MENTAL HEALTH
carers voice

Mental Health Carers Voice

"We Care Too"
Report into Mental Health Carer Engagement Tools

For use in ACT Mental Health Services

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Acknowledgements

Executive Summary

The biggest surprise we found that may not jump out when you read this report is just how passionate and engaged the staff were at all levels in Canberra Health Services. Or how strong the intent was to work with all necessary parties to achieve the best possible outcome for the person receiving care and their family and friends.

One of the core aims underpinning these consultations was to create a safe and deidentified environment for staff so we could capture authentic and accurate data. We believe this was achieved this and have included snap shots of staffs' thoughts around the carer engagement process throughout the document.

Staff told us the evidence-based carer engagement tools used were all great, however implementing them may not be possible due to a range of reasons discussed throughout this paper.

We presented staff with the following engagement tools

- Very Important Partner Program
- 15-Minute Family Interview
- Patient/family-activated rapid response teams
- 'Ask 3 Questions'
- 'TOP 5'
- Staff De-escalation training
- Carer Checklists
- Carer Information Packs

At the end of the report we have included key recommendations around

- Changes across the whole of the ACT Mental Health Services
- Engagement tools for Adult Mental Health Unit
- Engagement tools for Adult Community Mental Health Services

We know that the Mental Health, Justice Health and Alcohol and Other Drugs Division of Canberra Health Services is hearing the mental health carer voice and commend them for their efforts towards continual improvement of mental health carer engagement.

Introduction to Mental Health Carers Voice

Mental Health Carers Voice (MHCV) is the Peak Body for Mental Health Carers in the ACT. MHCV actively engages with mental health carers to have their voice heard and create positive change in the sector through both individual and systemic advocacy. The Mental Health Carers Voice Advocacy and Policy Advisory Group (APAG) provides a guiding voice for our Mental Health Carers Voice Peak Body work. Our strategic plan was developed with significant input from mental health carers. APAG regularly consults mental health carers to provide a basis to distil current problems and major concerns within that community. One overwhelming finding was that carers inevitably put their own concerns behind their concern for those they care for, and in the process suffer high levels of stress, exacerbated by feelings that their efforts are neither recognised nor valued by the wider community.

Vision

A Canberra that recognises, values and includes mental health carers.

Principles and Values

- Mental health carer wellbeing is central.
- Effective advocacy leading to reform.
- Informed by mental health carer experience and evidence-based research.
- Carer focused decision making.
- Mental health carers are informed and central to MHCV work.

Goals by 2023

- Mental health carers are safe in their homes.
- Mental health services recognise, include and value carers.
- Mental health services are of high quality and available when needed.
- Services in Canberra are inclusive.
- Mental health carers have good outcomes on the Wellbeing Indicators.
- Mental health carers are engaged in their workplace and education.
- Awareness of mental health caring increases in the community.
- Mental health carers have an identity outside of caring.

Introduction and Research Aims

Both ACT Legislation, ACT Health and Canberra Health Services Policy outline how the mental health services of the ACT should interact with and involve mental health carers in service provision for their loved ones.[i] Previous research from Mental Health Carers Voice found that while staff in the mental health service across clinical and non-clinical roles are eager to engage with carers, they lack the resources, time and training to do so.[ii]

This research was commissioned by the Office of Mental Health and Wellbeing, with the view of investigating particular engagement tools and strategies and the barriers to implementing these. The aim was to run group activities with ACT Mental Health staff in acute and adult community settings to provide insight into the barriers clinicians perceive in service delivery, and facilitate the development and consensus on simple, cost-effective tools and strategies that staff viewed as promising ways to improve carer inclusion.

This project also marks the first instance in which Mental Health Carers Voice has gathered extensive data on staff experiences of their interactions with carers. As the peak body for mental health carers, Mental Health Carers Voice is tasked with understanding the views and experiences of mental health carers and assisting in their translation into policy. This model, however, has the potential to manifest as an adversarial relationship with the mental health service.

To counter this, the project has been designed on the assumption that all stakeholders, including staff, are approaching carer inclusion with the best intentions. Rather than treating staff as a barrier to carer inclusion, we are assuming that staff are in fact facing their own barriers, and work to improve carer inclusion should follow the approach of 'all of us against the problem', rather than 'us versus them'. It was hoped that this project would test this principle of 'flipping the peak' and demonstrate the efficacy of applying this to achieve actionable outcomes and recommendations. At Carers ACT, we recognise that the staff, as well as carers, have insight and experiences which can help improve outcomes for consumers and carers, while also improving their own workplaces and development as professionals.

Research Methods

There is extensive academic literature on engagement tools used to help staff communicate with carers in a variety of clinical settings. For the purpose of this research, a literature review was undertaken, and a selection of those tools which had demonstrated positive outcomes was prepared. A complete list of the tools, and supporting research, is included in the Appendix. Many of these tools were developed for use in a clinical setting not related to mental health, often for patients with dementia, cancer, or other ongoing conditions. Due to the lack of research to support the implementation of these tools, specifically in mental health settings, it was imperative to consult with staff to better gauge, which may be useful.

In consultation with Canberra Health Services, it was determined that this project would focus on staff at the Adult Mental Health Unit (AMHU) and the Adult Community Mental Health Teams. Due to the narrow timeframe of the project, the surveying of two branches of the service was considered ideal. Conducting research on branches with very different clinical roles allowed for a richer data set to be collected within the specified time, as staff have very different experiences with carers in acute and community settings.

