal component to good carer engagement.

With so many different areas of change there is a need to define our methods for carer engagement and develop clear decision-making regarding priorities based on carer need.

This will hopefully involve capturing a broad range of carer experiences, across the many changing areas of mental health, maintaining carer wellbeing in this unstable environment and ensuring that the information is purposeful and producing good outcomes for carers

Development of the Framework – Consultation

In developing our current framework, we returned to what was important to mental health carers, what were the values of our program to ensure that we stayed true to the mental health carer voice for the program's future.

This process was undertaken through a long process of formal and informal consultation with carers whereby we interviewed carers who had been committee representatives, carers who had attended trainings but decided not to become committee representatives and carers who attended our focus groups why they participated that way and we started to understand carer engagement more.

Speakably broadly, carers found the committee representation difficult to engage with, even the carers who worked in the sector felt that they were talked down to and never able to keep up. We also had some targeted conversations with specific cohorts of carers. The young carers, Aboriginal and Torres Strait Islander carers and CALD carers found engagement with our program particularly difficult because of the focus on committee representation and within the committees the language barriers and jargon were difficult even for those who were proficient in English.

Time was also a large factor for carers, they wanted to feel informed for the meeting, read the meeting papers, know what was happening in the wider carer community and then report back what was happening to us which took a long time. This meant that there was great difficulty in people in current caring roles participating whilst the person was unwell and also people who were working participating in the program.

This then led to a large amount of our committee representatives being retired former carers.

Some carers talked about their wellbeing and feeling like they had signed up to another commitment and it was hard to say no.

The positive aspects carers talked about was having a say, the transparency and accountability, the reimbursement (being valued) and knowing that people were being held to account and that your story and your opinion could be used to change the way the system worked and could go all the way to the top.

We were being faced with a series of factors – we had increased demands for carers to provide feedback and we had fewer carers who wanted to participate. We also had carers who were telling us it was starting to impact negatively on their wellbeing to participate so much.

We knew that whatever we did, carers had to lead the decision making and that transparency and accountability needed to be included.

We also paid particular attention to the time, value and wellbeing components of the conversations. Carers are time poor, they are often not valued by society for their contribution and they already have difficulty maintaining wellbeing so our engagement model needs to support carers with effective use of their time, valuing their contribution and supporting their wellbeing.

From our consultations the carers that engaged with us that had the most positive experiences were the carers that saw what they had done had achieved positive impact – so we started looking at models for focusing on engagement that leads to real change, such as more co-design and deliberative democracy etc.

What our consultations and review of the program led us to was developing some core engagement principles for the Mental Health Carers Voice which are;

- Our decision-making process puts mental health carers at its peak
- We are committed to Purposeful Advocacy and to creating meaningful change
- Mental Health Carer Wellbeing is a High Priority in the Work we do
- We are informed by what carers experience and by evidence-based interventions
- We keep Carers Engaged in the change in the Sector and the work we do

Our model for engagement is based on the core values of Public Participation; *(IAP2.2019)*

1. Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.
2. Public participation includes the promise that the public's contribution will influence the decision.
3. Public participation promotes sustainable decisions by recognising and communicating the needs and interests of all participants, including decision makers.
4. Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.
5. Public participation seeks input from participants in designing how they participate.
6. Public participation provides participants with the information they need to participate in a meaningful way.
7. Public participation communicates to participants how their input affected the decision.

Decision making framework and Carer Led

The most meaningful change for this program sits with its governance framework. As a cohort, mental health carers are experiencing change and requests for input into a vast amount of sector reform. This includes, but is not limited to, inpatient mental health, primary mental health, carer supports, community mental health, disability, housing, education, welfare payments and more. As a result, and as stated above, there is a need to prioritise the issues and to utilise carers time and expertise on the issues that are most likely to have direct impact on mental health carers.

To undertake this, two carer-led approaches are utilised for the decision making regarding the priorities for carer engagement and the methods utilised for each priority.

Firstly, the establishment of an annual Mental Health Carer Priority Needs survey for identifying the priority issues and secondly the MHCV Advocacy and Policy Advisory Group that are responsible for

1. distilling the survey results into a Strategic Plan for the Mental Health Carers Voice program.
2. Reviewing the survey results the following year to update the strategic plan if necessary
3. Directing the workflow of the MHCV program assuring it aligns with the Strategic Plan.

