Staff Perceptions of Carer Engagement in The ACT Mental Health Services

A research paper produced for Carers ACT in partnership with the Australian National Internship Program

Carers ACT is the Peak Body in the ACT for Mental Health Carers

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Executive Summary

Carer engagement has been identified by ACT legislation and ACT Health policy as a central part of devising and providing treatment for consumers. Although guidelines exist to facilitate staff engagement with carers across the ACT Health service, and specifically within the mental health space, the implementation of these policies has not been widely researched in the ACT from the perspective of staff. Through a survey of ACT Health staff, particularly focusing on staff at The Canberra Hospital's Adult Mental Health Unit. This report found that staff are willing to engage with carers on a variety of consumer- and carer-specific issues. Many staff, particularly nurses, are supportive of a multidisciplinary approach to engaging with carers. Staff identified that they faced with barriers when working with carers which impacted on their engagement on a day-to-day basis. This research demonstrates that the willingness of the workforce to engage with carers is there. However, reflection on the sentiment of 'carer inclusion being everyone's responsibility' is that it has not been mirrored with procedural documentation for staff and may have led to no one taking ownership, leadership or benchmarking quality. This research demonstrates that whilst carer inclusion involves everyone, there needs to be systems and strategies for increasing engagement, assigning roles and ensuring that carers are getting the information they need. This paper recommends more staff training on communicating carer and consumer rights, utilising the treatment plans more effectively, and being more explicit to the staff regarding the role of carer consultants.

Regarding the process, it is recommended that the staff be consulted in the development of possible strategies to increase capacity for carer engagement, in particular suggestions: 'TOP 5', carer checklists, and a clinical leader system for a clearer delineation of professional role responsibilities. There is substantial scope to expand this research to more comprehensively monitor the implementation of carer engagement strategies.

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Key Terms and Abbreviations

Consumer   A person experiencing a mental illness, receiving treatment and support from a GP, public or private mental health service or staff of a community-managed organisation.[1] (Practical Guide) In some cases, 'consumer' and 'patient' are used interchangeably in this report, specifically in discussion of survey questions that use the term 'patient'.

Carer   A person who provides personal care, support or assistance to a person who has a mental disorder or mental illness. This care is not provided as part of volunteering, a commercial agreement, or education.[2] (Mental Health Act)

AMHU   Adult Mental Health Unit at The Canberra Hospital

CAMHS   Child and Adolescent Mental Health Service

AIHW   Australian Institute of Health and Welfare

CYPS   Child Youth Protection Service

TCH   The Canberra Hospital

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[1] "A practical guide for working with carers of people with mental illness," Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia, and Mental Health Australia., March 2016, https://www.health.act.gov.au/Culture-Review.

[2] *The Mental Health Act 2015* (Australian Capital Territory). Republication No. 9, Ch. 2 s12.

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Introduction and Literature Review

i. Models of Carer Engagement, Current ACT Legislation, and ACT Health Policy

Carer engagement describes the involvement of carers in the development and implementation of treatment for consumers. This requires staff to recognise the expertise carers possess through lived experience, ensure that carer concerns are inquired after and understood, and that referrals to the correct support services are provided.[3] Carer engagement falls under a broader model of how consumers are treated in the health service, the 'Triangle of Care', develop by the NHS as an evidenced-based model of best practice.[4]

The Mental Health Act (2015) outlines the requirements for carer engagement in the Canberra Health service. It also clarifies conduct concerning patient consent and information sharing. Section 6 outline that mental health services should involve carers 'in treatment, care or support decisions *in partnership* with medical professionals' (emphasis added), 'recognise the experience and knowledge' of carers and 'promote inclusive practices in treatment'.[5] ACT Health policy reflects this legislation, and espouses a commitment to patient-centred care. In the case of mental health, this involves providing information about treatment options, involving carers and consumers in decision making about service delivery, inclusion in the review of clinical policy, and eliciting feedback about the service.[6] Since this standard has been identified as best practice, and is legally required, it is the benchmark against which implementation of carer engagement should be monitored.

ii. Stakeholder Consultation

Consultation with staff at Carers ACT, MHCC, AMHU, and others in the ACT mental health space revealed several issues which carers reported in relation to the practical implementation of carer

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[3] "A practical guide for working with carers of people with mental illness," Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia, and Mental Health Australia., March 2016, https://www.health.act.gov.au/Culture-Review.

[4] "The Triangle of Care – Carers Included: A guide to best practice in Mental Health Care in England," Carers Trust, accessed April 22, 2019, https://professionals.carers.org/sites/default/files/toc_for_limited_contact_services_.pdf.

[5] *The Mental Health Act 2015* (Australian Capital Territory). Republication No. 9, s 6.

[6] "Adult Community Mental Health Services Model of Care," ACT Government, 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.

engagement. In addition, ongoing reports from the Productivity Commission, submissions from NGOs and other groups to the Productivity Commission inquiry into mental health services, and Carers ACT research corroborated many of the issues anecdotally identified in consultation.[78] Issues included:

- Lack of clarity around privacy, consent and rights under the Mental Health Act, particularly for staff and carers who are new to their role or the ACT system
- Insufficient notification or preparation for discharge for carers
- Little to no carer involvement in development of treatment plan
- Need for staff training on carer engagement, and implementation of the *Practical Guide to Working with Carers of People with a Mental Illness*[9]
- Understaffing and high workloads mean staff do not have the time to implement preventative care, and instead are reactive to immediate patient needs[10]
- Staff frustrations with service design and perceptions of poor consumer outcomes can contribute to 'therapeutic nihilism'[11]

Taken together, these issues suggest that there are several structural barriers to carer engagement, frustrating both staff and carers, and that implementation of engagement strategies is not universal.

iii. Academic Literature

Academic literature and studies were consulted to substantiate the feedback obtained through stakeholder consultation. Though none of these studies focused on the ACT, their findings provided possible causal mechanisms and underlying issues related to carer engagement.