 A survey was distributed to all Adult Community Mental Health and AMHU staff. Staff were invited to complete the survey even if they did not intend to attend the forums, in order to gather a larger data set. The survey was intended to provide contextual information to better structure the group forums. A copy of the survey can be found in the Appendix. Mental Health Carers Voice conducted several forums with staff in AMHU and across the Adult Community Mental Health Teams. Three forums were held at AMHU, one forum at Community Mental Health in Belconnen (open to all northside staff), and one at Community Mental Health in Woden (open to all southside staff). All staff were welcomed to attend.

Forums were semi-structured and were designed around a deliberative democratic process, based on the VicHealth citizens forum on obesity held in 2015.[iii] Forums were 60-90mins in length and included an explanation of the carer engagement tools and a facilitated group discussion to gain feedback from staff on each tool. Worksheets were given to staff to aid in the organisation of their thoughts, and to gather specific information on the benefits and drawbacks of each specific engagement tools, as well as any modifications staff thought necessary to translate the tools to the ACT setting. Forums were recorded and transcribed.

A dot-mocracy was completed at the end of the session, where staff could indicate the engagement tools they most preferred. In this process, staff were given four dots which they could assign to any of the engagement tools. They could distribute the dots as they pleased (e.g. if they thought only two of the tools would be effective, they could assign each two dots, or if they liked one more than the other, they could split their dots 3-1 etc.). This provided a quantitative indicator for staff support for individual engagement strategies

MHCV consciously established a safe consultation environment for staff to share their thoughts by assuring deidentification, establishing professional boundaries and being clear the end goal of better carer engagement benefited both carers and staff. A consent form was signed by all participating staff outlining how the data that was gathered would be used, including the management of the recording of the forum and deidentification of all data.

Results and Discussion

This discussion has two main areas of focus: broad themes identified by staff relating to perceived barriers to engaging with carers, and the staffs' opinions of the engagement tools presented to them. Only the tools with the most staff support will be discussed here, but staff comments on all tools can be found in the 'Worksheets' in the Appendix. A summary of recommendations and promising engagement tools is included in the conclusion of this report.

Several forms of data were collected to provide a comprehensive understanding of the experiences and opinions of staff. This included:

- Survey distributed to all staff
- Transcription of forum discussion
- Worksheet for staff to fill out during the forum
- Dot-mocracy tally for quantitative assessment of engagement tool preferences
- Feedback form

The survey received only 8 responses, which is insufficient to perform a robust analysis. Although the survey data was useful for providing contextual information for forums, it will not be used in this report to address the research aims specifically.

The attendance for each forum is shown in Table 1. To ensure deidentification and prevent the attribution of comments to individual staff, the specific roles of staff members were not linked to any of their statements other than a general title (e.g. allied health, nurse). In accordance with the consent obtained from participants, all forums were recorded, and the discussions transcribed. The transcriptions were analysed using inductive thematic approaches previously employed by ACACIA, The ACT Consumer and Carer Mental Health Research Unit at the ANU, to identify research priorities in the mental health space.[iv] Two types of data were extracted from the transcripts. Firstly, any direct comments about the specific engagement tools discussed were identified and combined with the commentary provided on the worksheets. In addition, recurring keywords and discussion topics were identified, coded, and organised to provide an understanding of the systemic issues which impact the implementation of the engagement tools, and staff capacity to engage with carers more broadly.

Staff were encouraged to fill in the worksheet provided as a group during the forum discussion, to organise their thoughts on each tool specifically. The comments on all worksheets were combined into two documents – one from the AMHU forums, on one from the Community Mental Health forums – which are included in the Appendix. This data provides contextual information for the dot-mocracy, modelled on the preferencing process used by ACACIA researchers.[v] The dot-mocracy results are included in Table 2. Even when combining all forums, the attendance did not constitute a sample size large enough to perform robust statistical analysis of the dot-mocracy results. Instead, these results were used to assess relative enthusiasm for certain tools.

The feedback form provided information about the efficacy of the forum as a means for engaging with staff. This is discussed at the end of this section.

Table 1. Attendance Data

	AMHU #1	AMHU #2	AMHU #3	Belconnen	Woden
No. attendees (consent forms signed)	6	3	5	11	9
No. feedback forms	2		5	9	7
Professions	Nurse, Allied Health	Nurse	Nurse, Allied Health, Social Worker, Management	Clinician, Nurse, Social Worker, Allied Health Assistant, Policy	Nurse, Team Leader, Ambo quality assurance, psychologist

Table 2. Dot-mocracy Results

Engagement Tool	AMHU #1	AMHU #2	AMHU #3	Overall % AMHU	Belconnen	Woden	Overall % Community
Very Important Partner Program	3	2	3	18	4	1	5
15-Minute Family Interview	3	2	5	22	9	3	13
TOP 5		1	3	9	3	5	8
Family Activated Rapid Response Team		4		9	2		2
'Ask 3 Questions'	1		4	11	2	2	4
Communication and De-Escalation training	1	2		7		2	2
Carer Checklists	3			7			
Carer Information Packs	3	2	2	16	1	4	5
Staff Idea 1			Tech/app support: 1	2	Carer Space: 6	Structured Supervision/Professional Development: 8	CS:6 PD:8
Staff Idea 2					Training for Carers: 6	Carer Orientation: 5	T: 6 CO:5
Staff Idea 3					Carer drop-in service: 12	MH Training for AH Professionals: 3	DI:13 AH: 3

Barriers to Engagement: AMHU

In the course of discussing each of the engagement tools, staff also made insightful contributions about the function of the service more broadly, including many personal experiences. In their view, these issues required careful consideration when designing engagement tools, as they were seen as the underlying causes of difficult interactions with carers. In the analysis of the transcripts from the three forums, several key themes emerged, primarily relating to breakdowns in communication both between staff and between staff and carers.