The Advocacy and Policy Advisory Group is comprised of Canberra mental health carers and is advised by the Manager of Policy and Stakeholder Engagement for the MHCV. They are ultimately responsible for the direction of the program. More detail regarding the committee Terms of Reference, Code of Conduct, Application Process etc. will be provided in supporting documentation.

All members of the committee are responsible for adhering to their role responsibilities and are reimbursed if they wish to be for their involvement. The Group decides whether the activities/positions of the MHCV align with the Strategic Plan priorities and if so, the level of carer engagement needed to form a response.

Putting the Carer First

A central principle for this carer led framework to be successful is a commitment from carers to think about their own needs. It is often difficult in the carer advocacy space for carers to identify their needs as separate to the needs of the person they care for. For families, the needs are too entwined to separate, and many carers consider their advocacy role to sit as acting to advocate for more mental health services for the person they care for.

Whilst this is undeniably a major issue within mental health advocacy and the MHCV continues to promote the enormous need for greater investment in all levels of mental health to ensure the right treatment is available at the right time. This is advocacy that is taking place through most, if not all, the mental health peaks and we would have little new to add to that conversation.

Therefore, part of the decision making and the program direction needs to be about being non-duplicative, partnering with other peaks where it is best for an advocacy position and also solidifying our role as Peak Body for Mental Health Carers in the ACT.

This framework, therefore, identifies that focus for advocacy work needs to meet the following criteria;

- Does the issue have a significant impact on mental health carers? What is that impact?
- Is this an issue specific to the ACT or one where the ACT is uniquely positioned to comment?
- Is this an issue where carers and consumers may have different views?
- Is there any other significant work being undertaken that we should participate and collaborate on instead?
- What is the likely outcome for undertaking this activity and is the timing right?

It will be the responsibility of the Mental Health Policy Officer to provide this advice throughout the year to the APAG to incorporate into their decision making.

Purposeful Advocacy

What this means is that the work we do is focus on achieving undertaken through a decision making framework focused on;

- What is the Impact on Mental Health Carers?
- What is Mental Health Carer Influence on the Decision that is being made?
- What is the level of interest that Mental health carers have in the issue?
- What is the best method for us to achieve the best outcome for Mental health carers?

Mental Health Carer Wellbeing is a High Priority in our Engagement

When making a decision about what we advocate on and how to approach our advocacy method, a duty of care responsibility is beholden to us.

Carer wellbeing is complex, as we have known that carers can become highly enmeshed in their caring roles, we have made a conscious wellbeing position to emphasise life outside of caring as a priority for our carers as well, which is why most of our advocacy involvement is going to be time limited, and targeting people with a highly recent caring experience. We ideally want a carer to become involved to have a clearly defined advocacy role and to have it end at the expected time and be able to see what they contributed to and feel positively about it because they have seen the project completed.

We are informed by what carers experience and by evidence-based interventions

All of our position statements, responses, budget submissions etc. are to be based on carer feedback that is gathered in a high-quality method and from a wide variety of carers and also evidence informed ie. research based or best practice-based interventions.

We want to have a breadth of carer experiences informing our positions but also a depth of understanding of the issues as well.

For example; APAG will need to be consulted at the start of developing a position statement to ensure that it is

1. An issue that requires a position statement
2. To determine the scope of the consultation required to develop the position
3. To determine if it is a particularly sensitive issue that we may need to run the consultation differently

We would then bring back the draft report to APAG for approval; edits if necessary, for clarity etc. concerns. Then;

4. To develop the communication strategy of the findings.
5. For any recommendations that may result from the findings for projects etc.

We keep Carers Engaged in the change in the Sector and the work we do

Inform

We keep carers informed about the changes that are occurring through an e-bulletin, a website, social media updates and regular information sessions that are face to face in the community.

We have approximately 750 subscribers to our e-bulletin. We regular engage with key partner organisations and have established relationships with the other mental health peaks, health peaks, family peaks and youth peaks to facilitate exchange of information and ideas.