[7]"What do ACT mental health carers need from mental health clinicians?" Carers ACT, published Aug. 2017. https://www.carersact.org.au/wp-content/uploads/2017/08/What-do-ACT-mental-health-carers-need-from-mental-health-clinicians.pdf.
[8] "The Social and Economic Benefits of Improving Mental Health," Productivity Commission (J. Frydenburg), published November, 2018, https://www.pc.gov.au/inquiries/current/mental-health/issues.
[9]"Submission to the Productivity Commission Inquiry into Mental Health," Private Mental Health Consumer Carer Network (Australia) Limited, March 2019, https://www.pc.gov.au/inquiries/current/mental-health/submissions.
[10] "Submission to Productivity Commission inquiry into 'The Social and Economic Benefits of Improving Mental Health'," NSW Nurses and Midwives' Association, April 2019, https://www.pc.gov.au/inquiries/current/mental-health/submissions.
[11] The Royal Australian and New Zealand College of Psychiatrists. "Improve the mental health of communities." Submission to the Productivity Commission (April 2019). Retrieved from https://www.pc.gov.au/inquiries/current/mental-health/submissions.

MacAteer *et al*. surveyed mental health staff across a range of professions to determine whether the shifting model of care from a medical to a social, recovery-oriented focus affected the role perceptions and self-efficacy of staff.[12] This research found that where staff perceived ambiguity about their role, self-efficacy was reduced.[13] In the case of carer engagement, these results suggest that ambiguity surrounding responsibility for carer engagement will reduce staff information sharing with carers on a day-to-day basis.

Haidet *et. al.* conducted a longitudinal study of medical students in the UK which found that the paternalistic, doctor-centred attitudes of students developed as they progressed through their studies.[14] They emphasised diagnosis and treatment of symptomology rather than viewing the patient as a whole person whose illness bears emotional and personal implications.[15] It is therefore worth investigating if clinical staff in the mental health space prioritise the sharing of medical information over engagement on personal issues (e.g. inquiring after carer concerns, such as safety in the home).

Karnieli-Miller *et. al.* conducted one of the few pieces of research focusing specifically on doctor-carer conversations. Discussions between doctors, carers, and newly-diagnosed dementia patients were recorded and analysed, and it was concluded that doctors will switch between two dyadic conversations - one with the patient and one with the carer - in which different topics were discussed while the third party was essentially excluded.[16] Not only does this suggest that information communicated to the carer would be selective, it also suggests that engagement is not collaborative, and does not follow the 'triangle of care' model without specific intervention.

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[12] Aidan MacAteer, Roger Manktelow, and Lelia Fitzsimons, "Mental health Workers' Perception of Role Self-Efficacy and the Organisational Climate Regarding the Ethos of Recovery," *British Journal of Social Work 46* (2016): 748-49.

[13] MacAteer *et al.*, "Perceptions of Role Self-Efficacy," 748-52.

[14] Paul Haidet, Joyce E Dains, Debora A Paterniti, Laura Hechtel, Tai Chang, Ellen Tseng, and John C Rogers, "Medical student attitudes toward the doctor-patient relationship," *Medical Education* 36 (2002): 572-573. https://doi-org.virtual.anu.edu.au/10.1046/j.1365-2923.2002.01233.x.

[15] Haidet *et al.*, "Medical student attitudes," 573.

[16] Karnieli-Miller, Orit, Wener, Perla, Neufeld-Kroszynski, Galit, and Shmuel Eidelman, "Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinic encounters," *Patient Education and Counselling* 88 (2012): 388-389. http://dx.doi.org/10.1016/j.pec.2012.06.014.

iv. Justification for Research Focus

Both carers and consumers have identified the implementation of carer engagement policy as a research priority in Australia.[17] Though there is substantial literature on broader issues in the mental health space, existing data on *engagement in practice*, particularly in the ACT, however, is minimal. In the Productivity Commission's ongoing reporting on mental health services and annual reporting from the AIHW, only one data point relates to carer engagement: the number of 'carer workers' available in each state and territory. In the ACT, there are 0.4 FTE carer workers.[18] In particular, this is the single carer consultant at AMHU. The specific role of the carer consultant, however, is to provide feedback to AMHU staff about carer experiences, not to facilitate carer involvement in a consumer's journey through AMHU.[19] It is, therefore, not a role dedicated to engaging with carers, but a role designed to improve the engagement of *other* staff members with carers.

Furthermore, staff perceptions of carer engagement have not been investigated in the ACT, although feedback from carers has been well documented by Carers ACT. Consultation for the development of the (Australian) *Practical Guide for Working with Carers of a Person with a Mental Illness* revealed ongoing staff concerns about confidentiality, but it did not explore how staff perceive carer engagement fitting into their broader understanding of their professional responsibilities. Since engagement is, at its core, reliant on a conversation between two people – the carer and the health professional – it is only logical to consult both participants to understand how engagement can be better facilitated.

v. Research Aim and Hypotheses

The aim of this research was to investigate how different health professionals within AMHU perceive their responsibility to engage with carers according to their professional roles. ACT

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[17] 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* 16, no. 119 (2018): 8, https://doi.org/10.1186/s12961-018-0395-9.