Rights and Responsibilities: staff reported that the relationships between staff and carers is often strained because it is unclear to both parties what are the rights and responsibilities of carers and staff. While it was clear to carers what responsibilities staff had relating to the care they provide to consumers, staff's right to a safe and respectful workplace was less well understood. Furthermore, staff recognised the importance of explaining to both carers and consumers what their rights were under current legislation and policy, while also making clear that certain behaviours, including destruction of property and abuse of staff, would not be tolerated. A consumer document developed outlining rights and responsibilities does exist, but there is not one for carers which could potentially be used to inform carers.

Managing Expectations of Carers: All staff who participated in the forums expressed their understanding of the stress and anxiety that carers deal with when they're loved one is hospitalised. Staff also said that due to carers' expectations of what types of services are provided in acute care, relationships with staff can become fraught. As one staff member stated;

> *[When you're a carer] you're at your wits end. You've dropped [your loved one] off at hospital and you think that once you get them into hospital then, bang, they're fixed.*

Staff recounted several instances where carers coming into contact with acute services for the first time perceived hospital admission for a mental illness as similar to admission for physical illness. To paraphrase one staff member, carers thought if you go into hospital with a broken limb, you will leave hospital with a cast and with a specific appointment to return and

have the cast removed, at which point you have been 'fixed'. Without adequate time or resources to provide psychoeducation to carers on the recovery model of care, these perceptions can shape what carers believe an admission for mental illness will resemble, and that AMHU will 'fix' their loved one. Staff agreed that these issues needed to be addressed when carers first come into contact with the service, to help manage carers' expectations of what the service can provide for their loved one.

Staff also sympathised with carers who expressed their frustrations when trying to contact the treating teams. In particular, carers who had not been provided adequate information about how a multidisciplinary team functions often expressed confusion;

> *Because I've talked to a lot of [carers], and all they really want is a conversation with the treating team … [but they become distressed and say] 'I've been told x by the doctor, but then I get a call from y' – Allied Health*

Again, staff across all three forums agreed that providing information to carers about how treating teams works, and why their loved ones have a variety of allied health and clinical staff involved in their care, would dispel this confusion.

Variation in staff experience of the workplace: Staff who attended forums were in a wide range of professions, and at different stages of their careers. This allowed us to capture a variety of experiences. In particular, staff reported different encounters with the treating teams and different opportunities for professional support. While some staff found it easy to contact treating teams, arrange family meetings, and prompt social workers to contact families, others had found these to be points of difficulty.

For example, staff in one forum unanimously recognised that the role of Aboriginal Liaison Officer was well-supported by staff at AMHU, and this staff member was in an ideal position to serve as a channel for communication between treating team staff, and consumers and carers. Participants expressed a desire for other staff members, particularly the floor staff who often are the main point of contact for carers, to be similarly supported.

Staff Preferences for Engagement Tools: AMHU

The dot-mocracy showed the greatest levels of support for the 15-Minute Family Interview, Very Important Partner Program, and Carer Information Packs, representing a combined 56% of the votes cast by staff. Not included in the dot-mocracy, however, were staff suggestions for a fulltime carer consultant and expanded responsibilities for the discharge liaison. These two staff positions were seen as essential to the success of implementing all of the engagement tools presented to them, primarily due to insufficient time and resources for staff to complete additional tasks. The floor staff, both in nursing and allied health, felt that these positions were vital to ensure clear communication between carers and the staff at AMHU. A carer consultant would serve as a single point of information flow to and from carers, to address the issues staff had highlighted around managing the expectations of carers. As one participant stated:

> *I think it would be nicer for families, to know that this is the person I call. I'm not calling ten times in one day and talking to ten different nurses. – Nurse*

If carers knew they would always be talking to a single staff member whose role was dedicated to them, staff felt that communication would improve. Staff acknowledged that there is already a carer consultant at AMHU, but expressed a desire for the role to be made fulltime, and for their duties to be adjusted to include the role of facilitating communication as described, rather than having carer enquires come straight through to floor staff. Furthermore, participants in forums 1 and 2 agreed that rollout of other tools, such as the 15-Minute Family Interview, would require management from not just from clinical managers but also the carer consultant. In addition, staff expressed a desire for the role of the discharge liaison at AMHU to be adjusted to include more involvement with carers to identify any issues (e.g. housing) that may need referral to a social worker or other staff member, rather than only providing clinical referrals for the consumer.

The 15-Minute Family Interview is a structured interview format developed as part of Family Systems Nursing.[vi] The format includes therapeutic questions designed to help staff guide conversations with family and carers about their loved one (e.g. 'what was the most/least

helpful part of your loved one's previous hospitalisation/contact with the service?').[vii] The format can be used any time a staff member talks to a carer, and is intended as a guide to facilitate communication, rather than a didactic tool. Although staff thought that 15 minutes was too short a timeframe for a conversation, they viewed it as a useful tool to ensure that carers felt included, their needs were addressed and that key information was properly communicated at first and last contact with the service.