Consult

We want to get feedback from those 750 through a range of different mechanisms including having them responding to surveys, sending in their stories and giving us feedback regarding specific papers and policies

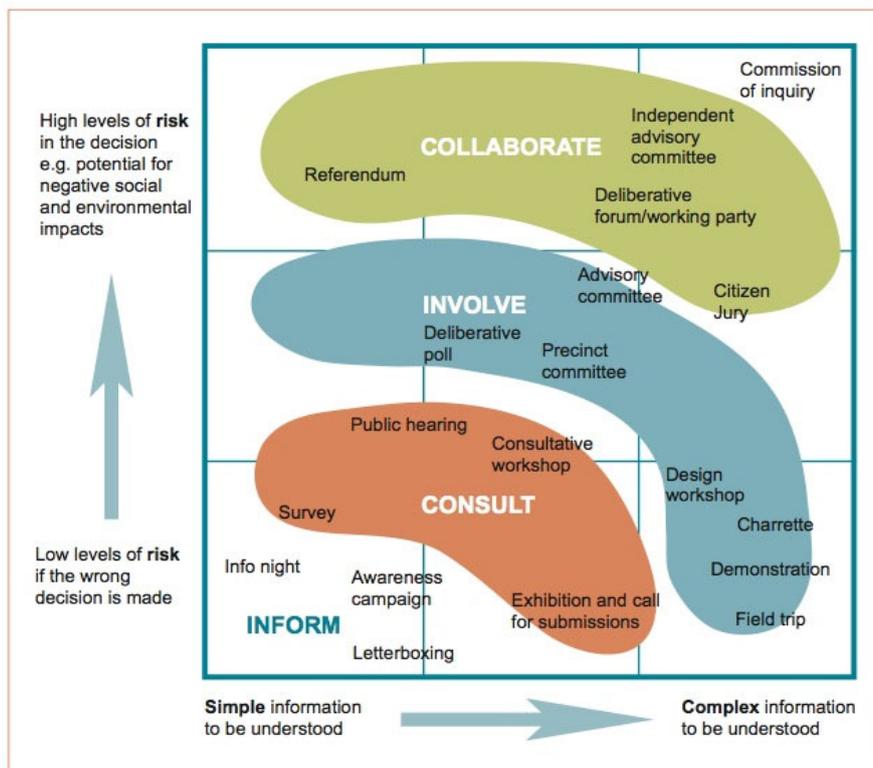
that come out. That helps us to develop our positions and understand what carers are experiencing on the ground.

Involve

We also want to involve carers in a bit more discussion through focus groups and workshops where we can really unpack that information, evaluate the evidence, get their recommendations for what we should write in our response specifically and have carers help us to craft our positions in more depth.

Collaborate

Bring mental health carers and the other parties to the table for deliberative discussions/co-designing workshops/world cafes developing more comprehensive plans where we can all work together to improve what is out there through collaborative approaches that can tackle the complex issues.



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This framework is constructed to value carers' time and expertise. It is most valuable for carer expertise to be utilised in the areas of most impact as defined by them. It is also crucial to utilise the most appropriate method for the type of information to be evaluated as in the above diagram.

The intent of the design is that more methods and therefore more carer input will be sought for issues that are likely to have the greatest impact on mental health carers. It is also intended to enable more proactive work to be undertaken in addition to responding to opportunities as they present, within the sector.

With a greater push in the sector to be consultative, we have witnessed the impacts on carers of 'consultation fatigue' whereby carers feel that they have been asked their opinion on an issue many times and witnessed minimal change. This can have many negative impacts on carers whereby they become disenfranchised with being consulted, feel it is tokenistic, a waste of time and that they are powerless in the system. This has

negative impacts on carers mental wellbeing and has the opposing outcome from that intended, whereby carers became less engaged in the conversation. This model also aims to address that by enabling us to proactively seek carers views on services and topics that arise regularly and then utilising that feedback to advocate for carers needs.

In this way proactive work shall be an investment into responsive work to reduce the amount of demand for input from mental health carers on the same issues and reduce duplication. This shall also assist with ensuring good follow up is prioritised from previous consultations so that carers are made aware of the positive impact their input has had. It also addresses some of the barriers to engagement identified in the previous section where carers will be able to participate in a manner that acknowledges their caring role and capacity.

For example, we have accumulated a few carer stories following the Mental Health Carers Voice Budget Response with the intention of following up with those carers who contacted us to let them know what is happening regarding updates specifically on the projects that they were interested in. This carer feedback maintenance is not time consuming and setting reminders on outlook can ensure that there is ongoing valuing of the contribution that those carers made.

This engagement responsibility will fall to the MHCV Program Officer, who will manage the carer engagement activities whilst the Manager of Policy and Advocacy role will take a more active role in engaging with decision makers.