[18] Productivity Commission, "Chapter 13: Mental Health Management," in *Report on Government Services 2019* (2019): 13.16. Downloaded from https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/health/mental-health-management.

[19] ACT Government, "Welcome to the Adult Mental Health Unit," (Retrieved April, 2019) : 8. https://www.health.act.gov.au/sites/default/files/2019-02/Welcome%20to%20the%20Adult%20Mental%20Health%20Unit.pdf

Health policy stipulates that all staff engage with carers. While this is crucial in the promotion of an inclusive culture across the service, ambiguity in the specific roles of staff has been linked to work stress and emotional exhaustion in staff in academic literature.[20] This research also sought to investigate how understanding of professional roles shape the implementation of carer engagement strategies on a day-to-day basis.

Three hypotheses were identified in relation to carer engagement in the Canberra Health service:

H1.a) There is a lack of consensus about which staff members are responsible for sharing different types on information with carers.

H1.b) Views about professional roles and carer engagement are specific to each profession.

H2. Staff in Canberra Health are not able to share all of the information they would wish to with carers on a day-to-day basis.

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[20] MacAteer *et al.*, "Perceptions of Role Self-Efficacy," 741.

Methodology

A survey was distributed by Carers ACT to staff in the Canberra Mental Health Service through the MHJHADS Corporate governance committee to some of the Canberra Mental Health Services. The relatively small workforce of ACT, especially compared to health services in other states, or nationwide, ensured that robust analysis could be undertaken on a small number of survey responses. Correspondingly, however, the conclusions and recommendations included in this report apply only to the Canberra Health setting. Surveys have been previously used to research the perceived role-responsibilities of clinicians, and so were deemed appropriate for this project.[21][22][23]

As outlined above, there are a wide range of pressures on staff in the ACT mental health space. The object of the survey was not to demand that staff answer for the shortcomings of the service, but rather to help identify how they would like the service to operate and how they believe carer engagement could best fit into their professional responsibilities of staff members. A copy of the survey is included in the Appendix.

Staff were asked two questions:

1. Who should share different types of information in an ideal scenario (referred to as 'ideal engagement' in this paper), with patient consent and ample time.
2. How much information they have the opportunity to share on a day-to-day basis.

The first question was designed to test H1.a) and H1.b), while the second was designed to test H2..

Information topics were split into patient-specific and carer-specific categories, and included topics such as medication, development of treatment plan, and carer and patient rights. The selection of these topics was informed by feedback from carers about the types of information

[21] Richard Clancy, Terry J. Lewin, Jenny A. Bowman, Brian J. Kelly, Antony D. Mullen, Karen Flanagan, and Michael J. Hazelon, "Providing physical health care for people accessing mental health services: Clinicians' perceptions of their role," *International Journal of Mental Health Nursing 28* (2019): 256-267. DOI: 10.1111/inm.12529.

[22] Bart Debyser, Veerle Duprez, Dimitri Beeckman, Joeri Vanderwalle, Ann Van Hecke, Eddy Deproost, and Sofie Verhaeghe, "Mental health nurses and mental health peer workers: Self-perceptions of role-related clinical competences," *International Journal of Mental Health Nursing 27* (2018): 987-1001. DOI: 10.1111/inm.12406.

[23] MacAteer *et al.*, "Perceptions of Role Self-Efficacy," 737-755.

they would like to know, while some, such as discharge, were included as they had been anecdotally mentioned as areas of insufficient communication.

Surveys are a common tool used by Carers ACT, which has in place internal practices for approving surveys, and the anonymous and secure collection of data. As surveys are 'business as usual' for the organisation, separate ethics clearance from the ANU was deemed unnecessary. This was agreed to by ANIP supervisor Prof. Laurence Brown.

Results

47 responses from staff members at Canberra Health were received. The demographic data is summarised in Table 1.

Table 1. Demographic information of Survey Respondents

Profession of Respondent	Number of Responses	Place of Work	Average Years in Profession
Doctor	9	AMHU (7) TCH (2)	5.4
Nursing	23	AMHU (19) Health Directorate (2) MHSC (1) No Response (1)	7.1
Clinical Psychologist	3	CAMHS (2) AMHU (1)	5.9
Social Worker	3	AMHU (1) TMHP (1) CAMHS (1)	14.3
Allied Health	2	AMHU (2)	2.3
Administration	3	AMHU (3)	6.7
Student	4	AMHU (3) Nursing Home (1)	NA

Note: In the cases where respondents identified 'MHSC' and 'TMHP' as their place of work, no employer or branch of the Canberra Health service could be linked to these acronyms, and so their place of work could not be determined.

Certain professions were grouped together for ease of analysis. Those who identified themselves as doctors, psychiatrists, consultants, medical officers (MO) or registered medical officers (RMO) were classified as 'doctors'. Registered nurses, enrolled nurses, and assistants in nursing (AIN) were all classified under 'nursing'. All allied health occupations, including occupational therapy and exercise physiology, were classified under 'allied health'. Ward clerks, receptionists, and self-identified administrators were all classified as 'administration'. Clinical psychologists, social workers, and students (all nursing) were each an individual category. Where respondents were asked to specify someone else to share specific information with carers, their responses of various professions were categorised in the same manner.