Although staff identified several potential issues with the Very Important Partner (VIP) Program during the group discussion, it received substantial support in the dot-mocracy. The original trial of the VIP program involved both consumers and carers. It allowed consumers to give someone of their choice a 'Very Important Partner' badge, identifying them as the 'VIP' in their life who they choose to be a part of the treatment team and involved in discussion of their care.[viii] Staff at AMHU identified that this was very similar to the current policy in the ACT which allows consumers to have a Nominated Person involved in their care. The VIP program was seen by staff as an extension to this, where the symbol of handing over a badge would make carers feel more included, and consumers respected for their choices.

Staff, however, were clear in the group discussion that several issues would need to be resolved to make the implementation of this program feasible. In particular, procedures would need to be developed to deal with large and complicated families, where a single VIP may spark tensions between multiple carers who view their input as equally important. In addition, provisions would need to be made for when the consumer does not consent to any information being shared with a carer, and hence does not want to give anyone VIP status, or when the consumer wishes to change their choice of VIP. The administration required to keep track of this was also seen as a hurdle. Although the VIP Program received substantial support in the dot-mocracy, these concerns raised in the discussion, and recorded on worksheets, indicate that implementation of this tool would require considerably more planning and consultation than the others.

Carer Information Packs were suggested by Mental Health Carers Voice' previous report on staff perceptions of carer engagement released in 2019.[ix] Packs would consist of a collection of relevant referral information to assist carers with identifying supports available when their loved one is discharged from acute care. The rollout of these packs would include a warm handover of the pack from a staff member, allowing carers to clarify any points of confusion.

Although staff were concerned that the hand over would place an additional burden on staff, they were generally supportive of providing tools to help educate carers. In particular, staff saw the information packs dovetailing with the recovery model of care, where carers can be empowered to make their own choices about the supports they wish to access when provided with adequate information. Participants also stated that information in these packs would need to be substantially changed from those currently published, as their wording is overly bureaucratic and difficult to understand.

Analysis of the forum transcripts, worksheets, and dot-mocracy from the AMHU forums indicates strong staff support for expanded responsibilities for the roles of carer consultant and discharge liaison as a means of increasing the services' capacity to engage effectively with carers. Furthermore, these discussions indicated staff support for developing an implementation framework for the 15-Minute Family Interview and Carer Information Packs with the carer consultant. Although receiving support in the dot-mocracy, there were many obstacles identified with the possible rollout of the VIP Program. We recommend that this tool only be revisited for potential implementation when the two mentioned above have demonstrated successful adaptation to the mental health setting.

Barriers to Engagement: Community Mental Health

Adult Community Mental Health staff, like their AMHU counterparts, discussed many issues surrounding carer engagement which informed their preferencing of the tools presented to them in the forum discussion. Staff saw psychoeducation of carers as a key aspect of their professional roles, and community care more broadly.

Communication Procedures: Staff identified several issues around communicating with carers, particularly over the phone. While staff attempted to address carers when they made direct enquires, they did not proactively call carers, as this was not considered part of their remit. Staff recognised that carers could often provide very useful information, as they knew their loved ones best, but they expressed caution around talking to carers;

> *... usually we don't approach them... I find it hard, especially when the client isn't on the same page as the carer. Like how much I can disclose, what can I say without the client's consent, especially when the client doesn't appreciate the carer commenting on how they are. And so it is hard to approach, so it is only when they call with their concerns that you communicate with them more. - Clinician*

Staff expressed a desire to have tools to address this issue, as they reported that carers often only called them when they were overwhelmed or in a time of crisis. Participants wanted training on the issue of consent, and how to de-escalate carers who may call the community team when they are highly agitated.

All interactions with carers are noted as part of their electronic records. Staff, however, found the system difficult to use, as records with large numbers of entries were difficult to sort through when information was urgently required.

Working with consumers when they are well: For most of the engagement tools discussed, staff suggested implementing them when the consumer was relatively well, as opposed to drawing on the tools only in a time of crisis. For example, participants suggested implementing the VIP program when the consumer was well, as they may not have the capacity to do so when they are unwell. Staff reported that although they do have the opportunity to organise family meetings with the treatment team, consumers and carers,

these often take place when the consumer is more unwell. Additionally time is spent on de-escalation and family conflicts, which detracts from building positive relationships with carers and consumers.

Staff, however, identified that consent can become an issue when Advanced Agreements are put in place when the consumer is relatively well. Sometimes, when a consumer's illness deteriorates, they no longer want the involvement of their carer or family member;

> *The thing is people could change their minds… so in the consent form, if you put this person [their carer], they are entitled to know, but then they [the consumer] change their mind… and then they say 'I don't want them [my carer] to know so I'm actually not going to come to the service anymore'. – Allied Health*

Addressing this was a concern for many of the engagement tools, which are primarily designed to facilitate communication when consent has been given to share information in the first instance.

CALD carers: Several staff from diverse backgrounds discussed the stigma around mental health that exists within their own communities and in the communities of many of their clients from a variety of cultural backgrounds. They reported that often mental illness is not understood in many communities, and religion, in particular, is seen as the only way for a person with a mental illness to be 'fixed'. Furthermore, carers often feared the reaction of their own, often close-knit communities, to their loved one's mental illness;

> *There's a stigma against it, and you [the carer] don't want to accept that maybe your child has a mental illness, because the other members of that community will push you away. And I think that's a big thing, where you don't get proper data … they don't want their kids to go into the system, so you don't get clear numbers – Allied Health*

Staff reported that although they often try to provide carers with information about mental illness, the recovery model of care, and evidence-based interventions, this information was often not taken on board. Staff were interested in those tools that would facilitate conversations with CALD carers which focused on psychoeducation.