Do No Harm Principles underpin our program

Introduction

These principles underpin all engagement events with mental health carers and act as a strengths-based risk management strategy for our program

Principles

The Mental Illness Education ACT Do NO Harm Principles govern participant and facilitator conduct at all events hosted by the Mental Health Carers Voice Program, and these Principles are explained at the start of larger events and at appropriate facilitated workshops and focus groups.

For larger forums, MIEACT shall be invited to present a brief introduction on the principles of Do NO Harm. In keeping with this, staff and carer advocate Do NO Harm Training shall be provided annually through our program to improve understanding of safe talking in mental health.

Our program acknowledges the importance of privacy, confidentiality and informed consent in all its undertakings and that carers who attend may be at different stages of their caring journey. As carers attend these sessions to obtain information and increase their knowledge of advocacy and the mental health sector there is no expectation or obligation on carers to disclose anything they are not comfortable discussing (ie. who they care for, what the person they care for is diagnosed with etc.).

These sessions are not targeted at providing emotional or social support; however, information on those Carers ACT services will be made prominently available. We support all mental health carers to participate in systemic advocacy when and how they are ready to do so.

When running events jointly with the Carers ACT Support Services, clear roles and responsibilities will be designated based on area of expertise and outcomes wanted from the session.

All facilitators will be given clear instructions on what is wanted from the session and debriefed on the Do NO Harm Principles as well as the MHCV event principals to make no request on carers to disclose information prior to the event.

Facilitators will provide the Mental Health Carers Manager Policy and Stakeholder Engagement with their full presentation for approval before the event and Carers ACT reserve the right to request presenters to edit the presentation on the basis of mitigating risk to carers.

In organisation of events, the content of the session is assessed to determine the sensitive nature of the topic. For sessions that are on sensitive topics, a higher risk management strategy shall be implemented which shall include the booking of a counsellor to attend the event, hosting the event during the day where possible, self-care plans and a mindfulness exercise to end the session. This would be true for an emotive topic such as a consultation on caring for someone with an Eating Disorder.

For sessions that are deemed lower in risk (such as “what is systemic advocacy?” etc.) the facilitator (and the Mental Health Carers Manager Policy and Stakeholder Engagement) shall be responsible for ensuring risk management via maintaining the Do NO Harm principals throughout the session and that information on self-care is provided to participants at the start and the end of the session. (ie. they can book an appointment to see a counsellor, they are providing the opportunity to take time-out from the session and/or debrief with a staff member of the program following the session).

Any carer who appears distressed from the session will be spoken to before they leave individually and followed up with (as necessary).

Carer will be provided with the opportunity to provide anonymous feedback and any concerns will be actioned, provided to the facilitator directly or, as appropriate, referred to the manager of the presenter.

Working our Engagement Framework into Tailored Solutions

Largely we continue to receive our primary engagement requests to participate on various issues through a request to have a representative sit on a committee. We continue to need to respond to the requests with a tailored response depending on how we want to be involved and what objective they are seeking.

Often the issues are very aligned with our strategic plan and so we want to engage on them, however committee membership is rarely the best method for us to achieve our objectives. This is where we elect to develop a Tailored Stakeholder Engagement Plan depending on how important the issue is to our Strategic Plan.

We approach the group who requested our participation on the committee and ask them to be more specific about what they want to know about mental health carers. We ask them specifically how the project/policy will impact on mental carers. We then discuss some options regarding what we could facilitate. We also discuss the Influence that we would have on the outcomes for those sessions depending on how it was run.

Our aim is to achieve a strategy that can return a clear plan for both parties for engagement with impact, influence and interest and with clear purpose. This meeting also needs to discuss the communication of information regardless of it being ‘engaged’ on directly so just utilising our networks to keep information

flowing in both directions, regarding carer feedback if I hear it on the ground I have a contact and a channel to feed it through and regarding updates, they have a contact and a person who will distribute it through our website and social media etc, on the project so that we do not lose that opportunity. We may even decide that there is a need for a specific information night with carers if enough questions are being asked and that could be arranged.

The Manager of Policy and Stakeholder Engagement then completes the Engagement Template with these details and takes it to APAG for endorsement and then final timelines can be agreed upon from there.

This gives a clear agreement between all parties regarding expectations, time frames and delivery and ensures the mental health carers voice is delivery a professional quality service.