For specific responses for ideal and actual engagement, the results from doctor and nurse responses will be discussed most thoroughly, as the greater number of responses makes the analysis more robust. An overwhelming majority of responses came from AMHU and TCH. Therefore, while the responses from doctors, nurses, and administration staff can provide useful information on carer engagement at AMHU, the responses from social workers and psychologists in particular are too varied in locations given the low number of responses, making it difficult to draw robust conclusions from the data.

i. Staff perceptions of Role Responsibilities and Ideal Carer Engagement

The professions identified as responsible for each type of information sharing in an ideal case were tallied and organised according to the profession of the respondent. Table 2 shows the responses from nurses. Where the respondent ticked the 'other staff' box, rather than specifying a profession, this was interpreted to mean that all other staff were responsible, classified as 'team' in Table 2. In many cases, respondents specified more than one profession, and the tallies reflect this. The sum of responses on each information topic may exceed the total number of responses.

The tables for doctors, psychologists, social workers, allied health, administration staff and students are included in the Appendix.

Scenario	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team	Patient and Family	Case Manager	Tribunal Officer
Symptomology of the diagnosis	19	5	-	-	-	-	8	-	-	-	-	-
Medication, including administration and monitoring	21	7	-	-	-	-	6	-	-	1	-	-
Seeking patient information from carer	19	3	-	3	-	-	5	-	-	-	-	-
How to perform day-to-day caring tasks for the patient	20	-	-	-	-	-	1	-	1	-	-	-
Rights of the patient under the Mental Health Act	19	4	-	2	2	-	5	-	2	-	-	2
Development of treatment plan	19	6	-	1	-	-	6	-	1	1	-	-
Preparing patient for discharge	21	3	-	1	-	-	5	-	1	-	1	-
Comforting an emotional or agitated carer	21	1	-	2	-	-	8	-	2	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	20	-	-	2	-	-	3	-	3	-	1	-
Referrals to carer support services	17	1	-	7	-	-	3	-	1	-	1	-
Rights of the carer under the Mental Health Act	18	3	-	1	-	-	3	-	2	-	1	-
Preparing carer for discharge	21	3	-	1	-	-	5	-	2	-	1	-

le: In the case of rights of the patient under the Mental Health Act, 19 of the 23 nurses sponsible for sharing this information with carers. 4 respondents identified doctors, 2 ified the treatment team, 2 identified simply 'everyone' or 'team', and 2 identified the ents identified more than one staff member/group for sharing this information, and so ied to discuss patient rights exceeds the total number of respondents (23). Responses e number of roles identified by respondents, as the sample size was too small

Table 2. Frequency with which each staff role was **identified by nurses (23 responses)** to scenario

The percentage of instances in which respondents identified themselves for information sharing is given in Table 3. The first column, 'information sharing', is an average across all information topics, while the other two columns separate patient- and carer-specific information. These were calculated by averaging the number of staff who nominated themselves to share information across all specified topics. This average was converted to a percentage of the total number of respondents in that profession. An example of this calculation is included with a copy of the table in the Appendix.

Table 3. Percentage of staff in each profession identifying themselves for information sharing

	Identified themselves for information sharing	Identified themselves for sharing patient information	Identified themselves for sharing carer information
Doctor	87%	90%	82%
Nursing	85%	86%	84%
Administration	36%	24%	53%
Student	71%	64%	80%
Psychologist	92%	90%	93%
Social Worker	86%	76%	100%
Allied Health	54%	43%	70%
Average Across Treatment Staff	**67%**	**64%**	**72%**
Average Across All Staff	**73%**	**68%**	**80%**

Note: 'Treatment Staff' includes all respondents except students and administration staff.

ii. Information Sharing on a Day-to-Day Basis

Table 4 summarises the percentage of respondents who answered that they share a specific type of information on a day-to-day basis. The average across all treatment staff incorporated responses from doctors, nurses, psychologists, allied health, and social workers. Since many of the information topics were clinical in nature, it was also useful to see what information was shared by clinical staff, without results being skewed by those student and administration staff who would not be equipped to share this information in any case.

Table 4. Percentage of staff in each profession who shared information on specified topic on a day-to-day basis

	Percentage of staff who share each information type on an average day								
	Symptomology of the Diagnosis	Medication	Patient Information from Carer	How to Perform Day-to-Day caring tasks	Patient Rights under Mental Health Act	Treatment Plan	Comforting Agitated/Emotional Carer	Carer Rights under Mental Health Act	Preparing Carer for Discharge
Doctor	66.67	77.78	44.44	11.11	44.44	77.78	66.67	33.33	77.78
Nursing	60.87	65.22	60.87	65.22	39.13	43.48	78.26	39.13	65.22
Administration	0.00	0.00	0.00	0.00	33.33	0.00	66.67	33.33	0.00
Student	0.00	50.00	0.00	50.00	0.00	0.00	50.00	0.00	0.00
Psychologist	33.33	0.00	33.33	33.33	0.00	33.33	33.33	0.00	66.67
Social Worker	33.33	66.67	100.00	66.67	66.67	66.67	100.00	66.67	100.00
Allied Health	0.00	0.00	50.00	50.00	50.00	0.00	50.00	50.00	50.00
Average Across Treatment Staff	55.00	60.00	57.50	50.00	40.00	50.00	72.50	37.50	70.00
Average Across All Staff	46.81	55.32	46.81	44.68	34.04	42.55	68.09	31.91	57.45

Discussion

The surveys were not completed by respondents in the way originally anticipated. Most staff expressed a desire to be involved in almost all aspects of carer engagement that were surveyed, regardless of their profession or specific skill set. Many respondents identified multiple professions in addition to their own for discussing each information topic, and several responses also included additional unsolicited comments. Though it was originally intended that this data be analysed using regression, to test whether the average frequency of sharing for specific information points was correlated to diversity of professions identified to share that information point in the ideal case, this analysis would not be robust considering the way in which respondents interpreted the questions, and the relatively low number of responses in several professions.