Staff Preferences for Engagement Tools: Community Mental Health

Overall, the dot-mocracy indicated strong staff support for the 15-minute family interview, a carer drop-in service, TOP 5, and structured supervision/professional development for staff. These tools represented 42% of the preferences expressed by staff. This figure is comparatively lower to that from the AMHU staff due to the larger number of tools the participants voted on.

Adult Community staff, like their counterparts at AMHU, expressed most support for the 15-Minute Family Interview. Staff commented on the therapeutic aspect of the interview questions, and the opportunity it provided to quickly and effectively exchange information and develop a stronger relationship with carers. They were concerned, however, that carers would not be able to take off work and come in, especially for a meeting that only lasted 15 minutes. As staff already organised more lengthy family meetings with consumers, carers and the treating team, it was suggested that the principles and questions of the 15-Minute Family Interview could be incorporated into these meetings. They also suggested tailoring the questions in the interview to the carer, and specifically focusing on psychoeducation and helping the carer to navigate the mental health system. Across both forums, staff also suggested adding TOP 5 to the end of the interview, a proposal that was met positively by other participants.

TOP 5 was also well-received by staff - it was seen as 'strengths-based' and a good way to build rapport based on the carer's expertise. TOP 5 is a tool developed and trialled in NSW Health for use in aged care settings. It involves staff engaging with carers to generate a list of five key points of information which could help staff care for patients, including hobbies, triggers, and suggestions for de-escalation.[x] One participant in the Woden forum had used the tool while working for NSW Health and reported that the tool was often used by staff, particularly to assist in successfully de-escalating agitated patients. They stated that the TOP 5 sheets of all patients were kept in a hard copy folder to ensure ease of access. Other staff identified that TOP 5 would be incompatible with the current electronic records system, as it could not be pinned to the top of a person's file. A hard copy is a possible solution to this problem.

The carer drop-in service received unanimous support from participants at the Belconnen forum. It was not discussed at the Woden forum, and so support there should not be inferred. As described by staff, the drop-in service would be a regular block of time where carers could come to the community teams, without their loved ones, and have an informal chat with staff about any concerns that they may have. They believed that this service would give carers the chance to discuss topics which there is not necessarily time for in clinical meetings, ask questions about support services, and develop stronger relationships with staff by talking to them in a non-threatening environment. As one participant stated;

> *It is good for carers and clients to see us from a different perspective. Not just as coming to give them [consumers] an injection, but to see us as professionals … see us more relaxed. – Allied Health*

Participants from the Gungahlin team (attending the Belconnen forum) stated that they had a de-escalation room in their facility for clients, which was well-designed, used often, and potentially a more relaxed space where they could talk to carers as well. Other staff in the discussion from Belconnen, however, said they found it difficult to book rooms in their facility that were ideal for talking to carers. They suggested that the drop-in sessions take place in a dedicated carer space which was purposely designed to be inviting and relaxed, and not resembling a doctor's office or meeting room.

Staff at the Woden forum identified inconsistencies in training opportunities as a key barrier to professional development, including their ability to engage with carers, and a contributor to the high turnover rate of staff in the service. While some staff in attendance reported that they had received mentorship opportunities through structured graduate pathways, others, particularly nurses, reported that their opportunities were largely dependent on their caseload and their manager. All staff were supportive of mentoring and professional development frameworks which were consistent across the entire service.

For example, staff had received a variety of different de-escalation trainings depending on which branch of the service they worked in. The Violence Prevention and Management program was seen as the most useful for developing de-escalation skills, but only those participants who worked in forensic facilities had received this training. Staff members from

other services expressed a desire to receive this training as well, even when working in community settings.

The carer drop-in service, carer space and professional development were seen as a gateway to implementing other engagement tools. These changes, along with the development of a 15-Minute Family Interview/TOP 5 hybrid, represent a comprehensive approach to carer engagement. Though staff expressed personal preferences for other engagement tools, both forums reached a consensus on this approach, and staff were confident that it would improve their relationship with carers. This represents a strong outcome for the deliberative group process implemented in this research.

Staff Feedback

This engagement process received 100% positive feedback from all participants who returned the feedback form. Of those staff who elected to provide a numerical rating, all gave a rating at or above an 8/10. Staff themselves identified that the relationship between the mental health services and carers has been fractured for some time. Participants appreciated having a dedicated time to discuss carer engagement, 'debrief and come up with new ideas', and 'bridge the gap between staff and carers'. They viewed these forums as a productive step towards repairing communication.

This research project was underpinned by an innovative principle, 'flipping the peak', where Mental Health Carers Voice would for the first time formally engage with staff to assist our translation of the needs of mental health carers to impactful policy. The data gathered in the course of this project has generated a deeper understanding of staff experiences with carers, actionable recommendations which will benefit staff, carers, and the broader functioning of the service. Therefore, this project has fulfilled one of its key aims, to demonstrate the efficacy of 'flipping the peak' to meaningfully contribute to new policy developments.

Key Findings and Conclusions:

This report has several specific recommendations; suggestions for how the ACT Mental Health Service can generally support their staff to engage with carers, those engagement tools which staff viewed as most likely to be useful in their work setting, and the future research required to develop engagement tools for all services in the mental health space for carers.

- **Recommended changes across the whole of the ACT Mental Health Services**
  - Development of rights and responsibilities for carers
  - Ongoing training opportunities and consistent professional development frameworks for all staff members, including contract and casual staff
  - Engagement tools should focus on managing carers' expectations of the health service, and providing targeted psychoeducation specific to the needs of a variety of carers (e.g. CALD carers)
  - This research generated a rich qualitative data set which can now be used as a base for developing new policy and procedures to improve carer engagement. Further research, including all branches of the ACT Mental Health Services, should be conducted to build on this foundation.

- **Recommended engagement tools for AMHU**
  - Carer consultant and discharge liaison roles expanded to facilitate the implementation of other strategies, and serve as a single point of contact for carers to ease information flow
  - Development of an implementation plan for 15-Minute Family Interview training for all staff
  - Development of new information and resources, tailored to the carer audience, to be used in Carer Information Packs

- **Recommended engagement tools for Adult Community Mental Health Services**
  - Violence Prevention and Management training for all staff, and development of training for de-escalating carers over the phone
  - Dedicated carer drop-in service for each of the community teams, in a purposefully designed space where carers can have an informal chat with clinicians in a calm environment

o   Development of an implementation plan for 15-Minute Family Interview training for all staff, incorporating TOP 5 into the interview structure to help staff develop positive and therapeutic communication strategies

All staff who participated in this research project were engaged, passionate, contributed productively to group discussions and expressed enthusiasm for developing new ways to improve service delivery and their professional expertise. The consensus developed on new paths forward for carer engagement demonstrates the benefit of collaboration of staff to improve carer engagement.

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[i] ACT Government, "Adult Community Mental Health Services Model of Care," Published Oct. 2017, https://www.health.act.gov.au/sites/default/files/2018-12/Adult%20Community%20Mental%20Health%20Services%20-%20Model%20of%20Care%20-%20Final.pdf.

ACT Health, "Policy: Consumer and Carer Participation in ACT Health," Last Reviewed Dec. 2018.

The Mental Health Act 2015 (Australian Capital Territory), Republication No. 9.

[ii] Mental Health Carers Voice, "Staff Perceptions of Carer Engagement in The ACT Mental Health Services," published July 2019, https://www.carersact.org.au/wp-content/uploads/2019/07/Staff-Perceptions-of-Carer-Engagement-in-ACT-Mental-Health-Services.pdf.
[iii] new DEMOCRACY, "Process Design for VicHealth: How can we make it easier to eat better?", accessed October 7, 2019, https://www.newdemocracy.com.au/2015/09/25/vichealth-victoria-s-citizens-jury-on-obesity-2015/.
[iv] Michelle A. Banfield, Alyssa R Morse, Amelia Gulliver and Kathleen M. Griffiths, "Mental health research priorities in Australia: a consumer and carer agenda," *Health Research Policy and Systems* 19, no. 119 (2018): 1-11. https://doi.org/10.1186/s12961-018-0395-9.
[v] Banfield, Morse, Gulliver and Griffiths, "Mental health research priorities in Australia," 1-11.
[vi] Martinez, A.-M., D'Artois, D., & Rennick, J. E. "Does the 15-Minute (or Less) Family Interview Influence Family Nursing Practice?," *Journal of Family Nursing* 13, no.2 (2007): 157–178. https://doi.org/10.1177/1074840707300750
[vii] Martinez, D'Artois and Rennick, "15-Minute Family Interview," 157-178.
[viii] Kinsala EL, "The Very Important Partner program: integrating family and friends into the health care experience," *Prog Cardiovasc Nurs* 14, no. 3, (1999): 103-10.

[ix] Mental Health Carers Voice, "Staff Perceptions of Carer Engagement," 26.
[x] Luxford, Karen, et al., "Improving clinician-carer communication for safer hospital care: a study of the 'TOP 5' strategy in patients with dementia," *International Journal for Quality in Health Care* 27, no. 3 (June 2015): 175-182. https://doi.org/10.1093/intqhc/mzv026

References

ACT Government. "Adult Community Mental Health Services Model of Care." Published Oct. 2017, https://www.health.act.gov.au/sites/default/files/2018-12/Adult%20Community%20Mental%20Health%20Services%20-%20Model%20of%20Care%20-%20Final.pdf.

ACT Health. "Policy: Consumer and Carer Participation in ACT Health." Last Reviewed Dec. 2018.

Banfield, Michelle A., Morse, Alyssa R., Gulliver, Amelia and Griffiths, Kathleen M. "Mental health research priorities in Australia: a consumer and carer agenda." *Health Research Policy and Systems* 19, no. 119 (2018): 1-11. https://doi.org/10.1186/s12961-018-0395-9.

Greenhouse PK, Kuzminsky B, Martin SC, et al. "Calling a condition H(elp)." *Am J Nurs* 106, no. 11 (Nov, 2006): 63-6.

Kinsala EL. "The Very Important Partner program: integrating family and friends into the health care experience." *Prog Cardiovasc Nurs* 14, no. 3 (1999): 103-10.