Therefore, this discussion will only identify those trends which can be robustly identified based on descriptive statistics. More complex relationships, and the testing of specific causal mechanisms and the influence of demographic factors is left to future research.

This discussion will be divided into two parts; the first will address results from the first survey question and address H1.a) and H1.b), while the second will incorporate the second survey question to address H2.. This analysis will primarily focus on the responses from doctors and nurses, as these groups had the greatest number of responses and most consistent place of work, AMHU. The responses from other professions will be included where appropriate, but it must be noted that particularly for social workers and psychologists, the variety of workplaces makes it difficult for their responses to directly be compared to doctors and nurses, as they operate in different work environments with different coworkers and available resources.

i. Responsibility for Information Sharing

As has been identified, most staff across all professions indicated that they would ideally be involved in most types on information sharing, and often indicated shared responsibility with other staff. This suggests that staff, with notable exceptions, do not appear to limit their scope for engagement based on the idea that a different professional expertise might be better for conveying certain information. Furthermore, the widespread willingness for staff to engage

with carers suggests that there would be interest to improve current levels of carer engagement (which staff reported is lower than the ideal, discussed in the next section).

Clear assignment of staff responsibility, however, does exists for a few information topics. This responsibility is identified both by the staff themselves and their peers of other professions. Firstly, social workers were identified as responsible for providing referrals to carer support services by 7 of 23 nurses and 2 of 9 doctors. All social workers surveyed also identified themselves to provide referrals to carers. Furthermore, allied health and nurses were more often identified for showing carers how to perform day-to-day caring tasks for the consumer, particularly by doctors. Lastly, administration staff (all at AMHU) strongly identified that they were responsible to communicating patient and carer rights to the carer, and this was the only topic which all administration staff identified as their responsibility. Therefore, while in specific topics there was a loose consensus for certain staff being responsible for sharing information with carers, on the whole there is no clear division of responsibilities for engaging with carers. This finding provides support for H1.a).

The survey results suggest differences views amongst staff about who, or how many others, should assist them with information sharing, supporting H1.b). Doctors did not identify other staff for information sharing responsibility as often as their peers. Specifically, no doctor specified the treatment team to assist in information sharing, while it was specified by nurses in 19% of cases (statistically significant, t-score: 8.04, 95% confidence interval), Though this may have simply indicated a different interpretation of the question to identify a *specific* profession or staff member, nurses generally were more likely to identify other staff members to share information, *in addition to* themselves. Nurses also identified a wider variety of staff to share information – case managers, tribunal officers, and two identified the patient and family themselves, none of whom were identified by doctors. This finding is supported by research from Debyser *et al.*, which found nurses self-perceive their responsibilities with respect to how their roles are defined by their employer/institution, and how their actions work in tandem with other staff.[24]

Like doctors, social workers were also less likely to identify their peers to share information, with only one respondent specifying doctors to share information about a patient's diagnosis

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[24] Debyser *et al.*, "Self-perception of role-related clinical competencies," 997.

and medication. 2 of the 3 social workers surveyed, however, worked at CAMHS, which is a very different environment to AMHU, where they are likely responsible for a greater portion of the interaction with patients and carers.

Consumer consultants were identified by a small number of nurse and doctor AMHU respondents as responsible for carer-specific information sharing. This suggests a notable misunderstanding of the consumer consultant role, which is to provide feedback to staff rather than providing information to carers.

ii. Gaps in Information Sharing

Overall, the survey results showed a disparity across all professions between the information staff would like to share with carers, and what they have the opportunity to share on a day-to-day basis. Across all staff, respondents identified themselves to discuss a particular information topic 73% of the time. On an average day, however, topics were discussed with carers 32%-68% of the time, depending on the topic. These findings provide very strong support for H2.

This is consistent with the conclusions from stakeholder consultation and grey literature from Carers ACT and Productivity Commission submissions, which revealed substantial time and resource constraints. Furthermore, this is reinforced by the unsolicited comments written on some survey responses. One AMHU nurse commented 'I wish I had more time to spend with carers', while another stated 'consent is too often denied', making it impossible to realise the ideal case of information sharing. Although these comments are singular, and hence cannot be taken as representative of the experience of all staff, they must be taken into consideration as the respondents felt strongly enough to take the extra time to add comments.

Discussion of patient and carer rights under the Mental Health Act is the most neglected topic – discussed with by only 32% and 34% of all staff respectively. This deficit in communication of patient and carer rights matches the trend identified in the ideal scenario, where this information was the topic of discussion most often *not* identified as the responsibility of the respondent. In the case of doctors, sharing information about carer rights under the Mental Health Act was only identified by 5 of 9 respondents, compared to almost full identification with sharing information in other categories. The exception was administration staff, the only group to identify these topic for discussion universally and more so than other topics.

With the exception of doctors, treatment plans were also discussed substantially less than other topics. It was discussed with carers by 43% of all staff and 50% of clinical staff. As the development of a treatment plan is an important area for involving carers under the 'Triangle of Care' model, this is of particular concern.

Comforting agitated carers was the most common interaction of all options to take place. Among treatment staff, medication information is also more frequently discussed with carers (reported by 73% of staff). This is in line with anecdotal evidence from carers and other staff members in the sector. Particularly when staff are time poor, only the information deemed most essential by staff is communicated to carers, including issues like medication where correct administration is considered of high importance to the welfare of the consumer. This is consistent with research from Haidet *et al.* and Karnieli *et al.* which supported the assertion that the service emphasises a clinical focus and does not fully integrate carers, as carer concerns and information obtained from carers are consistently underreported by staff.[25][26]

iii. Limitations

Due to the time constraints of this project, the survey collection window was narrow, and most surveys returned originated from a single service: AMHU. Few consumers in the ACT mental health system come into contact with AMHU, as it is exclusively an acute inpatient unit. The consumers and carers that staff come into contact with, therefore, are not necessarily representative of the entire community, and have experienced uniquely stressful circumstances. Therefore, the recommendations in this report are applicable primarily to AMHU. The results cannot provide any information on how division of responsibility is viewed between different branches of the service, or within branches outside AMHU.