Martinez, A.-M., D'Artois, D., & Rennick, J. E., "Does the 15-Minute (or Less) Family Interview Influence Family Nursing Practice?." *Journal of Family Nursing* 13, no.2 (2007): 157–178. https://doi.org/10.1177/1074840707300750

Mental Health Carers Voice. "Staff Perceptions of Carer Engagement in The ACT Mental Health Services." published July, 2019, https://www.carersact.org.au/wp-content/uploads/2019/07/Staff-Perceptions-of-Carer-Engagement-in-ACT-Mental-Health-Services.pdf.

newDEMOCRACY. "Process Design for VicHealth: How can we make it easier to eat better?." accessed October 7, 2019, https://www.newdemocracy.com.au/2015/09/25/vichealth-victoria-s-citizens-jury-on-obesity-2015/.

NHS. "Ask 3 Questions." Accessed October 3, 2019, https://www.pat.nhs.uk/downloads/patient-information-leaflets/other/Ask%203%20Questions%20Leaflet.pdf.

NHS. "Carer support and involvement in secure mental health services." Accessed October 3, 2019, https://www.england.nhs.uk/wp-content/uploads/2018/05/secure-carers-toolkit-v2.pdf.

The Mental Health Act 2015 (Australian Capital Territory), Republication No. 9.

VicHealth. "Safewards handbook." Published September 2018, https://www2.health.vic.gov.au/-/media/health/files/collections/policies-and-guidelines/s/safewards-victoria-handbook-2016.pdf

Appendix

Evidence Base: Carer Engagement Strategies

Strategy	Implementation	Research
Very Important Partner Program	Consumers have 'VIP' buttons that they give to family/friend who they see as part of their care team. Nurses actively include VIP throughout hospital stay	Kinsala EL. "The Very Important Partner program: integrating family and friends into the health care experience." *Prog Cardiovasc Nurs* 14, no. 3 (1999): 103-10.
15-Minute Family Interview	Interview technique and supplementary materials (genogram) to assist nurses in conducting therapeutic interviews following a family systems nursing (FSN) approach	Martinez, A.-M., D'Artois, D., & Rennick, J. E. "Does the 15-Minute (or Less) Family Interview Influence Family Nursing Practice?" *Journal of Family Nursing* 13, no. 2 (2007): 157–178. https://doi.org/10.1177/1074840707300750
Patient/family-activated rapid response teams	Internal phone line that patients and family can call when they feel they are not being listened to/concerns not addressed. Rapid response from interdisciplinary team (nursing supervisor, other doctor, advocate/patient liaison etc.) to review case	Greenhouse PK, Kuzminsky B, Martin SC, et al. "Calling a condition H(elp)." *Am J Nurs* 106, no. 11 (Nov, 2006): 63-6.
'Ask 3 Questions'	A credit card-sized matron card with essential contact/hospital information on one side, and an 'ask 3 questions' invite on the back. Designed to encourage friends and family to feel confident talking to staff, provides suggested questions they can ask.	"Ask 3 Questions," NHS, accessed October 3, 2019, https://www.pat.nhs.uk/downloads/patient-information-leaflets/other/Ask%203%20Questions%20Leaflet.pdf. "Carer support and involvement in secure mental health services," NHS, accessed October 3, 2019, https://www.england.nhs.uk/wp-content/uploads/2018/05/secure-carers-toolkit-v2.pdf.
'TOP 5'	All patients have a 'TOP 5' sheet on the top of their notes. Staff ask friends/family for 5 'tips or tricks' about caring for their loved one (e.g. music is a great way to calm them down). Helps establish rapport with carers while also getting to know the consumer	Luxford, Karen, Axam, Anne, Hasnip, Fiona, Dobrohotoff, John, Strudwick, Maureen, Reeve, Rebecca, Hou, Changhao, Hou, and Rosalie Viney. "Improving clinician-carer communication for safer hospital care: a study of the 'TOP 5' strategy in patients with dementia." *International Journal for Quality in Health Care* 27, no. 3 (June 2015): 175-182. https://doi.org/10.1093/intqhc/mzv026

Staff De-escalation training	Providing training in talk down methods, physical resources and ongoing support to implement de-escalation techniques.	"Safewards handbook," published September 2018, VicHealth, https://www2.health.vic.gov.au/-/media/health/files/collections/policies-and-guidelines/s/safewards-victoria-handbook-2016.pdf

Other Possible Engagement Strategies: Evidence-informed but not trialled

Strategy	Implementation	Evidence
Carer Checklists	Checklist on patient notes identifying level of information-sharing consent given by patient, revision of consent, and list of information to be communicated to carers, checked off when discussed.	Mental Health Carers Voice, "Staff Perceptions of Carer Engagement in The ACT Mental Health Services," published July, 2019, https://www.carersact.org.au/wp-content/uploads/2019/07/Staff-Perceptions-of-Carer-Engagement-in-ACT-Mental-Health-Services.pdf.
Carer Information Packs	Information packs given to all carers, with specific information on their loved one's diagnosis (non-specific where necessary), and where to go for help upon discharge. Delivered in person so staff can go over any concerns	"Carer support and involvement in secure mental health services," NHS, accessed October 3, 2019, https://www.england.nhs.uk/wp-content/uploads/2018/05/secure-carers-toolkit-v2.pdf.

Survey Questions

1. What is your profession?

2. During a typical shift, do you get to talk to carers as much as you would like?
   a. Always
   b. Usually
   c. Sometimes
   d. Rarely
   e. Never

3. How often is it possible to identify and contact carers and nominated persons?
   a. Always
   b. Usually
   c. Sometimes
   d. Rarely
   e. Never

4. What information do you like to ask carers about, when possible? Tick any that apply
   a. Service user's symptoms
   b. Service user's history of mental health
   c. Service user's history of physical health
   d. Carer's living situation
   e. How the carer is coping
   f. Supports in place for carer once service user is discharged
   g. Other

5. What makes it difficult to talk to carers the way that you would like to? Tick any that apply
   a. Caseload/time constraints
   b. Lack of clarity around consent legislation
   c. Carer not always identified
   d. Carers sometimes struggle to understand my point of view
   e. I don't have enough training to handle difficult conversations with carers
   f. Other

6. What has made it easier to talk to carers? Tick any that apply

    a. Informal supervision/mentoring from other staff

    b. Training from ACT Health

    c. Training from another health service (e.g. while working interstate)

    d. Training from university or professional association

    e. Personal experience or watching peers

    f. Other

7. Think of a positive experience that you have had engaging with a carer. What made this experience positive?

8. Think of a difficult experience you have had engaging with a carer. What made this experience difficult?

9. Is there a staff member that you recognise as someone who is particularly good at talking to carers? What do you admire about their approach?

10. What is one thing that you want carers to know about your job?

Adult Mental Health Unit: Worksheet on Carer Engagement Tools

Strategy	Pros	Cons	Alterations
Very Important Partner Program	Input from carers is valuable Simple and inclusive Helps with organisation of large families	Doesn't resolve conflict over meaning of 'direct involvement in care' What if the consumers change their choice of VIP? Could cause conflict in fractured or blended families	Match the VIP to the Nominated Person Would need to be done when the consumer is well
15-Minute Family Interview	Valuable as it provides context Good idea to provide family with info at admission and/or discharge	Process: unclear who performs the interview and when Not long enough, difficult to contain family conversations	Combine with TOP 5
TOP 5	Useful information for staff	Process: unclear who will collect information and when	Need to consider where to locate TOP 5 to be accessible when other medical records are electronic
Family-Activated Rapid Response Teams	Get useful information potentially missed	Criteria not clear enough Not clear how information is conveyed or how family concerns are addressed	Clarify whether it relates to physical or mental deterioration
'Ask 3 Questions'	Informs carers who the nurse is Good 'ice breaker' Doesn't take clinical time	There are some questions that only the treating team could answer – can't just ask anyone	Clarify when carers can ask these questions – in person, over email etc.

Strategy	Pros	Cons	Alterations
Communication and De-Escalation Training	Safewards coming in already	Staff did not see why this was necessary beyond the training already in place	
Carer Checklists	Simplifies communication – in particular for information sharing that happens after hours	Legal issues of overlapping roles with the discharge nurse – unclear who is in charge Difficult to do with time constraints and inconsistency of doctors/nurses	
Carer Information Packs	Helpful for family and carers	Currently, consumer information packs are not distributed adequately – no resources to do carer pack in addition to this	Language must be understandable
1: Discharge Nurse	Sit down with consumer and carer prior to discharge to anticipate possible issues (for consumer/carer to address on their own)		Expand on the current discharge nurse role – currently does referrals for clients, liaises with Access etc.
2: Carer Advocate/Liaison (full-time)	Provides single point of contact for carers, rather than getting lost between different members of treating team One person dedicated to the carer, not their loved one		There is already a carer consultant, but the position needs to be fulltime
3: Technological Assistance/App	Information carers can access without taking staff time, can read when in the waiting room		

Adult Community Mental Health: Worksheet on Carer Engagement Tools

Strategy	Pros	Cons	Alterations
Very Important Partner Program	Respect client's wishes Could help resolve grey areas of consent Clear identification	Not always able to identify VIP – e.g. divorced parents of unwell young person both involved Conflict possible between family members	Program would need to be flexible Include education
15-Minute Family Interview	Opportunity for comprehensive background information in initial meeting Therapeutic relationship developed	15 minutes not long enough Consumer may feel excluded	Combine with TOP 5 Involve consumer in some parts of discussion Develop more focused questions for mental health setting
TOP 5	Strengths-based Good to get tips/strategies from carer's viewpoint Easy to integrate into care plan	Not clear how to document in a way that is compatible with electronic records	
Family-Activated Rapid Response Teams	Carers know their loved one best	Difficult to integrate with HAART and Access MH services which already exist	Create a non-crisis advice line for carers to operate during business hours Make carers aware of the HAART and Access teams available to them
'Ask 3 Questions'	Convenient and time-friendly Can tailor question to particular branch of service Creates framework for carers to approach conversations	Not tailored to specific consumers Impersonal	Each service branch would need to develop their own questions to go on card

Strategy	Pros	Cons	Alterations
Communication and De-Escalation Training	Reduces adverse outcomes Staff feel safer at work Increase staff understanding of carers	Low consistency – training programs already offered vary a lot	Forensic staff member suggested the VPM training as the best de-escalation training provided by ACT Health Training to de-escalate over the phone Standardised training across all settings
Carer Checklists	Good for new staff Easy handover between staff members	Time consuming and may not match consumer's needs Compassion fatigue Similar to tools that already exist	Alter document to match care plans that are already in use
Carer Information Packs	Increase access to carer services in the community	Too much information for carers to digest/information fatigue	Include smaller pieces of information, fridge magnet with key phone services
1: Carer Space	Relaxed and informal, similar to the sensory modulation rooms available to consumers		