It must also be noted that both selection and recall bias likely shaped the survey results. The survey relied on self-nomination to fill in and return the forms, and required staff to recall their *average* experience of information sharing, which may have been heavily influenced by their more recent or particularly memorable interactions (positive or negative) with carers.

The survey was also limited in length. With the object of maximising participation in mind, the survey was designed to produce the highest response rate from time-poor staff while still

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[25] Haidet *et al.*, "Medical student attitudes," 568-574.
[26] Karnieli-Miller *et al.*, "Are you talking to me?!" 381-390.

eliciting useful information. Questions about staff opinions on possible intervention strategies were not included. Furthermore, the survey used the act of sharing information with carers as a proxy for carer engagement, which encompasses a broader variety of practices. Though chosen because it was easy for respondents to identify, information sharing cannot alone be used to monitor carer engagement.

These limitations leave substantial scope for future research to expand the data set, by encouraging more responses from other branches of the ACT Health service, and conducting in-depth interviews with staff.

Conclusions and Recommendations

From the responses to the survey, the following conclusions can be drawn:

- There is a lack of consensus amongst staff about who is responsible for information sharing, as most staff identify their own profession as responsible for sharing information with carers

- Staff, and in particular nurses, indicated a desire for a collaborative, multidisciplinary approach to sharing information with carers

- There are some topics, specifically referrals to support services, carer and patient rights, and day-to-day caring tasks, which are more often regarded as the responsibility of a particular staff member

- Consistently, staff are unable to share all of the information they would wish to on a day-to-day basis

- Information, such as patient and carer rights, which is least often shared with carers are often the topics not identified by staff as their own responsibility to share

This survey has also identified key topics where information sharing must be improved, specifically, consumer and carer rights and the development of the consumer's treatment plan. More regular training for staff is advisable, particularly at AMHU, where 20 of the respondents have been in the service for less than 5 years. Training should not only convey the importance of this information, it should also provide staff with strategies for dealing with agitated carers, complex families and other situations. Training could also incorporate possible intervention strategies for improving carer engagement.

Based on the responses to this survey, several possible intervention strategies have been identified. Luxford et al. conducted research which demonstrated the effectiveness of the 'TOP 5' system in improving engagement with carers and staff job satisfaction.[27] TOP 5 is a simple tool for staff to use, where they simply ask carers for 5 key pieces of information about the person they care for, and these 'tips and tricks' are placed in the consumer's file to assist

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[27] Karen Luxford, Anne Axam, Fiona Hasnip, John Dobrohotoff, Maureen Strudwick, Rebecca Reeve, 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 in caring for the consumer during their time in the service.[28] Not only does this recognise the expertise of the carer, it was found to serve as a gateway for developing an ongoing rapport between staff and carers.[29] This could complement or be hybridised with a checklist system, where a specific checklist for carers in the patient's file can be used by staff to check what information has been communicated to carers, and whether consent has been obtained and reviewed with patients. Such task-specific approaches have supporting evidence from research previously conducted on staff perceptions of self-efficacy in mental health.[30]

Another intervention to consider would be a clinical leadership system, which supports a multidisciplinary approach while playing to the particular strengths of certain professions. These survey results have suggested a few key areas where specific staff are more universally identified as responsible for certain tasks. In particular, social workers are seen by most staff, and themselves, as responsible for referrals. Administration staff, though not identified by other staff, feel strongly responsible for discussing carer and patient rights. By complementing the ACT Health policy of a collaborative approach to engagement, while appropriately promoting staff as leaders on certain information, communication could be improved.

Importantly, further research and policy design in the carer engagement space should endeavor to follow the approach of this research – non-accusatory, open to all perspectives, and actively engaged with staff members. In particular, the interventions outlined above should be presented to staff for alterations before they are implemented, and research should be expanded to obtain a more comprehensive data set for monitoring carer engagement.

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[28] Luxford et al., "TOP 5," 176.
[29] Luxford et al., "TOP 5," 181.
[30] MacAteer et al., "Perceptions of Role Self-Efficacy," 752.

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Appendix

i. Copy of survey sent to ACT Health staff

CarersACT

Carers ACT, in partnership with a student from the Australian National Internship Program, are seeking feedback from ACT MHJHADS staff about their experiences with carers. We know that there can be many pressures on staff, but we want to know how you would like to engage with carers in the ideal case. Information from this survey will be used to identify broad trends amongst health professionals in carer communication and the final report will ensure survey responses are de-identified.

What is your profession?   **Where Do You Work?**

How long have you worked in this profession (in years)?

Assume that a patient has given consent for all information about their diagnosis, treatment plan, and medication, to be shared with their carer/nominated person. Based on your expertise and role, what topics of discussion would you like to bring up with carers in the ideal case? Tick any option on the left hand side.

In some situations, your role may not be suited to discussing some topics. For these options, please identify which staff members you think should discuss these topics with carers.

Tick Here	Communicating with Carers: Patient-Specific Information	Other staff members who should discuss this information
	Symptomology of the diagnosis	
	Medication, including administration and monitoring	
	Seeking patient information from carer	
	How to perform day-to-day caring tasks for the patient	
	Rights of the patient under the Mental Health Act	
	Development of treatment plan	
	Preparing patient for discharge	

Tick Here	Communicating with Carers: Carer-Specific Information	Other staff members who should discuss this information
	Comforting an emotional or agitated carer	
	Inquiring about any carer concerns (e.g. carer safety in the home)	
	Referrals to carer support services	
	Rights of the carer under the Mental Health Act	
	Preparing carer for the patient's discharge	

Reflecting on the various pressures on your role, we recognise that often it's not possible to have an ideal conversation with a carer.

In your role, what information, on average, do you get the chance to share with carers?

All of the below

- ☐ Symptomology of the diagnosis
- ☐ Medication, including administration and monitoring
- ☐ Referrals to carer support services
- ☐ How to perform day-to-day caring tasks for the patient
- ☐ Rights of patient under the Mental Health Act
- ☐ Development of treatment plan
- ☐ Comforting and emotional or agitated carer
- ☐ Referrals to carer support services
- ☐ Rights of carer under the Mental Health Act
- ☐ Preparing carer for discharge

ii. Staff Perception of Responsibility for Information Sharing with Carers

Percentage of staff in each profession identifying themselves for information sharing

	Identified themselves for information sharing	Identified themselves for sharing patient information	Identified themselves for sharing carer information
Doctor	87%	90%	82%
Nursing	85%	86%	84%
Administration	36%	24%	53%
Student	71%	64%	80%
Psychologist	92%	90%	93%
Social Worker	86%	76%	100%
Allied Health	54%	43%	70%
Average Across Treatment Staff	67%	64%	72%
Average Across All Staff	73%	68%	80%

	Doctor
Symptomology of the diagnosis	8
Medication, including administration and monitoring	9
Seeking patient information from carer	9
How to perform day-to-day caring tasks for the patient	7
Rights of the patient under the Mental Health Act	7
Development of treatment plan	8
Preparing patient for discharge	9
Comforting an emotional or agitated carer	7
Inquiring about any carer concerns (e.g. carer safety in the home)	9
Referrals to carer support services	7
Rights of the carer under the Mental Health Act	5
Preparing carer for discharge	9

Example calculation

Consider the percentage of doctors who identified themselves for information sharing, 87%. Taking the 'Doctor' column from the table of professions identified by doctors for information sharing, we see that 8 of the 9 doctors identified themselves for discussing the symptomology of the diagnosis, 9 identified themselves to discuss medication and so on down the column. The average of these self-identifications is 7.833333. Therefore, doctors identified themselves on average 7.8333/9 = 87% of the time to share any given piece of information.

iii. Frequency with which each staff role was **identified by doctors (9 responses)** to discuss different topics with carers in an ideal scenario

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team
Symptomology of the diagnosis	1	8	-	-	-	-	-	-	-
Medication, including administration and	3	9	-	-	1	-	-	-	-
Seeking patient information from carer	1	9	-	1	-	-	-	-	-
How to perform day-to-day caring tasks for the patient	2	7	-	-	3	-	-	-	-
Rights of the patient under the Mental Health Act	-	7	-	-	1	1	-	-	-
Development of treatment plan	-	8	-	1	1	-	-	1	-
Preparing patient for discharge	2	9	-	1	2	-	-	1	-
Comforting an emotional or agitated carer	2	7	-	2	-	1	-	1	-
Inquiring about any carer concerns (e.g. carer safety in the home)	2	9	-	1	1	1	-	-	-
Referrals to carer support services	1	7	-	2	-	1	-	-	-
Rights of the carer under the Mental Health Act	1	5	-	1	-	1	-	-	-
Preparing carer for discharge	1	9	-	1	-	1	-	-	1

*iv. Frequency with which each staff role was **identified by nurses (23 responses)** to discuss different topics with carers in an ideal scenario*

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team	Patient and Family	Case Manager	Tribunal Officer
Symptomology of the diagnosis	19	5	-	-	-	-	8	-	-	-	-	-
Medication, including administration and monitoring	21	7	-	-	-	-	6	-	-	1	-	-
Seeking patient information from carer	19	3	-	3	-	-	5	-	-	-	-	-
How to perform day-to-day caring tasks for the patient	20	-	-	-	2	-	1	-	1	-	-	-
Rights of the patient under the Mental Health Act	19	4	-	2	-	-	5	-	2	-	-	2
Development of treatment plan	19	6	-	1	-	-	6	-	1	1	-	-
Preparing patient for discharge	21	3	-	1	1	-	5	-	1	-	1	-
Comforting an emotional or agitated carer	21	1	-	2	-	-	8	-	2	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	20	-	-	2	-	1	3	-	3	-	1	-
Referrals to carer support services	17	1	-	7	-	-	3	-	1	-	1	-
Rights of the carer under the Mental Health Act	18	3	-	1	-	1	3	-	2	-	1	-
Preparing carer for discharge	21	3	-	1	-	-	5	-	2	-	1	-

*v. Frequency with which each staff role was **identified by students (4 responses)** to discuss different topics with carers in an ideal scenario*

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team	Patient and Family	Student	Community Services
Symptomology of the diagnosis	-	-	-	-	1	-	-	-	-	-	4	-
Medication, including administration and	-	1	-	-	-	-	-	1	-	-	1	-
Seeking patient information from carer	-	-	-	-	-	-	-	1	-	-	3	-
How to perform day-to-day caring tasks for the patient	-	-	-	-	-	-	-	-	-	-	4	-
Rights of the patient under the Mental Health Act	-	-	-	-	-	-	-	-	-	-	4	-
Development of treatment plan	-	-	-	-	-	-	-	-	-	-	1	-
Preparing patient for discharge	2	2	-	-	-	-	-	-	-	-	1	-
Comforting an emotional or agitated carer	-	-	-	-	-	-	-	-	-	-	4	1
Inquiring about any carer concerns (e.g. carer safety in the home)	-	-	-	-	-	-	-	-	-	-	3	1
Referrals to carer support services	-	-	-	-	-	-	-	-	-	-	4	1
Rights of the carer under the Mental Health Act	-	-	-	-	-	-	-	-	-	-	3	1
Preparing carer for discharge	2	2	-	-	-	-	-	-	-	-	2	1

vi. Frequency with which each staff role was **identified by administration staff (3 responses)** to discuss different topics with carers in an ideal scenario

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team	Patient and Family	Student	Community Services
Symptomology of the diagnosis	2	1	-	-	-	-	2	-	-	-	-	-
Medication, including administration and	2	1	-	-	-	-	2	-	-	-	-	-
Seeking patient information from carer	2	1	1	-	-	-	2	-	-	-	-	-
How to perform day-to-day caring tasks for the patient	2	1	-	-	-	-	2	-	-	-	-	-
Rights of the patient under the Mental Health Act	2	1	3	-	-	-	2	-	-	-	-	-
Development of treatment plan	2	1	-	-	-	-	2	-	-	-	-	-
Preparing patient for discharge	2	1	1	-	-	-	2	-	-	-	-	-
Comforting an emotional or agitated carer	1	-	2	-	-	-		-	-	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	2	1	1	1	1	-	1	-	-	-	-	-
Referrals to carer support services	1	-	1	-	-	-	1	-	-	-	-	-
Rights of the carer under the Mental Health Act	2	1	3	-	-	-	1	-	-	-	-	-
Preparing carer for discharge	1	-	1	-	-	-	1	-	-	-	-	-

vii. Frequency with which each staff role was **identified by social workers (3 responses)** to discuss different topics with carers in an ideal scenario

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team	Patient and Family	Student	Community Services
Symptomology of the diagnosis	-	1	-	2	-	-	-	-	-	-	-	-
Medication, including administration and	-	1	-	2	-	-	-	-	-	-	-	-
Seeking patient information from carer	-	-	-	3	-	-	-	-	-	-	-	-
How to perform day-to-day caring tasks for the patient	-	-	-	1	-	-	-	-	-	-	-	-
Rights of the patient under the Mental Health Act	-	-	-	3	-	-	-	-	-	-	-	-
Development of treatment plan	-	-	-	2	-	-	-	-	-	-	-	-
Preparing patient for discharge	-	-	-	3	-	-	-	-	-	-	-	-
Comforting an emotional or agitated carer	-	-	-	3	-	-	-	-	-	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	-	-	-	3	-	-	-	-	-	-	-	-
Referrals to carer support services	-	-	-	3	-	-	-	-	-	-	-	-
Rights of the carer under the Mental Health Act	-	-	-	3	-	-	-	-	-	-	-	-
Preparing carer for discharge	-	-	-	3	-	-	-	-	-	-	-	-

*viii. Frequency with which each staff role was **identified by psychologists (3 responses)** to discuss different topics with carers in an ideal scenario*

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	CYPS	Patient and Family	Student	Community Services
Symptomology of the diagnosis	-	-	-	-	-	-	1	3	-	-	-	-
Medication, including administration and	-	1	-	-	-	-	1	3	-	-	-	-
Seeking patient information from carer	-	-	-	-	-	-	1	3	-	-	-	-
How to perform day-to-day caring tasks for the patient	-	-	-	-	-	-	1	3	-	-	-	-
Rights of the patient under the Mental Health Act	-	-	-	-	-	1	1	2	-	-	-	-
Development of treatment plan	-	-	-	-	-	-	1	2	-	-	-	-
Preparing patient for discharge	-	-	-	-	-	-	1	3	-	-	-	-
Comforting an emotional or agitated carer	-	-	-	-	-	-	-	3	-	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	-	-	-	-	-	-	-	3	1	-	-	-
Referrals to carer support services	-	-	-	-	-	-	-	3	1	-	-	-
Rights of the carer under the Mental Health Act	-	-	-	-	-	-	-	2	1	-	-	-
Preparing carer for discharge	-	-	-	-	-	-	-	3	-	-	-	-

*ix. Frequency with which each staff role was **identified by allied health (2 responses)** to discuss different topics with carers in an ideal scenario*

	Nurse	Doctor	Administration	Social Worker	Allied Health	Consumer Consultant/Advocate	Treatment Team	Psychologist	Team
Symptomology of the diagnosis	1	1	-	-	-	-	-	-	1
Medication, including administration and	1	1	-	-	-	-	-	-	1
Seeking patient information from carer	-	-	-	1	1	-	-	-	-
How to perform day-to-day caring tasks for the patient	-	-	-		2	-	-	-	-
Rights of the patient under the Mental Health Act	-	-	-	1	1	1	-	-	-
Development of treatment plan	-	1	-	-	1	-	-	-	-
Preparing patient for discharge	1	-	-	-	1	-	-	-	-
Comforting an emotional or agitated carer	-	1	-	-	1	-	-	-	-
Inquiring about any carer concerns (e.g. carer safety in the home)	-	-	-	1	2	-	-	-	-
Referrals to carer support services	-	-	-	1	1	-	-	-	-
Rights of the carer under the Mental Health Act	-	-	-	1	1	-	-	-	1
Preparing carer for discharge	-	-	-	-	2	-	-	-	-